



DEPARTMENT OF ELDER AFFAIRS



# **PURPLE RIBBON TASK FORCE**

*Division of Statewide Community-Based Services*

## 2013 FINAL REPORT AND RECOMMENDATIONS

---

State Plan on Alzheimer's Disease and  
Related Forms of Dementia (ADRD)

**RICK SCOTT**  
*Governor*

**DON GAETZ**  
*President of the Senate*

**WILL WEATHERFORD**  
*Speaker of the House of Representatives*

# Table of Contents

<b>Executive Summary</b> – .....	<b>Page 3</b>
<b>Introduction</b> – .....	<b>Page 4</b>
<b>Overview of Alzheimer’s Disease or Related Dementias</b> – .....	<b>Page 5</b>
<b>PRTF Finding</b> – .....	<b>Page 6</b>
<ul style="list-style-type: none"><li>• Assessment of the needs of persons with ADRD and their caregivers, including persons of all cultural backgrounds having ADRD</li><li>• Assessment of the current and future impact of ADRD</li><li>• Assessment of existing services and resources available to Florida’s population</li><li>• Identification of gaps and limitations</li></ul>	
<b>PRTF Recommendations</b> – .....	<b>Page 16</b>
<ul style="list-style-type: none"><li>• Assessment of the needs of persons with ADRD and their caregivers, including persons of all cultural backgrounds having ADRD</li><li>• Assessment of the current and future impact of ADRD</li><li>• Assessment of existing services and resources available to Florida’s population</li></ul>	
<b>References</b> – .....	<b>Page 76</b>
<b>Recognized Purple Ribbon Task Force Contributors</b> – .....	<b>Page 80</b>
Purple Ribbon Task Force Members Department of Elder Affairs Support Staff	
<b>Appendices</b> – .....	<b>Page 82</b>
<ol style="list-style-type: none"><li>1. Purple Ribbon Task Force 2013 Interim Report</li><li>2. 2013 Purple Ribbon Task Force Surveys on Alzheimer’s Disease and Related Dementias</li><li>3. Florida Memory Disorder Clinics Map 2013</li><li>4. Alzheimer’s Analysis Report</li><li>5. Geographical Distribution</li><li>6. Florida Alzheimer’s Disease Initiative Brain Bank Data 2011-2012</li><li>7. Memory Disorder Clinics Statewide Report 2011-2012</li></ol>	

## **Executive Summary**

In 2012, the Florida Legislature passed HB 473 declaring:

- Alzheimer's disease (AD) is a slow, progressive disorder of the brain that results in loss of memory and other cognitive functions and eventually leads to death;
- Because AD is accompanied by memory loss, poor judgment, changes in personality and behavior, and a tendency to wander or become lost, a person with this disease is at an increased risk for accidental injury, abuse, neglect, and exploitation;
- Approximately one in eight Americans age 65 and older and almost half of Americans age 85 and older develop Alzheimer's disease or a related form of dementia (ADRD);
- There were 459,806 probable cases of AD in Florida in 2011, whose population is expected to triple by the year 2050;
- AD takes an enormous toll on family members, with an estimated one in four family members providing caregiving support for individuals with the disease;
- Caregivers for persons having AD witness the deteriorating effects of the disease and often suffer more emotional stress, depression, and health problems than caregivers of people having other illnesses, which can negatively affect such caregivers' employment and income;
- Younger-onset ADRD strikes a person who is younger than age 65 when symptoms first appear. Younger-onset AD can strike persons as early as age 30, 40, or 50, with new data showing that there may be as many as 500,000 Americans under the age of 65 who have dementia or cognitive impairment at a level of severity consistent with dementia; and
- The State needs to assess the current and future impact of AD on Floridians and the state's health care system, programs, resources, and services to ensure the continued development and implementation of a more inclusive, integrated, comprehensive, coordinated, and current strategy to address the needs of the growing number of Floridians having ADRD and the corresponding needs of their caregivers.

HB 473 established the Purple Ribbon Task Force (PRTF) within the Department of Elder Affairs (Department) and consisting of 18 culturally diverse individuals appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives. The legislation required the PRTF to submit to the Governor, the President of the Senate, and the Speaker of the House of Representatives a report of its findings and date-specific recommendations in the form of an Alzheimer's disease state plan. The state plan is based upon the January 2013 "PRTF Interim Report." The interim report includes the PRTF's assessment of the needs of persons with ADRD and their caregivers, including persons of all

cultural backgrounds having ADRD and how their lives are affected by the disease from younger-onset, through mid-stage to late-stage; the current and future impact of ADRD; and the existing services and resources available to Florida's population, and the identification of gaps and limitations. The information from the interim report provides a foundation for Florida's comprehensive plan to address the needs of individuals with ADRD and their caregivers. Although the legislation terminates the task force with the submission of the AD state plan, the findings and date-specific recommendations in the state plan provide a catalyst to mobilize a state response to this public health crisis, and a guide to modernize state policy with respect to persons having ADRD.

## **Introduction**

The legislation required the PRTF to provide information regarding the following: 1) State trends with respect to persons having ADRD and their needs, including, but not limited to the following: a. The role of the State in providing community-based care; long-term care; and family caregiver support, including respite, education, and assistance to persons who are in the early stages of AD, who have autosomal dominant younger-onset AD, or who have a related form of dementia; b. The development of state policy with respect to persons having AD or a related form of dementia; and c. Surveillance of persons having ADRD for the purpose of accurately estimating the number of such persons in the state at present and projected population levels; 2) Existing services, resources, and capacity, including, but not limited to the following: a. The type, cost, and availability of dementia-specific services throughout the state; b. Policy requirements and effectiveness for dementia-specific training for professionals providing care; c. Quality care measures employed by providers of care, including providers of respite, adult day care, assisted living facility, skilled nursing facility, and hospice services; d. The capability of public safety workers and law enforcement officers to respond to persons having ADRD, including, but not limited to, responding to their disappearance, search and rescue, abuse, elopement, exploitation, or suicide; e. The availability of home and community-based services and respite care for persons having ADRD and education and support services to assist their families and caregivers; f. An inventory of long-term care facilities and community-based services serving persons having ADRD; g. The adequacy and appropriateness of geriatric-psychiatric units for persons having behavior disorders associated with ADRD; h. Residential assisted living options for persons having ADRD; and i. The level of preparedness of service providers before, during, and after a catastrophic emergency involving a person having ADRD and their caregivers and families; and 3) Needed state policies or responses, including, but not limited to, directions for the provision of clear and coordinated care, services, and support to persons having ADRD and their caregivers and families, and strategies to address any identified gaps in the provision of services. These topics include all of the information necessary to ensure a comprehensive description of the effects of ADRD in Florida, as outlined in the January 2013 "PRTF Interim Report."

The PRTF reviewed the topics from four major perspectives: law enforcement, disaster preparedness; consumer care issues (providers, caregivers, and associations); and research and created four specialized committees comprised of the PRTF membership. The full PRTF, as well as the specialized committees, began meeting at least monthly through publicly noticed Webinar

sessions, beginning in October 2012 and November 2012, respectively. The meetings and activities of the PRTF and committees, including development and editing of recommendations, adhered to a timeline agreed upon by the PRTF. Although many of the recommendations were developed and vetted within committee meetings, prior to review and discussion within the full PRTF meeting, an equal number of recommendations were developed by individual PRTF members for review and discussion by the full PRTF. All recommendations include a rationale associated with the PRTF findings, action steps, a timeline, and cost considerations. The full PRTF determined the appropriateness and viability of each recommendation to contribute to the value of the Alzheimer's disease state plan in addressing the needs of persons with ADRD, caregivers, and families.

## **Overview of Alzheimer's Disease or Related Dementias**

Dementia is the decline of a person's memory and other mental abilities to the point that the decline interferes with interactions and the ability to do daily tasks on the job or at home (*Florida Alzheimer's Disease Initiative Education Manual, 2012*). Alzheimer's disease is the most common form of dementia and accounts for an estimated 60 to 80 percent of dementia cases (Alzheimer's Association, 2013).

ADRD is not a normal part of aging, although the greatest known risk factor is increasing age, and the majority of people with Alzheimer's disease are 65 and older. Alzheimer's disease does not only affect the older population. Up to 5 percent of people with the disease have early onset Alzheimer's, which may affect individuals in their 40s or 50s (National Institute on Aging, 2011). According to the "2013 Alzheimer's Association Facts and Figures" report, other risk factors for Alzheimer's include having family history of Alzheimer's, mild cognitive impairment with memory problems, cardiovascular disease, fewer years of education, mental and social inactivity, and moderate to severe brain injury.

The 2012 National Institute on Aging Alzheimer's Disease Fact Sheet provides the following information regarding changes in the brain with Alzheimer's disease:

### **Very Early Signs and Symptoms**

Memory problems are typically one of the first warning signs of cognitive loss, possibly due to the development of Alzheimer's disease. Some people with memory problems have a condition called amnesic mild cognitive impairment (MCI). Individuals with this condition have more memory problems than normal for people their age, but their symptoms are not as severe as those seen in people with Alzheimer's disease. Other recent studies have found links between some movement difficulties and MCI. Researchers also have seen links between MCI and some problems with the sense of smell. The ability of people with MCI to perform normal daily activities is not significantly impaired. However, older individuals with MCI, compared with those without MCI, develop Alzheimer's.

A decline in other aspects of cognition, such as word finding, vision or spatial issues, and impaired reasoning or judgment, may also signal the very early stages of Alzheimer's disease.

## **Mild Alzheimer's Disease**

As Alzheimer's disease progresses, memory loss worsens, and changes in other cognitive abilities become evident. Problems can include getting lost, experiencing trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, using poor judgment, and having some mood and personality changes. People often are diagnosed in this stage.

## **Moderate Alzheimer's Disease**

In this stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought. Memory loss and confusion grow worse, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out tasks that involve multiple steps (such as getting dressed), or cope with new situations. They may have hallucinations, delusions, and paranoia, and they may behave impulsively.

## **Severe Alzheimer's Disease**

By the final stage, plaques and tangles have spread throughout the brain, and brain tissue has generally shrunk significantly. People with severe Alzheimer's cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down.

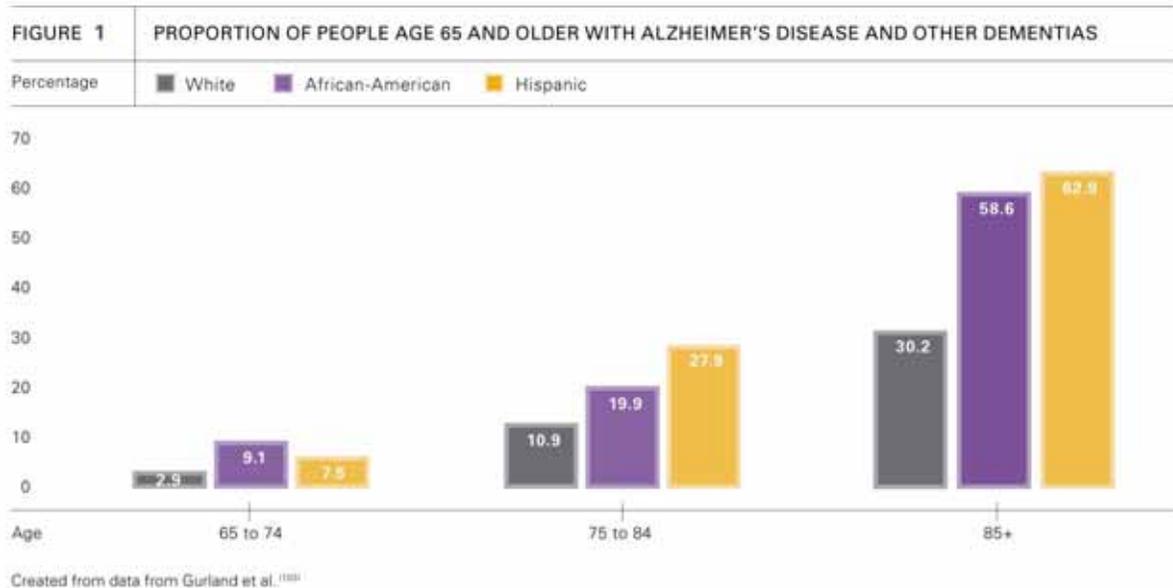
## **Purple Ribbon Task Force Findings**

The PRTF conducted an inventory of resources available to assist and support persons having ADRD, their caregivers, and families. To reinforce this effort, the Department conducted five surveys developed in collaboration with the PRTF. The surveys addressed the experiences of five groups of stakeholders, including persons with ADRD; family caregivers of persons with ADRD; concerned family members and friends of persons with ADRD; health care providers and paid caregivers of persons with ADRD; and policy, legal, education, and other professionals. A total 840 people responded to the surveys. The inventory of resources and the surveys together highlighted needs of persons with ADRD and their caregivers, the impact of ADRD, and the existing services and resources, and also provided an identification of gaps and limitations.

### **Assessment of the needs of persons with ADRD and their caregivers, including persons of all cultural backgrounds having ADRD**

The prevalence of ADRD is found to be proportionately higher among members of the African American and Hispanic population than members of the Caucasian/white population. According to the "2013 Alzheimer's Association Facts and Figures" report, data indicate that in the United States, older African-Americans are probably about twice as likely to have Alzheimer's and other dementias as older whites. Hispanics are about one and one-half times as likely to have Alzheimer's and other dementias as older whites.

The difference in the prevalence of ADRD among racial groups is attributed to health conditions, such as high blood pressure and diabetes that may increase the risk for ADRD more so than genetics. Lower levels of education may also attribute to the increased prevalence of ADRD. Another factor regarding ADRD among other cultures is that missed diagnoses are more common among older African Americans and Hispanics than among older whites (Alzheimer’s Association, 2013).



2013 Alzheimer’s Disease Facts and Figures, Alzheimer’s Association

Cultural diversity within older African Americans may shape health perceptions and knowledge of ADRD. This diversity may contribute to disparities in the detection and treatment of ADRD in this high-risk population. Cultural perspectives differ across ethnic groups and may affect caregiver experiences in several domains, including perceptions of the caregiving role, utilization of support services, and clinical presentations and interactions. In addition, psychological characteristics often predict adjustment among family members in a theoretically consistent and interpretable manner (Chan, Lee & Lieh-Mak, 2000).

According to the “2013 Alzheimer’s Association Facts and Figures” report, among caregivers of people with Alzheimer’s disease and other dementias, the NAC/AARP found the following:

- A greater proportion of white caregivers assist a parent than caregivers of individuals from other racial/ethnic groups (54 percent versus 38 percent).
- On average, Hispanic and African-American caregivers spend more time caregiving (approximately 30 hours per week) than non-Hispanic white caregivers (20 hours per week) and Asian-American caregivers (16 hours per week).

- Hispanic (45 percent) and African-American caregivers (57 percent) are more likely to experience high burden from caregiving than whites and Asian-Americans (about one-third and one-third, respectively).

Among people age 70 and older who require dementia care, whites are the most likely to receive help from their spouses, Hispanics are the most likely to receive help from their adult children, and African Americans are the most likely to receive help from a non-family member (National Academy on an Aging Society, 2000).

According the “2013 Alzheimer’s Association Facts and Figures” report, the care provided to people with Alzheimer’s disease and other dementias is wide-ranging and in some instances all-encompassing. More than half of dementia caregivers report providing help with getting in and out of bed, and about one-third of family caregivers provide help to their care recipients with getting to and from the toilet, bathing, managing incontinence, and feeding. These findings suggest the heightened degree of dependency experienced by some people with Alzheimer’s disease or a related form of dementia. Fewer caregivers of other older people report providing help with each of these types of care. In addition to assisting with Activities of Daily Living (ADLs), almost two-thirds of caregivers of people with Alzheimer’s or a related form of dementia advocate for their care recipient with government agencies and service providers (64 percent), and nearly half arrange and supervise paid caregivers from community agencies (46 percent). Caring for a person with dementia also means managing symptoms that family caregivers of people with other diseases may not face, such as neuropsychiatric symptoms and severe behavioral problems. Caregivers of people with ADRD provide care for a much longer time, on average, than caregivers of older adults with other conditions.

In “The Department of Elder Affairs 2013 Purple Ribbon Task Force Survey,” caregivers were asked to indicate the areas in which the person they care for needed “a lot of help.” The predominant area of help needed was transportation outside the home (78%); taking care of the person’s residence and personal living space (76%); and helping the person with activities such as eating, dressing, or bathing (41%). Sixty-nine percent of respondents said that care recipients needed help in “other” areas, consisting mostly of medication management, toileting, issues related to disorientation and confusion, unpredictable behavior, and communication issues. In addition, caregivers indicated several areas of help needed by persons with ADRD who wish to remain in their homes. These included respite for the caregiver (65%), personal care (58%), financial assistance (52%), medical care (41%), and legal advice (36%). Caregivers were asked about the specific difficulties they experienced as a consequence of their caregiving. The highest rated difficulties reported were lack of time for themselves (53%); anxiety and depression (47%); “other” difficulties (46%); and to an equal extent financial burdens, difficult behaviors, and not enough time for oneself and family (39% each). “Other” difficulties reported by caregivers included understanding ADRD, the challenge of communicating with family and friends who are not educated about ADRD, loss of friends and feelings of social isolation, and feeling guilty about placing the person with ADRD outside of the home.

## **Assessment of the Current and Future Impact of ADRD**

As Section 430.501-504, F. S., indicates, the Florida Legislature found that “Alzheimer’s disease and similar major memory disorders affect an alarmingly high percentage of citizens, primarily those over 65 years of age, and yet little is known of the cause, prevention, or treatment of this disease,” and created the Alzheimer’s Disease Initiative (ADI).

According to the “2013 Alzheimer’s Association Facts and Figures” report, stigma around Alzheimer’s disease exists, in part, due to the lack of public awareness and understanding of the disease, preventing people from doing the following:

- Seeking medical treatment when symptoms are present,
- Receiving an early diagnosis or any diagnosis at all,
- Living the best quality of life possible while they are able to do so,
- Making plans for their future,
- Benefitting from available treatments,
- Developing a support system, and
- Participating in clinical trials.

Stigma and lack of awareness also impacts Alzheimer’s disease research. The government funds Alzheimer’s research at lower rates than other diseases, even when the cost of caring for Alzheimer’s disease is significantly higher.

David Hilfiker, 68-year-old retired physician who was diagnosed with Alzheimer’s disease, noted, “We tend to be scared of Alzheimer’s or embarrassed by it. We see it as the end of life rather than a phase of life with all its attendant opportunities for growth, learning, and relationships.” (From *A Memoir from Inside Alzheimer’s Disease*, 2012.).

The Department of Elder Affairs 2013 Purple Ribbon Task Force Survey indicated persons with ADRD were most concerned about being a burden on others and reported that the loss of the ability to drive, anxiety, and depression were the most challenging issues they faced. Caregivers and family and friends reported that losing control over their lifestyle, difficulty communicating with the person with ADRD, and changing family relationships were the most challenging issues for caregivers or families of persons with ADRD. Families and friends as well as health care providers and paid caregivers were also concerned about caregiver depression and anxiety. In contrast, health care providers, paid caregivers, and other professionals considered paying for services the number one issue. Respondents perceived becoming a financial burden on children

of families with a person with ADRD and dealing with financial, legal, and insurance issues as further major concerns for families involved with ADRD in the professional group.

The Purple Ribbon Task Force Survey indicated thirty-nine percent of caregivers reported that they were employed, of which 29 percent were employed fulltime. The ability to remain employed poses another challenge for caregivers. Forty-nine percent of respondents said that caregiving responsibilities affected their employment. Of those who said that caretaking responsibilities affected their employment, 47 percent indicated that they had to cut back on hours of work, while 33 percent reported that they had left their job.

The Alzheimer's Association's "2013 Alzheimer's Disease Facts and Figures" report states an estimated 5.2 million Americans of all ages have Alzheimer's disease in 2013. This includes an estimated 5 million people age 65 and older, and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's.

Relative to the prevalence of ADRD in Floridians at the present and in future projections, the "2013 Alzheimer's Disease Facts and Figures" report states that one in nine people age 65 and older (11 percent) has Alzheimer's disease. The estimated numbers for people over 65 come from the Chicago Health and Aging Project (CHAP), a population-based study of chronic health diseases of older people. The report indicates that in the year 2000, the estimated number of Floridians with Alzheimer's disease was 360,000. The estimated number in 2010 was 450,000, and the estimated number for 2025 is 590,000. The study indicates the percentage of change in the number of people with Alzheimer's disease from 2000 to 2010 was 25 percent. The percentage of change in number of people with Alzheimer's disease from 2000 to 2025 is projected to be 64 percent.

The Department of Elder Affairs 2013 Purple Ribbon Task Force Survey reflected national trends. Caregivers as well as persons with ADRD reported that the most prevalent diagnosis was Alzheimer's disease (74% and 34%, respectively). However, the most frequent response of persons with ADRD was that they had not yet been diagnosed (38%). Family caregivers of persons with ADRD and respondents with ADRD reported that 28 percent and 19 percent of ADRD diagnoses, respectively, were dementia. An additional 15 and 24 percent reported memory loss. Eighteen percent of persons with ADRD reported a diagnosis with mild cognitive impairment compared to only four percent of persons with ADRD for whom family caregivers provide services. "Other" diagnoses included memory disorders that are complications of other diseases such as diabetes, Huntington's disease, reduplicative paramnesia, and muscular dystrophy. Family caregivers said that the majority of persons with ADRD were diagnosed by a neurologist (53%), followed by a family doctor or primary care physician (24%), a memory disorder clinic (9%), and a geriatrician (7%).

The "2013 Alzheimer's Disease Facts and Figures" report states the number of Americans surviving into their 80s, 90s, and beyond is expected to grow dramatically due to advances in medicine and medical technology, as well as social and environmental conditions. Additionally, a large segment of the American population is within the range of elevated risk for Alzheimer's and other dementias, with the first baby boomers having reached age 65 in 2011. By 2030, the

segment of the U.S. population age 65 and older is expected to grow dramatically, and the estimated 72 million older Americans will make up approximately 20 percent of the total population (up from 13 percent in 2010). As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer’s disease.

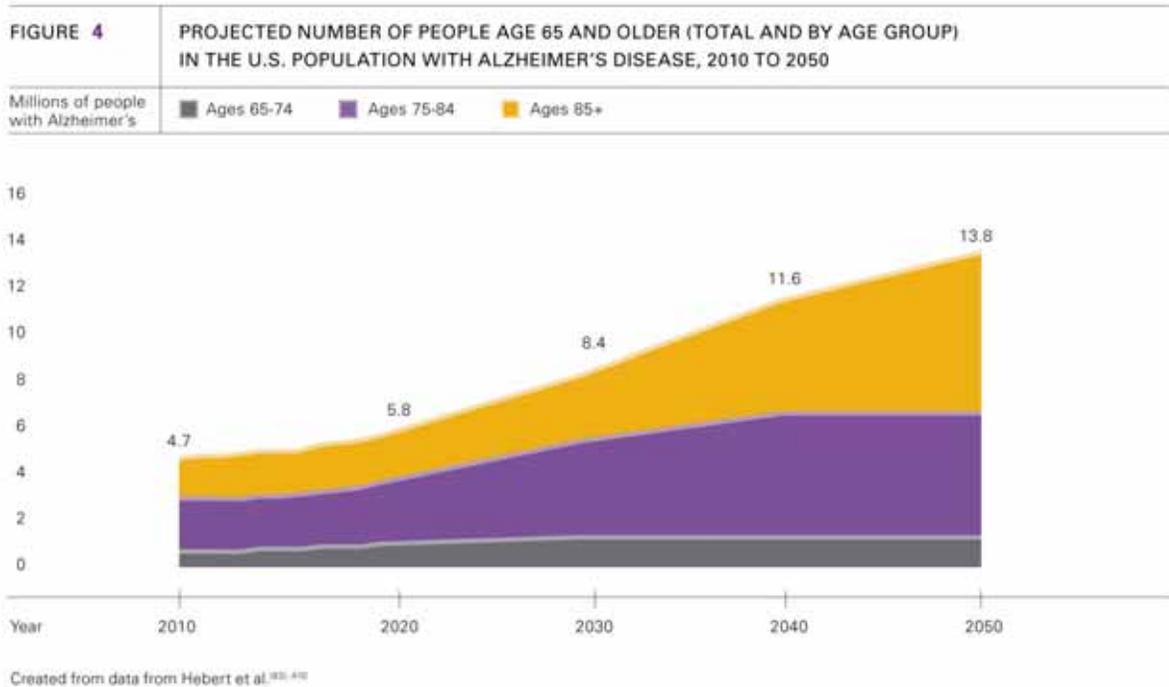
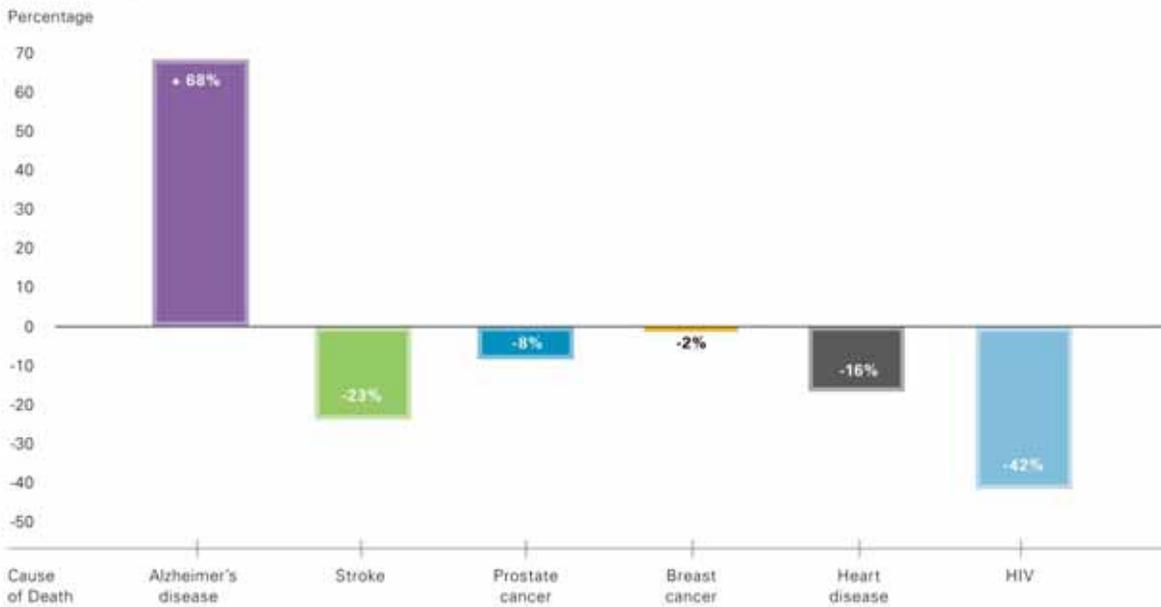


Figure 1 2013 Alzheimer’s Disease Facts and Figures, Alzheimer’s Association

In the United States, Alzheimer's disease is the sixth-leading cause of death and the only cause of death among the top 10 in the United States that cannot be prevented, cured, or even slowed (CDC, 2011). The Alzheimer's Association's "2013 Alzheimer's Disease Facts and Figures" report states between 2000 and 2010, deaths attributed to Alzheimer’s disease increased 68 percent, while those attributed to the number one cause of death, heart disease, decreased 16 percent.

FIGURE 5 | PERCENTAGE CHANGES IN SELECTED CAUSES OF DEATH (ALL AGES) BETWEEN 2000 AND 2010



Created from data from the National Center for Health Statistics.<sup>1113,1246</sup>

2013 Alzheimer's Disease Facts and Figures, Alzheimer's Association

According to the Alzheimer's Association's "2013 Alzheimer's Disease Facts and Figures" report studies indicate that people age 65 and older survive an average of four to eight years after a diagnosis of Alzheimer's disease, yet some live as long as 20 years with Alzheimer's. This indicates the slow, insidious nature of the progression of Alzheimer's. On average, a person with Alzheimer's disease will spend more years (40 percent of the total number of years with Alzheimer's) in the most severe stage of the disease than in any other stage. Much of this time will be spent in a nursing home, as nursing home admission by age 80 is expected for 75 percent of people with Alzheimer's, compared with only 4 percent of the general population. In all, an estimated two-thirds of those dying of dementia do so in nursing homes, compared with 20 percent of cancer patients and 28 percent of people dying from all other conditions. Thus, the long duration of illness before death contributes significantly to the public health impact of Alzheimer's disease.

Florida has a significant ADRD epidemic, with nearly 10 percent of the ADRD cases in the United States. The total cost of care for ADRD patients in Florida is estimated at \$20 billion annually. The current and future economic impact of ADRD on Florida is massive and growing. The State of Florida must be a leader, not a bystander, in the fight to cure ADRD by 2025.

### **Assessment of Existing Services and Resources Available to Florida's Population**

In Sections 430.02 and 430.03, F.S., the State delineated its intentions regarding the care and treatment of elders and established the Department as the primary state agency responsible for administering human services programs for the elderly and for developing policy recommendations for long-term care. The Legislature created the Alzheimer's Disease Initiative (ADI) in Sections 430.501 – 430.504 F.S. The Department administers the ADI, serving individuals age 18 or older with a diagnosis of Alzheimer's disease or related memory disorder, or 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.

The ADI is a state general-revenue-funded program consisting of the 1) Alzheimer's Disease Advisory Committee, comprised of 10 members selected by the Governor. The Committee advises the Department in the performance of its duties, including legislative, programmatic, and administrative matters that relate to Alzheimer's disease patients and their caregivers; 2) Memory Disorder Clinics (MDCs) that provide diagnostic and referral services, conduct basic and service-related multidisciplinary research, and develop training materials and educational opportunities for lay and professional caregivers of individuals with Alzheimer's disease; 3) Florida Brain Bank is the entity designated by the DOEA to collect postmortem normal (control) brains and brains of individuals who were clinically diagnosed as having Alzheimer's disease for the purpose of conducting comparative research aimed at learning about, finding a cause, and developing a treatment or cure for the disease; 4) Model day care programs that provide service delivery to persons suffering from ADRD and training for health care and social service personnel in the care of persons having ADRD; and 5) In-home and facility-based respite care and supportive services, including caregiver training and support, education, counseling, specialized medical equipment, services and supplies, and case management. The purpose of the ADI is to provide a continuum of services to meet the changing needs of individuals and families affected by Alzheimer's disease and related disorders (ADRD).

The Department of Elder Affairs 2013 Purple Ribbon Task Force Survey indicated, caregivers reported that they mostly accessed services such as support groups (45%), home health (43%), personal care/bath assistance (36%), legal services (29%), adult day services (27%), and hospice services (25%) to care for persons with ADRD. The majority of caregivers reported that services accessed were mostly private pay, either by the caregiver (74%) or by other family members (12%). Medicaid paid for 18 percent of service costs. Medicare was the most prevalent source of "other" payments (32%).

### **Identification of Gaps and Limitations**

Although the Department administers other programs and services that benefit persons having ADRD, caregivers and families, the ADI is the only publicly funded program specialized to address the needs of individuals affected by ADRD. In "The Department of Elder Affairs 2013 Purple Ribbon Task Force Survey," caregivers reported several areas of help needed to keep the

care recipient at home. The main types of support needed to help keep persons with ADRD at home included respite (65%), personal care (58%), financial assistance (52%), medical care (41%), and legal advice (36%). The Survey showed 27 percent of caregiver respondents accessed adult day services. Less than 20 percent of caregiver respondents said that they accessed respite services to care for the person with ADRD; however, 65 percent reported that the type of support needed to keep the person with ADRD at home was respite.

The Department of Elder Affairs 2013 Purple Ribbon Task Force Survey further indicated the majority of caregivers (73%) received some help from others in their caregiving responsibilities. The greatest sources of assistance were paid help (42%), spouses (29%), siblings (18%), and adult children (17%). “Other” sources of help consisted mostly of staff in nursing homes, hospices, assisted living facilities, and adult day care settings. An open-ended question asked caregivers who provided routine assistance to the person with ADRD when the caregiver was absent. The largest percentage of respondents (34%) said that a family member, spouse, or friend would help. Twenty-two percent said there was no additional help, and, of these, one-fifth said they provided care 24/7.

In 2012, the Florida legislators passed the “Specialized Alzheimer’s Services Adult Day Care Act.” An adult day care center may not claim to be licensed or designated to provide specialized Alzheimer’s services unless the adult day care center’s license has been designated as such pursuant to Section 429.918 F.S. “Specialized Alzheimer’s services” means therapeutic, behavioral, health, safety, and security interventions; clinical care; support services; and educational services that are customized for the specialized needs of a participant’s caregiver and the participant who is affected by Alzheimer’s disease or an irreversible, degenerative condition resulting in dementia. Within this statute are specific requirements for the delivery of services to persons with ADRD. There is need for full implementation of the “Specialized Alzheimer’s Services Adult Day Care Act.”

Assisted living facilities (ALFs) provide housing, meals, and one or more personal services for a period exceeding 24 hours, to one or more adults who are not relatives of the owner or the administrator. There is a specialty license available for limited mental health services, but there is no specialty license for ALFs that care for residents with Alzheimer’s disease. A facility that claims it provides special care for persons with ADRD must disclose those services in its advertisements or in a separate document. There is a need to define and specify ADRD ALFs.

Individual statutes address quality measures employed by providers of care, including providers of respite, adult daycare, assisted living facilities, skilled nursing facilities, and hospice services. There is a need to determine the standards and measures in place for each service provider type.

The Department of Elder Affairs 2013 Purple Ribbon Task Force Survey participants in the policy, legal, education, and other professional survey category perceived the greatest challenges for persons with ADRD to be difficult behaviors and the loss of driving ability (59 percent each) with wandering and safety closely following at 56 percent. Professionals identifying “other” issues affecting individuals with ADRD reported that their loss of independence, stress related to anticipating disease progression, and finding needed support and knowledgeable health professionals were major challenges.

Often legal issues affect the independence and dignity of people with Alzheimer's disease and related dementias. Florida's "Baker Act," residing at Chapter 394 of the Florida Statutes, deals with the voluntary or involuntary commitment of people whose cognitive function actually creates a danger to themselves or others. Sometimes voluntary or involuntary commitment proceedings are initiated by assisted living or skilled nursing facilities where the person resides. There is need to ensure that people who need intervention receive it even when the dangerous behaviors may not be immediately apparent to first responders and hearing officers while, at the same time, preserving human rights and the dignity of all involved. It may be possible to provide resources, regulation, and tools to better ensure that, whenever possible, residents receive "treatment in place" rather than being transferred by involuntary commitment to a mental health facility.

Chapter 744 of the Florida Statutes provides for different types of guardianships including an "involuntary guardianship," protecting people who are incapacitated, often from their own actions and vulnerability. The court determines whether the person is incapacitated and, if so, to what degree. The court can then appoint a "guardian" to exercise certain rights of the incapacitated person or "ward." There is need for better education on less restrictive alternatives to guardianship, including greater awareness of powers of attorney, advance health care directives, and other planning so that people can avoid guardianship.

Forty-eight percent of caregiver respondents in the "Department of Elder Affairs 2013 Purple Ribbon Task Force Survey" said they had not made any plans or other preparations for a natural disaster such as a hurricane. Only seven percent had registered with their local emergency management agency for assistance in evacuating to a special-needs shelter. Persons with ADRD and their caregivers may be at greater risk of unfavorable health outcomes and loss of independence if there is a disruption to their support network and continuity of care. Persons with ADRD depend on their family, friends, and caregivers for assistance with their activities of daily living, such as bathing, preparing meals, transportation, and taking medications. Factors such as the cognitive impairment of ADRD, along with diminished sensory awareness, and social and economic limitations affect the ability to prepare for, respond to, and recover from a disaster. Education and increased public awareness are both key components to a successful disaster preparedness plan for Floridians with ADRD and their caregivers. There is great diversity and disparity in Florida county emergency and disaster preparedness websites. There is need for intensified public-service efforts educating caregivers and persons with ADRD on how to plan and prepare for natural and man-made disasters and improved disaster preparedness planning and coordination in each community.

The Department of Elder Affairs 2013 Purple Ribbon Task Force Survey indicated the typical respondent in the health care provider and paid caregiver category was a 51-year-old white, non-Hispanic female. The majority (62%) said they had a training certificate or license. Forty-one percent had been providing care for persons with ADRD between six and 15 years. Respondents worked in a wide variety of settings caring for persons with ADRD including assisted living facilities (37%), private residences (21%), adult day or family care homes (19%), nursing facilities (12%), and hospices (8%). Sixty-five percent of the facilities employing the

respondents offered cognitive assessments or screening. In accordance with statutes governing assisted living facilities licensed under Section 429.178 F. S., nursing facilities licensed under Section 400.1755 F.S., hospices licensed under Section 400.6045 F.S., adult day care centers licensed under Section 429.917 F.S., and home health agencies licensed under 400.4785 F.S., the approval of ADRD-specific training is the responsibility of the DOEA. The ADRD Training Approval Program provides for review and approval of training providers and training curricula for health service providers that provide dementia-specific care. There is need for monitoring the use of approved curricula and training providers to ensure the materials and classes adhere to approved curricula, and whether they are appropriate for the care setting. In addition, there is need for required continuing education.

All respondent groups of “The Department of Elder Affairs 2013 Purple Ribbon Task Force Survey” were asked to identify the most critical ADRD issues state government should address. The majority of family caregivers indicated that access to affordable and appropriate dementia-specific care (85%); ensuring quality of care (80%); research on prevention, treatment, and clinical trials (77%); education and training for caregivers (75%); having an ADRD educated and trained workforce (75%); and assisting families in paying for care (72%) were “very important” issues for state government to address. The other survey response groups rated these issues similarly in importance, ranging from 56 to 85 percent. Some of the “other” critical issues recommended were fostering quality nursing homes that accept Medicaid, promoting caregiver support, better coordination of fragmented ADRD services, implementing a centralized informational resource for answering questions about service and payment availability, and offering more services.

## **PRTF Recommendations**

### **Assessment of the Needs of Persons With ADRD and Their Caregivers, Including Persons of All Cultural Backgrounds Having ADRD**

#### **Recommendation:**

**Revise the 701S Screening Tool to better identify issues related to ADRD so consumers can be properly prioritized for services and be referred appropriately. The tool should allow for the senior or caregiver to report whether there are memory issues. This is becoming more important with the anticipated aging trends forecasting large increases for those affected by Alzheimer's disease.**

- a. Add an additional question after #35 to ask the client or person completing the 701S "Are you experiencing any significant memory problems?"
- b. Add to the comprehensive list of "Health Conditions" (item #41) conditions related to ADRD.

#### **Rationale for Recommendation:**

The 701S is the screening tool used to prioritize individuals for placement on and removal from the waiting lists for supportive services. It is critical that dementia-related concerns be clearly identified for proper waitlist placement and appropriate referrals for services. It also needs to be included and weighted in the scoring of the prioritization score, which determines the order of which individuals are removed from the waiting list.

Action Steps:

- The Department should draft a revised 701S to include relevant questions related to dementia.
- The Department should hold rules workshops for public comment.
- The Department should promulgate rules and publish the final assessment.
- The Department should make necessary changes to the Client Information and Registration Tracking System (CIRTS) for proper scoring of the revised assessment.
- The Department should distribute the final assessment through a Notice of Instruction to the Aging and Disability Resource Centers for implementation.

Timeline:

This is as soon as possible, as determined by the Department of Elder Affairs.

Cost Considerations:

This is to be determined by the Department of Elder Affairs.

**Recommendation:**

**Conduct a survey of family caregivers affected by ADRD.**

Rationale for Recommendation:

Florida has one of the nation's largest populations affected by ADRD, most of whom are cared for by family caregivers. Every indication suggests that the state's population affected by ADRD is rapidly growing. However, there are no broad-based, current, hard numbers about the exact size and composition of the state's population affected by ADRD, and its family caregivers. (The State currently uses scholarly estimates and related projections to determine its ADRD and family caregiver populations.)

A series of coordinated surveys should be undertaken by both public and private sector entities, with each entity responsible for a specific geographic area and with these surveys conducted in a similar timeframe. By using a broad group of surveyors, the State will better ensure that this task is completed in a timely and cost-effective manner, as well as gaining insights about survey-related successes, failures, and costs for future survey efforts. These surveys would focus on age, sex, race, location, and types of local ADRD resources known, used, and needed.

A related survey of family physicians and pharmacists should also be undertaken to gain insights into the number of ADRD persons, types of local and regional ADRD services referenced, types of ADRD drugs prescribed and their related costs. It would also be helpful to know what percent of ADRD persons have insurance that discounts related drugs and the overall discount amounts.

The State can use this information to better determine the actual status of its ADRD population, as well as the on-going impacts of ADRD on various segments of its overall population. This information can be used to identify various regions where needs appear to exist or be emerging, so that better targeting of public information or service resources can be directed. If it appears that ADRD population needs are outstripping existing resources, the State will be better positioned to make requests for enhanced federal support. Furthermore, the State's research and public safety entities will have enhanced insight into existing conditions and emerging needs, which should provide sounder footing for their planning efforts.

The State already has a "head start" on this initiative. As part of the Purple Ribbon Task Force's preparation for this report, a limited survey was released online to gather a variety of recent ADRD insights.

#### Action Steps:

- The Department should create a list of public and private agencies that currently assist persons having ADRD and their family caregivers on a local and/or regional basis, making sure to have statewide coverage of ADRD-related services.
- The Department should seek to partner (for survey design, conduct, and interpretation) with a state university that is currently involved in ADRD research (e.g., University of South Florida, University of Florida, or University of Miami), using the previously administered ADRD survey as a substantive basis, and create a delivery and analysis methodology. The survey will be designed so that responses can be made online or through the use of hard copies at existing ADRD service facilities.
- Existing public and private ADRD service groups should be asked to urge families that it currently assists, either to complete the survey online or to fill out a hard copy survey at a participating ADRD service facility. Each local or regional ADRD service group will be responsible for monitoring the completion of its surveys and reporting related progress to the Department. (If a local or regional ADRD service group cannot conduct these surveys, the Community College serving that area should be asked to be responsible for the survey and monitoring tasks in that area.)
- The Department should collect all survey data from each state region and provide both monitoring and administrative support to the survey response effort, if necessary.
- The Department and its university research partner should analyze all survey data and produce a joint report.

#### Timeline:

Ideally, this survey should be conducted by the Department each year, but certainly no less than every five years. Lastly, in conjunction with its university research partner, the Department

should determine whether it is feasible to conduct a companion survey of all family physicians and pharmacists to gather and analyze their ADRD insights.

#### Cost Considerations:

- The costs related to this initiative should be relatively minimal.
- The two largest components involve the Department’s administrative oversight and survey analysis, as well as survey analysis by a designated university research partner. Furthermore, the Department has an existing survey model that could be used as a basis for this effort. Therefore, it should not have to expend inordinate resources to create a “new” survey tool.
- The university research partner should not incur significant costs for this project. Survey consultation and analysis could be addressed by existing staff with only a minimal project-related time commitment. In fact, the insights gained from this involvement could be used as a tool and a basis for future related research. However, the state may need to cover university travel costs for survey-related consultation with Department staff.
- The Department, in consultation with local and regional ADRD service groups, may have to provide minimal costs associated with the notification and collection of survey data from its ADRD family caregivers.
- If the Department decides to conduct a companion survey of family physicians and pharmacists, it will have to determine the costs associated with creating and administering surveys through the state’s medical association and pharmacies.

#### Recommendation:

**Create a statewide buying cooperative for family caregivers affected by ADRD.**

#### Rationale for Recommendation:

Most of the costs assumed by family caregivers affected by ADRD are not covered by health care insurance (Medicare, Medicaid, or private). Excluding medicine, caregivers must provide a variety of personal care items (such as adult briefs, sanitary wipes, pads, gloves, special foods and dietary supplements). As the ADRD symptoms worsen, the demand for these out-of-pocket expenditures increase. Conversely, when the same ADRD persons are treated by a health care facility, medical expenses are covered by their insurance.

Family caregivers must pay full price for ADRD-related personal care items, and these items are rarely discounted. The continued and increasing expense of these needed items creates a burden on already-strained household budgets.

However, there are two major obstacles to the realization of a statewide buyer cooperative:

- A new state-supported initiative could rival a potential private sector entity that could provide this service, even if that private entity does not now exist.
- There is no existing entity that provides this type of service in either the public or private sector.

Therefore, the state should explore the possibility of finding an existing buyer cooperative that might be enticed to address this need.

#### Action Steps:

- The Department should gather a list of all commonly used personal care and nutrition items that ADRD persons routinely require, as well as their related costs and places of common availability.
- In collaboration with other appropriate state agencies and certain private sector entities (possibly including Associated Industries of Florida), the Department should evaluate existing private sector entities that might be willing to expand their current activities to include a statewide buyer cooperative for ADRD family caregivers. (A potential starting point is the Southwest Florida Governmental Purchasing Co-Operative Group, which helps several local governments in Southwest Florida to purchase commodities at lower costs because of increased purchase volumes.)
- If this direction proves fruitless, the Department should examine the possibility of expanding the ADI, seeking the aid of the Florida Council on Aging or, perhaps, inquiring whether a statewide vendor like Wal-Mart might be willing to provide discounted products to eligible ADRD family caregivers.
- The Department should determine the level of commodity discount possible through bulk purchases on a regional or statewide basis.
- The Department should select entities that can provide key discounted commodities in strategic locations around the state.
- The Department should establish a contract with the selected entities to ensure how the sales will be transacted and how to identify savings that will be passed on to the ADRD family caregivers.
- The Department should create an identification source for eligible ADRD family caregivers.
- The Department should provide notification of this resource through the widest possible network of local, regional, and statewide sources.

#### Timeline:

It is probable that it could take 9-12 months to fully explore and properly structure this initiative. That would mean that it would not be ready for legislative consideration until the run-up to the 2015 legislative session.

#### Cost Considerations:

- It is probable that most private sector entities would be seeking start-up funds to offset initial administrative and logistical costs, until cost could be recouped through sales. If so, the state would need to anticipate the related initial costs and negotiate a feasible agreement to recover its investment.

- One potential way to avoid such costs would be to partner with a Wal-Mart, Costco, Walgreens, or Publix to provide the needed items at an agreed upon discounted amount to state-designated family caregivers affected by ADRD.

**Recommendation:**

**Pass legislation that will provide a tax credit to businesses that provide financial benefit assistance to employees using adult day care services for family members affected by ADRD.**

Rationale for Recommendation:

Since the 1997 MetLife Study of Employer Costs for Working Caregivers, new research is validating the issues facing employed caregivers and their employers. The report stated:

- At least six out of 10 employed caregivers reported that they had made some work-related adjustments as a result of their caregiving responsibilities;
- An estimated nine percent of the caregivers who were employed left the workplace as a result of their caregiving responsibilities;
- Three percent of the caregivers took early retirement;
- Six percent of the caregivers left work entirely; and
- An additional 10 percent of the employed caregivers reduced their work hours from fulltime to part-time.

Employer costs associated with eldercare and caregiving were as follows:

- Replacing employees,
- Absenteeism,
- Crisis in care,
- Workday interruptions,
- Supervisory time,
- Unpaid leave, and
- Reducing work hours from full-time to part-time.

Employers need to develop new workplace programs for eldercare as they did for childcare. The incentive of a tax credit will stimulate the use of adult day services and reduce absenteeism from the workplace. The added-value benefit to employees will also reduce health care costs based on episodes of stress and depression.

Action Steps:

- The Department and the Florida Adult Day Services Association (FADSA) should create a public and employer campaign that educates on the benefits of using adult day services as a employee benefit, and
- The Department should draft language for the development of a tax credit for employers or employee caregivers.

### Timeline:

**2015-2016** - FADSA and the Department will collaborate on an education campaign about using adult day services.

### Cost Considerations:

- \$100,000 to develop and conduct the campaign

### Recommendation:

**Ensure access to dementia-specific services, information, and resources for Hispanics/Latinos, African-Americans, and families living in rural areas.**

### Rationale for Recommendation

The Hispanic population is increasing in size and prominence, and it is the fastest growing ethnic group. One in eight people in the U.S. is Hispanic/Latino. By the year 2050, if the trend continues, one of four Americans will be of Hispanic/Latino origin. Studies have shown that Hispanics are twice as likely to have Alzheimer's disease as Caucasians. Hispanics develop symptoms of Alzheimer's disease up to seven years earlier than non-Hispanic Caucasians. Diabetes, high blood pressure, and vascular disease (all risk factors for AD) are very prevalent among Hispanic seniors.

Alzheimer's is more prevalent among African Americans than among Caucasians. A study in the Journal of American Medical Association shows that African-Americans may be up to four times more likely to have AD than Caucasians.

The impact on caregivers can be severe. Older Hispanics are more likely than other seniors to live with their families. Minorities are not receiving the support they need. There are a number of barriers that keep many minority and rural caregivers from receiving dementia services:

- **Cultural barriers:** The U.S. health care system is very different from those in Spanish-speaking countries. In addition, there is mistrust of traditional medical institutions, cultural insensitivity in medical professionals, and dissatisfaction with health care systems that often lead to care by alternative health care providers. The fear of intrusion by government may compound the problem.
- **Language barriers:** For many people, seeking information services about memory loss can be stressful. It can be even more difficult for non-English speakers and individuals unfamiliar with the health care system.
- **Limited services:** Culturally proficient care for minorities is limited in some communities.
- **Lack of awareness.** Many families are not aware of the disease, its demand on caregivers or the variety of resources available in the community. There is a general belief that

dementia is a normal aging process or a mental illness. Symptoms are often unrecognized until elders are unable to fulfill their family/social roles. As a result, services are not utilized until late in the disease, limiting the effectiveness of treatments that depend upon early intervention. AD outreach can be a gateway to educating caregivers and linking families with community-based organization and services which are needed to prolong family care.

From 2003-2007, the Florida Chapters of the Alzheimer's Association received state funding to partially fund the program, "Reach Out Florida," that assisted minority communities throughout Florida. This extremely successful program designated a statewide coordinator who worked with local organizations, groups, and churches to increase awareness about AD, access to AD services, and support for culturally diverse and underserved communities statewide.

Since 2001 until present, the Florida Gulf Coast Chapter of the Alzheimer's Association manages the Memory Mobile. The Memory Mobile is one of the most effective mobile AD support and education service delivery vehicles in the country, receiving national service awards. Many Alzheimer's caregivers are truly isolated and do not have the ability to leave their loved ones to go to an office or drive hours to a memory screening site. The Memory Mobile provides memory screens, outreach education, care consultations, and information services, and it assists those impacted by AD into ongoing medical care and support systems.

#### Action Steps:

- Public and private organizations should provide culturally appropriate information on dementia and caregiving.
  - a. Disseminate materials in Spanish and English. See materials and websites from the Alzheimer's Association, the Administration on Aging, the Family Caregiver Alliance, the National Institutes of Health (NIH), the Department, and the Department of Health (DOH).
  - b. Increase awareness through community outreach, education, networking, and utilizing county health departments.
- Public and private organizations should reach out to families in their homes and communities, and train caregivers on dementia and how to gain access to support.
  - a. Partner with and train community-based organizations about dementia, caregivers, and how to link to appropriate community services. Build a presence in each community by partnering with local groups and churches.
  - b. Present information through community events and Hispanic media.
- The Department should provide access to state and local dementia-capable services.
  - a. Ensure availability of local programs to help guide minority family caregivers to resources.
  - b. Ensure ADRCs connect caregivers to community resources with expertise in dementia care.
- The Department should support caregivers by ensuring that dementia-capable services exist in the community.

- a. Identify gaps in service and offer an array of options for families, such as care consultation, respite care, and adult day care.
- b. Identify best practices in specific areas, i.e., expansion of Memory Mobile or other programs.
- The Department should require more aggressive outreach programs with the MDCs.

Timeline:

- 2014: The Department, DOH, and public and private organizations will develop a plan for minority outreach.
- 2015: Implement the plan.

Cost Considerations:

- Staff and time of Department and DOH in developing a plan: \$200,000 will be incurred by departments.
- Public and private organizations, and the Alzheimer’s Association, will assume cost.

**Recommendation:**

**Ensure persons and family caregivers affected by ADRD have better access to memory screening and support.**

- Review MDCs to ensure maximum efficiency.
- Require MDCs to aggressively outreach to underserved, minority, and rural families.

Rationale:

ADRD is a major public health issue that will increasingly affect the well-being of society and communities. Unless and until the disease can be effectively treated or prevented, the number of Americans with ADRD will increase significantly. Florida has more than 450,000 persons age 65 and older with ADRD with a 31 percent increase expected in the next 12 years. Nearly one million family members and friends of persons with ADRD provide over 1.1 billion hours of unpaid ADRD care in the state of Florida.

Action Steps:

- The Legislature and the Office of Program Policy Analysis and Government Accountability (OPPAGA) should review MDC services to ensure maximum efficiency.
- The Department’s contract with the MDCs should require aggressive outreach to underserved and minority families.
- The Legislature should designate funding to increase the number of regional MDCs to enable more diagnoses, support, education, and research to be effective in addressing ADRD.

### Timeline:

- Increase funding for ADI services (during 2014 Legislative Session)

### Cost Considerations:

- Funding increases are subject to appropriation.

### **Assessment of the Current and Future Impact of ADRD**

### **Recommendation:**

- **Legislatively restructure the Alzheimer’s Disease Advisory Committee (ADAC) to create an effective and modern entity that will concentrate on the challenges that Florida faces in addressing the growing issues associated with ADRD.**
- **Create a specialized ADRD department within the Department that the ADAC would be reporting to regarding recommendations in the State Plan. This department would also be the source for access to community resources.**
- **The ADAC approves requests for the designation of Memory Disorder Clinics based on the needs of the State.**

### Rationale for Recommendation:

In accordance with Section 430.501 (2), F.S., the Alzheimer’s Disease Advisory Committee is comprised of 10 members selected by the Governor, which shall advise the Department in the performance of its duties under the ADI, and advise the Department regarding legislative, programmatic, and administrative matters that relate to Alzheimer’s disease victims and caretakers. Section 430.501 (5), F.S. indicates the Advisory Committee may establish subcommittees as necessary to carry out the functions of the Advisory Committee.

In an advisory capacity, the Advisory Committee is to offer recommendations to the Department in the performance of its duties. It is at the discretion of the Department to take action on those recommendations.

Revolutionizing the ADAC to be effective in its legislative responsibilities is imperative. The advancements and changes in the methodologies of care and treatment of ADRD have changed dramatically from 1985. Early estimates of the prevalence of Alzheimer’s disease were two million cases in the United States. Current estimates are four million. The increase is believed to be due to both an increase in awareness of the disease and an increase in median age of the U.S. population. Regional demographics also greatly affect the percentage of Alzheimer's disease cases found in each state (Robert I. Koester and David E. Stooksbury Lost Alzheimer's Subjects- Profiles and Statistics, 1987). The number of reported ADRD cases in Florida alone is 452,000 according to the Department and Centers for Disease Control.

The ADAC has the authority and the responsibility to consult with the Department in program and service policy development. The ADAC also has the responsibility to evaluate and make recommendations to the Department and the Florida Legislature concerning the need for additional memory disorder clinics in the state. However, there is no means to approve the designation of a MDC. In accordance with Section 430.501 (3) (b) 8, F.S., the members of the ADAC and subcommittees receive no salary, but they do receive reimbursement for travel and per diem expenses. Section 430.501 (3) (b) 7, F.S., requires the Department to provide staff support and assist the committee in the performance of its duties.

#### Action Steps:

- The Legislature should increase the ADI budget to fund specialized services to persons with ADRD and their caregivers.
- The Legislature should restructure the ADAC to make it a more pertinent part of Alzheimer's disease policy making process, and clearly outline these responsibilities in statute.
- The Department should create positions that are designated for coordination of the ADI services and dissemination of ADRD information.
- The ADAC should retain the authority to make additional MDC approvals.
- The Department should develop a single unified state communication system that will ensure the most current and accurate information on ADRD and access to services and programs.
- The Department should improve public awareness.
- The Legislature should designate sufficient funding to the MDCs to enable effective diagnosis, support, education, and research.
- The Department should eliminate the Model Day Care Centers and replace them with the Alzheimer's Specialized Adult Day Care Licensed Centers.
- The Legislature should provide new funding for Alzheimer's Specialized Adult Day Care licensed centers.
- The Department should continue ADI funding for adult day care center without a specialized license.

#### Timeline:

As soon as possible but to be determined by the Department of Elder Affairs.

#### Cost Considerations:

To be determined by the Department of Elder Affairs.

#### **Recommendation:**

**Create an annual statewide ADRD Family Caregiver Week.**

#### Rationale for Recommendation:

Annually, one week should be designated for the statewide formal recognition of family caregivers affected by ADRD at the local, regional, and state levels. This week should be marked by a series of ADRD-related events, as well as state-supported public outreach and information dissemination about both state-sponsored and local nonprofit efforts. Prominent people (from the public and private sectors) should be encouraged to make statements about their personal ADRD experiences and the need for broader public support of persons having ADRD, their family caregivers, and the community-based resources that support them.

The Alzheimer's Association's "2013 Alzheimer's Disease Facts and Figures" report states an estimated 5.2 million Americans of all ages have Alzheimer's disease in 2013. This includes an estimated 5 million people age 65 and older, and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's.

Family caregivers bear the increasingly significant physical, emotional, and financial burdens (as the ADRD symptoms progress) to enhance and prolong the lives and care of their ADRD charges. Furthermore, many of these caregivers function in relative ignorance of existing state and local ADRD support resources.

Much of the ADRD-related care consists of Medicare and Medicaid costs, and state-supported facilities are only able to assist a percentage of the ADRD population. It is unlikely that the state could support a massive increase in ADRD care, should a significant number of ADRD family caregivers no longer be able to care for their loved ones at home. Furthermore, it is probable that a massive increase in state responsibility for the total care and support of its ADRD population would probably devastate its ability to support other ADRD-related activities, such as research and training.

Therefore, the state of Florida should formally recognize and celebrate the role being played by its ADRD family caregivers. These caregivers provide enhanced care to a growing segment of the state's population, and annually save the state billions of dollars in ADRD health care expenditures. This celebration should also be used to expand public awareness of ADRD and urge local support for the various local nonprofit and state-supported ADRD resources.

#### Action Steps:

- The Department should convene a group of ADRD representatives, with a special emphasis on family caregivers and related services to do the following:
  - a. Identify each existing public and private sector ADRD support group and related service in the state;
  - b. List the various ADRD services and resources provided by each group;
  - c. List high profile public and private sector leaders, willing to make public information statements in support of ADRD family caregivers and the importance of their roles, and urging public support of their efforts;
  - d. Suggest a week when a dedicated set of ADRD media messages and activities could be offered in a coordinated statewide effort; and

- e. Draft an Executive Order for the Governor's signature, with support from the Legislature's leadership.
- The Department should seek the Governor's signature on the Executive Order.
  - The Department should produce a series of television, radio, and print ads that would highlight ADRD family caregiver contributions, as well as ADRD caregiver support, training, and services available in each various major media region.
  - Each local, regional, and statewide ADRD support group should hold related observances and activities that same week.
  - The Department should initiate a statewide media blitz of ADRD statistics, caregiver stories, high-profile leader statements, and listings of area resources during the designated week in each of the state's major media centers, using all forms of local media (television, radio, billboards, and newspapers).

Palm Beach County offers one example of how a similar observance is handled at the local level. Perhaps this initiative (and other local practices) could be used as a basis for a statewide celebration.

#### Timeline:

It would probably take about six months to plan and complete this process, but that timetable should begin as soon as possible.

#### Cost Considerations:

- The Department should determine the alternative costs of producing this effort, which would involve both public- and private-sector cost components.
- The state of Florida could bear the staff costs of organizing and producing the Executive Order, the various media pieces and the efforts to reach out to the various local, regional, and statewide ADRD groups.
- Private media firms will donate the release of messages in each of the state's primary media areas.

#### Recommendation:

**Support research consortia to enable successful competition for National Institute of Health (NIH) funded Alzheimer's Disease Research Centers (NIH ADRCs).**

#### Rationale for Recommendation:

NIH ADRCs serve a role much like national cancer center designations. They create infrastructure that supports clinical care for patients with ADRD, but also serve as hubs of translational science that are necessary to advance science in order to reach our shared goal of preventing or treating ADRD. They are essential to increasing enrollment for industry sponsored clinical trials, and for ensuring that advances in science and care for ADRD are efficiently and rapidly disseminated to all community-based medical practices.

In order to successfully compete for NIH ADRCs, there must be investment in basic organizational supports. Funds could be used to create the infrastructure for human capital, launch prerequisite collaborative studies, and enhance database support needed to successfully compete for these grants.

Notably, in contrast to Florida which has no active NIH ADRC's and 500,000 ADRD patients, California has six active NIH ADRCs and 600,000 patients with ADRD. Supporting efforts to compete successfully for NIH ADRCs provides an excellent return on investment.

- NIH ADRCs would be funded by the NIH at \$1.5M/year for five years. Most centers once funded are renewed providing another five years of funding potentially *doubling* the return on investment (ROI).
- Enhanced clinical trial capacity in ADRD resulting from each NIH ADRC could result in 100 additional clinical trial subjects/year enrolled in the state of Florida resulting in an additional \$2M-\$10M+/year. As the NIH ADRCs become more established, this capacity to attract clinical trials grows.
  - a. The vast majority of these funds would be from the pharmaceutical industry.
  - b. The head of ADRD research at a major pharmaceutical company views Florida with its huge number of elderly as a major opportunity for enrolling the large number of elderly subjects needed to advance promising AD drugs.
- As center grants, NIH ADRCs are mandated to support other research and clinical trial activity. After five years one can expect an additional \$1M/year of extramural support (commercial, public sector, private philanthropy/foundations)
- These centers serve as hubs for established science, technology, engineering, and mathematics (STEM) employees, as well as training centers for those interested in STEM jobs.
- These centers will result in medical tourism, as they represent a sign of clinical and scientific excellence to the outside world.
- These centers provide a basis for many private-public partnerships in the battle to cure ADRD
- Infrastructure developed for the NIH ADRCs would also be used to compete for other programmatic grants that provide a similar level of extramural funding

#### Action Steps:

The Department should create a legislative process for research consortia to obtain state funding for these efforts.

#### Timeline

ASAP, as at least one academic consortium is submitting a grant application this year to the NIH.

#### Cost Considerations:

\$1.25M for each consortium submitting an ADRC application

## **Recommendation:**

### **Provide state funding for a grant program for ADRD research.**

- Allocate \$10M annually to support NIH ADRD research through a peer-reviewed grant program; and
- Promulgate a license plate program to raise awareness and support for this initiative. (Florida Initiative for Neurodegenerative Disease, FIND). Funds raised from this program (expected to be \$1-2M/year) can partially offset the state commitment.

### **Rationale for Recommendation:**

The current measures of disease burden for ADRD show that it is grossly underfunded. For example i) on a per affected individual basis, NIH funding for HIV/AIDs is 23 times the level of that for ADRD and ii) for every \$2 that ADRD costs the United States, we spend less than 1 cent on research. Despite recent efforts to raise awareness of the societal and economic impact of ADRD, there have been very limited increases in ADRD research funding.

Florida, with 500,000 AD patients and a large elderly population at risk for ADRD is the epicenter of the ADRD epidemic in the U.S. (<http://download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012000325.pdf>). As outlined in the National Alzheimer's Prevention Act there is growing national commitment to address the AD epidemic. As a country, we cannot afford inaction (<http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>). Given the burden of ADRD in the state, Florida should be a leader, not a bystander, in the fight to cure ADRD by 2025.

The current and future economic impact of ADRD on the State of Florida is massive and growing. With 10 percent of the ADRD cases in the US, the total cost of care for ADRD patients in Florida is estimated at \$20B. ADRD may cost the state \$1B per year in Medicaid funds.

There is hope. Scientific advances over the last 25 years have provided sound rationale for the development of potentially disease-modifying ADRD therapies. These therapies primarily target the suspected trigger or triggers of the disease (proteins called A $\beta$  and tau). Thus, therapeutic advances, coupled with advances in presymptomatic detection of underlying ADRD pathology in non-demented individuals, suggest that concerted translational research efforts focusing on prevention or early intervention could dramatically reduce the incidence and prevalence of ADRD. Indeed, it is now well recognized that ADRD actually begins 15-20 years before it is clinically diagnosed, providing a window for intervention prior to a patient becoming symptomatic. Moreover, as researchers illuminate the downstream pathways that contribute to the degenerative process, there is also hope that we can better intervene and slow or even reverse the progression in those with clinically diagnosed ADRD.

Numerous examples exist of how providing "seed" or bridge funding provides an excellent return on investment. Based on previous experiences with state or benefactor funding, several

Florida institutions can show a greater than 8:1 return on investment. That is, if the state invests \$1, this can translate into \$8 in funding from other extramural sources.

#### Action Steps:

- The Legislature should create a granting program modeled after the James and Esther King and BankHead Coley Biomedical Research Programs in which a peer-reviewed process is used to award grants. Include technology transfer grants that can lead to new spin-off companies and awards for start-up biotechnology companies.
- The Department should convene a group of stakeholders to develop a grant review award, administration, and compliance process.
- The Department should seek approval for the FIND license plate initiative including some funds for marketing and design of these plates in the funding request.
- Private sector firms should partner with the state in supporting these awards.
- The Department should develop RFA(s) for these awards.

#### Timeline:

- Summer 2014: Develop a model for the grants and FIND license plates.
- Fall 2014: Seek Legislative approval for the model
- Spring 2015: Incorporate the project into State budget.

#### Cost Considerations:

\$10M annually to support ADRD research through a peer-reviewed grants program

#### **Recommendation:**

##### **Support ADRD Conferences in the State of Florida.**

#### Rationale for Recommendation:

Given the present and future impact of ADRD on the state, scientific conferences relating to ADRD can have a major impact on public awareness. Mt. Sinai Medical Center currently hosts a joint three-day international conference. This year the 11<sup>th</sup> annual symposium on Mild Cognitive Impairment and Second Annual Early Diagnostic and Treatment Workshop were held in Miami Beach with 250 participants. With additional funds from the State, these and other conferences could be expanded.

Luring one of the larger ADRD conferences to the State of Florida would have major economic impact. Several of the ADRD conferences attract more than 3,000 attendees and would be estimated to provide at least a \$4M economic impact related to food, lodging, and travel expense of the attendees. Intangible impacts will be the demonstration of advocacy and the public awareness that will derive from such conferences.

### Action Steps:

- Entities should seek funds from the Legislature.
- Entities should develop a funding model for such conferences along with economic impact and publicity guidelines.
- Entities should draft RFA for Conference Grants with Criteria for award (matching funds, economic impact, public awareness plans).

### Timeline:

- Summer 2014: Develop a model for conference grant review and administration.
- Fall 2014: Share the model with the Legislature for approval.
- Spring 2015: Incorporate the project into the State budget.

### Cost Considerations:

\$200,000 annually to support national/international conferences on AD to be held in Florida.

### **Recommendation:**

**Create a Dementia Specialist Position at the Department that can implement the Purple Ribbon Task Force recommendations and state plan.**

### Rationale for Recommendation:

There are more than 500,000 Floridians diagnosed with ADRD. As the “baby boomer” generation gets older, the already-burgeoning population of people expected to develop ADRD increases. There is need for more of the following: 1) services, 2) expert health providers, 3) education, 4) community outreach, 5) partnerships, and 6) research.

As the PRTF completes the State Plan for ADRD, Florida will require an ADRD Coordinator at the Department to implement the recommendations of the PRTF and implement the state plan. The ADRD Coordinator would keep abreast of the expanding needs of families struggling with progressive dementia and coordinate the statewide network of programs, organizations, and initiatives. This position would help these families and encourage the ongoing development of innovative education, training of medical and social service providers, research, and state-of-the-art care facilities.

### Roles of ADRD Coordinator

The ADRD Coordinator would be responsible for carrying out the recommendations of the PRTF and implementing the state plan. The coordinator would seek grants and other opportunities to expand State resources, update a directory of appropriate resources, maintain a database, facilitate partnerships for services, develop and promote educational workshops, research projects, and referrals, and serve as a central access point for in-state and out-of-state

inquiries for programs or research proposals. Working with current service providers, the ADRD Coordinator would identify gaps in underserved areas of the State and work with community organizations to pool public and private resources to fill these gaps. The ADRD Coordinator would provide ongoing updates to related agencies regarding innovative resources such as the Silver Alert, educational materials such as the *Florida Alzheimer's Disease Initiative Education Manual: Understanding & Dealing with Alzheimer's Disease & Related Disorders*, and regularly write and help to submit articles on ADRD issues to the *Elder Update*.

#### Skills of ADRD Coordinator

To maximize the potential of this role, the ADRC Coordinator should have a proven track record in grantsmanship, and an expertise in the basics of progressive dementia, including the evaluation process, management strategies and treatments, caregiving needs, and community resources. Communication and technical skills such as computer literacy are important to optimize links with state policymakers and the national network of government, civic, and private foundations dealing with progressive dementia issues.

The MDC Coordinators across Florida therefore recommend the designation of an ADRD Coordinator housed at the Department to further the mission of the State in addressing the needs of families affected by ADRD.

#### Actions Steps:

The Department should request one FTE position for ADRD Coordinator.

#### Timeline:

As quickly as possible

#### Cost Considerations:

No current ADI program funding such will be impacted.

**Questions:** Leilani Doty, PhD, Director, University of Florida Cognitive & Memory Disorder Clinics, Box 100236, Department of Neurology, McKnight Brain Institute, Gainesville, FL 32610-0236, Office: 352-273-5550; Fax: 352-273-5575, Direct line: 352-273-5620, Email: [dotyl@neurology.ufl.edu](mailto:dotyl@neurology.ufl.edu),

### **Assessment of Existing Services and Resources Available to Florida's Population**

#### **Recommendation:**

- **Increase the use of adult day care services for persons with ADRD.**
- **Increase ADI funding for adult day care services and respite.**
- **Provide one-time state funding for existing licensed adult day center renovations to modify the environments to accommodate ADRD (i.e., wander alert alarms, walking/pacing paths, and showers/baths).**

Rationale for Recommendation:

According to the MetLife National Study on Adult Day Services, the centers are a key provider of long-term care services in the United States. They provide a program of activities, health monitoring, socialization, and assistance with daily activities, which allows individuals to continue to live in their homes and receive needed care in a supportive, professionally staffed, community-based setting. Adult day care services also benefit family caregivers by enabling them to remain in the workforce or receive needed respite. The program provides both the caregiver and the participant with direct services. Adult day care services provide cost-effective care, while supporting individual autonomy, allowing individuals to “age in place,” and enhancing the quality of life for both participants and family caregivers.

As part of the Florida State Plan on Aging, Objective 2.7 is to prevent premature facility placement to persons with ADRD. Adult day care services are preferred to other forms of home and community-based services because adult day care services differ from other forms of long-term care. The focus on the strengths and abilities of a person rather than on his or her illness or loss of functional abilities is therapeutic in itself.

The program monitors medical conditions to prevent unnecessary hospitalization and increase or maintain optimal functional abilities. The strengths of adult day services can provide an extraordinary range of benefits designed to do the following:

- Stabilize medical conditions,
- Reduce crisis episodes of emergency rooms admittance through preventive monitoring and early intervention,
- Prevent secondary disabilities caused by inactivity,
- Improve functional ability through therapeutic and meaningful activities,
- Prevent or delay unnecessary institutionalization,
- Provide an alternative setting of health care to an aging population,
- Increase health and wellness programs/services,
- Improve or stabilize cognitive functioning,
- Increase socialization opportunities decreasing isolation and loneliness,
- Promote better nutrition,
- Educate caregivers,
- Provide respite to caregivers,
- Improve the quality of life,
- Increase the ability to access services and information, and
- Increase self-esteem and dignity.

There are 213 licensed adult day care centers under the Florida Agency for Health Care Administration (AHCA) with a total capacity to serve 10,801 individuals age 18 and older. These figures do not reflect centers that might be exempt from licensure under Chapter 429 F.S. Part III and Chapter 58A.6.0., including assisted living facilities, freestanding hospices, federal government entities, and nursing homes.

The Florida Legislation in 2012 enacted the “Specialized Alzheimer’s Services Adult Day Care Act” (F.S. 429.918) to ensure the quality of care for persons with ADRD. “Specialized Alzheimer’s services” means therapeutic, behavioral, health, safety, and security interventions; clinical care; support services; and educational services that are customized for the specialized needs of a participant’s caregiver and the participant who is affected by Alzheimer’s disease or an irreversible, degenerative condition resulting in dementia. Within this statute are specific requirements for the delivery of services to persons with ADRD and the center may hold itself out to the public as specializing in ADRD. There are additional costs to doing Specialized Alzheimer’s Services Adult Day Care that are prohibitive to small and rural programs. ADI or other funding to service ADRD should not require a “specialized license.”

The majority of adult day service programs cover a wide range of diverse populations that encompass a wide range of impairments (physical, medical, social, mental, and cognitive). The number of centers in geographic areas can range from zero centers in many counties to 78 centers in Broward and Dade counties.

Adult day care centers stimulate the economy and create employment opportunities. There are 150 centers out of the 213 licensed centers that have single owners who operate only one center. Not-for-profit organizations face the same challenge of using assets to choose services for participants rather than to do any capital improvements. Most adult day care centers operate on very tight budgets. The need for one-time funding to enable centers to renovate or modify existing centers to meet the specialized needs for ADRD will enable them to achieve more positive outcomes and better services. This could include modifications such as upgrading of bathrooms to provide showers, “WanderGuard” systems to prevent elopement, and equipment to engage ADRD participants to optimal functioning. This kind of capital improvement is what the Florida Senior Centers achieved in 2008 for community service improvement.

The Area Agencies on Aging can set the rate for adult day care services when those funds are disseminated from the Department. The rates are not consistent throughout the state. Many planning and service areas (PSAs) are not paying a fair rate, and many centers have been put out of business because of the low reimbursement. This not only has an effect on the economy, but it restricts the ADRD person and the caregivers’ choices in long-term care. As a result, Florida purchases more expensive options of care such as nursing homes.

Action Steps:

- Entities should establish fair and consistent rates for adult day services for persons with ADRD across PSAs.
- Entities should work with the State Planning Advisory Committee to achieve goals and objectives.

- The recommended new Office of ADRD and research groups should identify elements for data collection to substantiate the cost and quality of care and life benefits of adult day services.
- Entities should recommend legislative funding to create a one-time budget line for renovations or modification of existing licensed centers.
- The Department should examine the cost to provide adult day care services to persons with ADRD and compare to the current rates.
- The new Office of ADRD should monitor the Medicaid Managed Care organizations for appropriate care and the options to beneficiaries for adult day services.

Timeline:

**2013-2014**

- Amend the Department manual and state funding contracts to have adult day care services as a prerequisite prior to facility placement.
- Establish fair and consistent rates for ADRD adult day care services.
- Draft the elements for data collection and quality outcome measures.
- Report to the Office of ADRD and the ADAC on the progress of goal achievement.
- Increase ADI funding for adult day care services.

**2014-2015**

- Request one-time funding for existing licensed adult day care centers to renovate and improve their facilities to meet the needs of persons with ADRD.
- Develop a participant and caregiver satisfaction survey with Medicaid Managed Care services and organization.
- Establish outcome measures for quality care of persons with ADRD in adult day care centers.

Cost Considerations:

- The increased use of adult day care services should reduce the costs for facility placement.
- Funding sources should remain budget neutral with care plans reflecting the use of adult day care services.
- Increase ADI funding in proportion to waitlist.
- \$25,000 is needed for a Managed Care Satisfaction Survey.
- \$15,000,000 is one-time funding for existing licensed adult day center renovations and modifications of facilities to provide ADRD care.

**Recommendation:**

**Respite: Ensure all family caregivers have access to respite services if needed.**

- Review ADI respite process to ensure maximum efficiency and accessibility.
- Ensure that respite funds help support underserved, minority, and rural families.

### Rationale:

AD places an enormous emotional, physical, and financial stress on individuals who have the disease as well as their family members. Without family members to care for persons with ADRD, the alternative is facility placement. This would place an enormous burden on health care organizations and the government. The estimated annual cost for a person with ADRD to live in a nursing is \$78,000 per year. Caregivers use a disproportionate amount of health care resources as they are hospitalized two-to-three times as often as people the same age who do not provide care to a person having ADRD.

### Action Steps:

- The Legislature and OPPAGA should review the ADI respite funding process to ensure maximum efficiency.
- The Legislature should increase funding for ADI respite services to more caregivers and to remove persons from waiting lists.
- The Legislature should provide new funding for Alzheimer's Specialized Adult Day Care Licensed Centers.
- The Legislature should continue ADI funding for adult day care centers without a specialized license and increase the number in underserved areas.
- The Legislature should provide a Draft Memorial to Congress to create a specific funding source for ADRD CAREGIVER SERVICES as an incentive to states to invest in respite services. This will be a federal match to states' respite funds.

### Timeline:

Increase Funding for ADI services (during 2014 Legislative Session).

### Cost Considerations:

Funding increases for services and waitlists are subject to appropriation.

### **Recommendation:**

**Provide respite care vouchers for family caregivers of persons having ADRD.**

### Rationale for Recommendation:

The provision of assistance for persons having ADRD is a full-time task for many family caregivers, especially those who care for their loved ones at home. As ADRD symptoms progress, there is a need for increased assistance. ADRD caregivers also face increasing threats to their personal well-being (physical, emotional, and financial). Periodically, these caregivers need to travel without their ADRD family members for business or recreation. However, the cost of overnight respite care can range from \$150-200 per day, adding at least \$1,400 to the cost of a

one-week trip. This additional cost, plus a frequent lack of information about reputable facilities to provide overnight respite care, can offer significant barriers to making needed personal or professional trips.

If ADRD family caregivers are forced to provide continuous assistance without physical and mental breaks, their ability to provide increasingly demanding future assistance will be eroded. As a result, their health will be further jeopardized and their ability to care for their family members having ADRD will be diminished. That would result in the State caring for more persons having ADRD.

Florida already has a variety of public and private sector ADRD support groups that directly or indirectly provide short-term respite for family caregivers, but these respite programs do not provide overnight assistance and may have income limits for participation. Many family caregivers do not qualify for existing low-income programs, but do not have the financial flexibility to independently pay for overnight respite care.

There is a need for an initiative that would provide two resources:

- Limited financial subsidy for overnight respite care for ADRD family caregivers, so that they may take required out-of-town trips. The length of this subsidy should cover one-to-seven full days per eligible family.
- Enhanced communications about existing local facilities that provide overnight respite care for ADRD persons.

#### Action Steps:

- The Department should convene a group of organizations that currently provide both short-term and overnight respite care to persons having ADRD, and identify the issues expressed by family caregivers, i.e., typical length of stay and frequency of overnight respite usage. This group should also determine what existing programs could be used as a basis for an expanded statewide program. (Several existing entities that provide limited respite services or referral information include the ADI, Florida Respite Coalition, the RELIEF Program, the Alzheimer's Family Program, and certain hospices and assisted living facilities.)
- The Department should use the information gained from this group to provide and propose the following:
  - a. Profile of overnight respite care activities and needs for different parts of the state;
  - b. List of overnight respite care providers who are certified to assist persons having ADRD;
  - c. Estimated total of eligible persons having ADRD statewide;
  - d. Verified cost(s) for overnight respite care;
  - e. Eligibility criteria for family caregiver access of this resource; and
  - f. Identification of potential funding sources.

- The Department should meet with state legislators to outline the necessity of this program, discuss funding options, and urge programmatic support.
- If successful, the Department should conduct a statewide media blitz to announce its availability to as many ADRD family caregivers as possible, using existing local and regional ADRD assistance groups as primary information conduits.

Timeline:

- Although this resource is badly needed, the process needed to outline the criteria for this program and securing related funding could take at least 12 months. Therefore, it is likely that this initiative may not be available for legislative review until the 2015 session.
- It is unlikely that a significant new funding source can be found in time to include this initiative in the 2014 legislative session. Therefore, the time between the publication of this report and the primary preparation for the 2015 session should be used to find an adequate new funding source and to make an argument for its inclusion in the 2015 legislative and gubernatorial program and budget packages.

Cost Considerations:

A new and possibly significant source of state or federal funding will be needed to support even a modest version of this program. By multiplying 3,150 (an estimate of persons having ADRD to be served initially, based upon a percentage of the number of persons served in the ADI) by \$2,520 (seven full days and nights of certified respite care at \$15.00 hourly), the estimated cost of this program would be nearly \$8 million.

**Recommendation:**

**Provide a Community-Based Emergency Crisis Intervention Program for emergency intervention services that institutes a “course of action” to mitigate ADRD issues for families of all cultures and economic means who find themselves at immediate risk.**

Optional Course of Action:

Initiate a demonstration project that has elements of working initiatives that interface with the consumer, and private and public sectors within a local community for the specific purpose of maintaining the safety and well-being of the ADRD family throughout a crisis.

Rationale for Recommendations:

Presently Florida Statutes mandate that specific state agencies must respond to the need for emergency intervention for the community good, and provides the duties and powers for processing these matters. While a person diagnosed with ADRD is included in the broad definition of “vulnerable adult” (Section 415.102 (27) (28) F.S.), emergency interventions involving persons with ADRD need to be dementia-specific. For example, when the caregiver becomes unexpectedly incapacitated, the person with ADRD becomes completely dependent on

others for his or her welfare and well-being. When these conditions arise during a crisis, unless there are prearranged measures, (especially to keep the person with ADRD at home), much is left up to luck or available good Samaritans.

There are numerous professionals and agencies (Section 415.1034 F.S.) that are mandated to report abuse, neglect, and exploitation of vulnerable adults. Adult Protective Investigators are professionally mandated reporters and are directed to intervene. Those interventions normally include the Baker Act or displacement of the person having ADRD from familiar surroundings, which is not an appropriate intervention for ADRD families. Often the person with ADRD who has been displaced experiences “transfer trauma anxieties” and is not able to return home because of the disruptive experience. There is recognition in the United States that the potential hazard of relocation, especially in the elderly, is institutionalization; hence, they are submerged in a system that can cause premature death (Robertson C. Warrington J. Eagles. *JM Relocation morality in dementia: The effects of a new hospital*. International Journal of Geriatric Psychiatry, 1993; 8: 521-525).

Local law enforcement agencies are contacted daily, 24/7, because a cognitively impaired individual has become vulnerable to a life-impacting or life-threatening situation. Situations that persons suffering with ADRD are exposed to may include the following:

- A person with ADRD driving a car or walking away from home, with no identification, and no memory of who they are, where they live, or what their medical conditions are;
- A caregiver suddenly becomes ill or dies, unbeknownst to others, instantly creating an unsafe environment for the cognitively impaired person who is at home and alone;
- A cognitively impaired person is reported as being abused or exploited;
- A person who has aged in place and whose behavior comes to the attention of a neighbor, friend, remote family member, clergy, etc., who requests assistance; or,
- A person with ADRD having an extreme behavioral problem or an acute psychotic episode requires stabilization interventions, medications, or treatment.

Adult Protective Services (APS) is a state agency that by definition responds to reports of abuse, exploitation, and self neglect of anyone who is a vulnerable adult age 18 or older, received on the statewide, 24/7 Abuse Hotline (Section 415.101 F.S. and Section 415.103 F.S.). The Abuse Hotline staff is trained to question the caller to determine whether there is adequate information to indicate abuse, exploitation, or neglect. When a caregiver becomes incapacitated and the person having ADRD is left alone, he or she is at risk. APS will make a report if it is determined there is need for intervention.

APS protocols address incidents that *have* happened. A crisis involving a person having ADRD includes incidents that *are likely to* happen. In the situation with the absent caregiver, the person having ADRD is at risk for what is *likely to* happen. ADRD has complex severities that demand preventive action in order to avoid harm or loss of life. When the caregiver of a person who requires 24-hour supervision and care is unexpectedly hospitalized, mandated reporters, including law enforcement, must telephone the Abuse Hotline. In this instance, something has already happened, as the unforeseen removal of a caregiver leaves the vulnerable adult at risk

and APS recognizes services are needed. However if the Baker Act is used to remove the person having ADRD from the home as an intervention, that is not what is needed to keep the person having ADRD safe and stable. The removal of the person under sudden conditions (interventions by police, EMTs, caseworkers) could place that person at higher risk for life-impacting changes, compared to being in the home, safe, undisturbed, and with effective interventions that are dementia-specific and are applied expeditiously.

The list of criteria for the Baker Act is:

1. Is the person at risk to themselves or others?
2. Is the person being abused, exploited, or experiencing self-neglect?
3. Is the person suffering with medication issues?

### **An Example of Emergency Intervention: Alzheimer's Community Care's Crisis Management Model**

**2:00 a.m.** – The local Emergency Medical Technician (EMT) notified law enforcement of a female caregiver, age 74, being taken to the hospital by her son because of an acute medical condition. Also, there is a 93-year-old male diagnosed with AD sleeping in the home and should not be left alone, according to the caregiver. The daughter of the 93-year-old lived on the other side of the state and could not come to her father's aid until later on that day, according to law enforcement. In addition, APS was called by the officer, and were told that they would be at the home within three hours.

**2:30 a.m.** – Law enforcement called the Alzheimer's Community Care 24/7 Crisis Line and reported the situation. The Family Nurse Consultant (FNC), a registered nurse, responded to the call and coordinated with law enforcement to contact the daughter of the 93-year-old. The FNC explained the urgency of the situation and provided the daughter with the names and phone numbers of three home health agencies that would respond to her call. The FNC asked that she call her back with the name of the agency that was going to respond. Meanwhile the FNC e-mailed all three agencies letting them know that they may receive a call from a family member who may need their services. The daughter called the FNC with the name of the home health agency that was going to provide the care for her father.

**3:00 a.m.**– The FNC went to the home to wait for the home health agency representative to arrive and to relieve the officer. At 3:30 a.m., the APS worker arrived and assessed the situation. The 93-year-old was still asleep. The APS worker, seeing no risk according to the APS protocols, departed from the scene, requesting the FNC call with the outcome of the intervention. The home health agency's representative arrived at 4:00 a.m. and a call was made to the daughter by the FNC telling her that the representative was at the home. The daughter had received a call from the caregiver's son about caregiver's medical condition and when she was expected to be released from the hospital. The FNC left an Alzheimer's Community Care card and brochure for the caregiver to call for support, and the FNC left the home at 4:15 a.m.

### Outcome of Incident:

No Baker Act was required, and the patient slept through all the drama of making the arrangements and stayed safely in his home until the daughter arrived that afternoon.

The caregiver called the FNC two days later and was grateful for all she had done and an office meeting was scheduled so she could learn about appropriate services, the costs, and resources available so she did not feel overwhelmed with the care. Three outcomes occurred:

- The cognitively impaired person was enrolled in a local specialized Alzheimer's Day Services Center. During the first two weeks, he came two days each week and during the third week and thereafter, he came five days.
- The caregiver started attending support group meetings and attended educational seminars about ADRD.
- Lines of communications were opened, and everyone worked together on behalf of both the caregiver and the person with AD, as the disease progressed and as other medical issues became more critical. The patient died at home six months later, and the two families were together celebrating his life.

#### Justification:

Often in community-based crisis situations, if appropriate resources are established, ADRD families are better served when stabilization can occur within the home. This is a benefit to the patient and the family, and is considerably less expensive than a transfer to a hospital or institution. It is also a realistic goal.

The fact that the Baker Act is largely instituted because there is no alternative course of action makes the outcomes of these incidents more expensive and the ramifications present greater hardship on the families. The funds allocated to APS for emergency placements from a practical standpoint are not available for three reasons:

- The budget is limited and there is great demand;
- The Abuse Hotline initiates the investigation process to trigger intervention. When the investigation declares the complaint unsubstantiated, then it becomes a barrier for families to receive assistance; and,
- There is no state statute that addresses these community-based emergencies.

#### Conclusion:

All emergencies are local. To institute a plan that cultivates and establishes a local solution is important. The solution should incorporate a collaboration of the private, public, and consumer sectors to make the outcomes affordable, accessible, and appropriate.

These interventions cannot have limitations such as the following:

- A wait list for case management,
- Age limitation of 60-plus for case management,
- Limitations on short-term and long-term care management, and

- Limited on-going resources to diminish the risk of nursing home placement.

The overall goal is to sustain the family unit throughout the duration of the disease process. It must not be compromised because of a crisis that can be controlled with the appropriate resources.

No state funds were needed to initiate the Alzheimer's Community Care emergency intervention crisis service described in the example, because the services were planned in advance. Alzheimer's Community Care receives calls from law enforcement agencies, families, and health care providers regularly on its Crisis Line and they are served accordingly.

There are a projected 528,000 Alzheimer's families residing in Florida based on an annual survey done by the Centers for Disease Control and Prevention, but this estimate does not include the thousands of snowbirds who reside here during the winter season. Each case is unique and oftentimes requires "thinking out of the box" solutions; however, there are preventive measures that can be put in place in advance and they are as follows:

- Good family planning regarding the need to focus on diminishing risk factors.
- Maintaining a list of home health agencies and facilities that can make arrangements before such an emergency occurs. This exercise can be completed within the early stages of the disease process.
- Including children and other family members, who are available in the emergency planning process so they can be prepared to participate in assisting during the crisis, and lend support when needed.
- Maintaining contact with caregivers on a routine basis so emergent conditions are diminished. Update the patient's care plan so that these measures are visited and re-visited consistently for his or her continued safety and security.
- Educate law enforcement about the existence of the 24/7 Alzheimer's Crisis Line, its purpose and capabilities, and its limitations.

In the many years that Alzheimer's Community Care has followed these procedures, both home health agencies and assisted living facilities have always been reimbursed for the care that they provided to families during these very stressful times.

#### Action Steps:

- The Legislature should consider amending the definition of mental illness to exclude dementia, Alzheimer's disease, and traumatic brain injury.
- The Legislature, the Department of Children and Families, the Department, and other policymakers should adequately fund quality community supports and services for persons with ADRD and their families to mitigate long-term placements because of a lack of resources and expertise.
- The state should create a demonstration project that incorporates goals and objectives that are family centered, helps preserve quality of life, and allows patients to remain within their homes even if a crisis erupts.

- The state should effectively test demonstration projects in metropolitan, rural, and urban areas.
- The state should require goals and objectives with culturally appropriate values, based on the needs of law enforcement, APS, and the caregiver. This would necessitate their active involvement in structuring the project, ensuring that barriers to assisting ADRD families are removed within the shortest time possible. This assistance must be reliable, capable, and have resources that can address the whole problem with viable solutions.

### Timeline:

#### **2013/14**

- Create legislation to increase funding for APS to specifically respond to ADRD family crisis situations, within an hour of the report, on site, to diminish the removal of a person when experiencing an acute crisis from the home or their present residence.
- The Legislature should fund positions within DCF APS to explore less restrictive alternatives to involuntary placement and require DCF on them yearly.

#### **2015/16**

- Instruct an independent body to evaluate the effectiveness of APS in decreasing long-term care placements with their focus on serving ADRD families. Indicators can be measured by the effectiveness of the responses to emergent disease-driven behaviors and their consequences. The ultimate outcomes are the recognition of a best practice by implementing less restrictive alternatives to involuntary placements to the satisfaction of caregivers, which can be measured through survey instruments.

### Cost Considerations:

- The cost of the service should be based on a value model that is programmatic and dissimilar to a cost reimbursement payment model.
- A high value should be placed on collaborations with the private, public, and consumer sectors, which will contribute to its sustainability for the service. This could be one of the identified outcomes of the demonstration projects.
- If funding is based on the PSA service models, such as with the AAAs, then their annual budgets for the service would differ. The demographics of the ADRD population and its cultural diversity, as well as the PSAs' square miles will have an impact on the cost of the service and would differ from one area to another. In addition, there are urban, rural, and metropolitan communities that have their own set of challenges as well.
- The cost of such a service for each PSA could range from \$25,000 to \$40,000, but the savings are in the hundreds of thousands of dollars when you consider no Baker Act, no nursing home placements, no incarceration if misunderstood behaviors are present, etc.

### Recommendation:

**Implement additional emergency intervention in care facilities for when the following occurs:**

- A caregiver is feeling overwhelmed and needs a break;
- A caregiver is admitted to the hospital and there is no one else to care for the person with ADRD;
- A caregiver passes away and there is no one readily available to care for the person with ADRD; or
- A person with ADRD is found (by public safety workers) alone and in need of additional care, and there is no one to provide care, or time is needed in a court system to complete guardianship procedures.

**Implement additional emergency intervention in the home for when the following occurs:**

- It is in the best interest of the individual with ADRD to be moved to another setting; or
- There is not a facility available for the individual with ADRD.

The model for implementing this intervention is based on the Emergency Services Intervention (ESI) model originally used in the Community Care for the Elderly (CCE) program for high-risk APS clients. The recommendation based on the ESI model would be to use the existing CCE and ADI case management agencies. Trained case managers are on-call to receive calls from public safety workers. They would come to the location to meet with the public safety worker, the individual with dementia, and the caregiver (when one is available) and arrange for an in-home respite work to come into the home to stay with the individual with dementia. To implement additional emergency interventions, this would require funding for the case management agencies and for the respite providers. This concept is a proven model that the aging network is already experienced with implementing and would not require the creation of a separate response system.

Rationale for Recommendation:

First Responders are often called into crisis situations where there is a family member or caregiver who needs to leave and an individual with a dementia would be left unattended. First Responders need a mechanism to have the individual with dementia go to a care facility for the time being or have someone brought into the home in situations where a care facility is not available or moving the individual with dementia is not in the best interest of that individual so that he or she is not left unattended and vulnerable.

Action Steps:

- The Legislature should provide funding for the emergency respite service in a facility or in a home.

- The Department should promulgate rules and establish policies and procedures for implementation.
- AAAs should contract with facilities for the emergency respite and with case management agencies for the emergency in-home respite.
- AAAs and providers should notify first responder agencies of procedures.

Timeline:

The timeline would be determined by the legislative budget process, the process for promulgating rules, and establishing statewide policies and procedures, ready for implementation by 7/1/2014.

Cost Considerations:

This would need to be evaluated further and determined after the proper cost analysis has been completed.

**Recommendation:**

- **Standardize training for law enforcement, including recognizing signs of persons with ADRD, communicating with persons with ADRD, identifying different behaviors, offering Baker Act alternatives, understanding wandering behavior, and knowing local resources.**
- **Increase funding for senior service-type units within law enforcement agencies to follow up with senior crime or exploitation victims.**
- **Recognize the ability for specially trained public safety personnel to initiate guardianship procedures and conduct an evaluation on an individual.**

Rationale for Recommendation:

Law enforcement officers are confronted with life-saving actions every day on the job. In addition to being charged with protecting Floridians, they must be knowledgeable in protecting individuals with ADRD. However, before they can protect them, the front line of law enforcement must understand ADRD and identify behaviors associated with ADRD. Unusual actions by a person with ADRD may include the following:

- **Unsafe driving:** AD may cause erratic driving. Persons with AD who are driving may look drunk and even fail roadside sobriety tests simply because of inability to understand or remember instructions. They may also have accidents and leave the scene because they forgot it happened. Persons with dementia tend to drive more slowly; make errors at intersections; have less awareness of other drivers; have difficulty staying in their lane; and have more frequent and unexpected braking.
- **Shoplifting:** AD does not cause criminal behavior, but it does hinder memory and ability to think logically. As a result, persons with AD may take items from a store without paying for them.

- Indecent exposure: Inappropriate behaviors such as taking clothes off in public or being sexually aggressive are common.
- False reports: A person with Alzheimer's may report an "intruder" in the house who is actually a family member. They may misplace valuables and accuse others. They may also forget where they parked their cars and report them stolen.
- Victimization: Persons with Alzheimer's fall easy prey to con artists, robbers, and muggers. They may also go through evictions, repossessions, and the discontinuation of utility services resulting from delinquent (often forgotten) payments. Senior crime and exploitation is a growing problem. The majority of senior crime or exploitation victims need additional assistance through this process.
- Homicide and suicide: Caregivers may find themselves unable to handle the stress of caregiving and may choose to commit homicide and/or suicide.
- Abuse and neglect: The aggressive behavior of a person with AD can cause them to lash out physically to a caregiver. Distraught caregivers may abuse or neglect a person with Alzheimer's.
- Wandering and/or getting lost: Two-thirds of Floridians with Alzheimer's will wander away and become lost; if not found within 24 hours, nearly half will suffer major injury or death. Wandering can occur on foot, in a vehicle, or on public transportation (train, plane, bus, tractor, riding lawn mower, etc.). A search must begin immediately (do not wait for person to come back on their own).

Front-line law enforcement officers need to be trained on all possible behaviors and resources in the community for support. In 2003-2008, the Florida Chapters of the Alzheimer's Association received partial state funding to implement a statewide training initiative. The reason for success of the program was the contracting with former veterans and retired law enforcement officers who understand and adapt to law enforcement environment. Many presentations were offered to accommodate different time constraints. The most popular part of the program was the creation of a pocket card that can be stored in each cruiser for review when needed.

#### Action Steps:

- The Legislature should provide funding to establish a statewide training initiative for front-line law enforcement. FDLE will manage training contracts.
- The Legislature should increase funding to law enforcement agencies to either establish an active Senior Services Unit in each county or properly fund it at an adequate level. Currently, most Senior Services Units are inadequately funded and under-staffed.
- Public safety personnel should be trained to recommend initiation of guardianship procedures and of the individual. Currently these types of referrals can only be made by DCF APS.
  - a. This should include the ability of specially trained public safety personnel to refer an older adult or person with dementia in need of immediate services be given primary consideration for receiving community-care-for-the-elderly services.
  - b. Grant specially trained public safety personnel access to the Adult Protective Services Referral Tracking Tools (ARTT); this would be an excellent tool for public safety personnel to refer to when responding to a call involving an older

adult. This may alert the responder of services that have already been put in place for the older adult instead of starting the process all over.

Timeline:

- 2013: Work with FDLE on funding request for additional training
- 2014: Funding requests during 2014 Session for training law enforcement
- 2014: Funding requests during 2014 Session for Senior Service personnel
- 2013: Guardianship/DCF

Cost Considerations:

- Training law enforcement statewide \$800,00 recurring
- Additional funds for Senior Service personnel
- Guardianship training

Recommendation:

**Establish a system of acute crisis care for persons having ADRD to be accurately diagnosed and treated for medical issues and ADRD conditions simultaneously. This is an approach to stabilize persons having ADRD who are experiencing an acute crisis, either in home or within a secured behavioral psychiatric unit inclusive of follow-up wrap-around services.**

Optional Course of Action:

Establish a statewide task force with longevity of two years to review, examine, and assess past situations that resulted in persons having ADRD being placed in forensic facilities under the Baker or Marchman Acts and the process ultimately led to their untimely deaths. These persons were exposed to this treatment because they were found wandering and confused or perceived to be harmful to themselves or others due to psychotic episodes that were triggered by complex severities of ADRD as well as other medical co-morbidities such as urinary tract infections, reaction to a prescribed medication, etc. Following this two-year examination of cases, a plan would evolve for implementing several pilot demonstration projects that would establish dementia-specific behavioral treatment. This model would be complementary to local communities, respecting all cultures, inclusive of the local talent and resources, including existing evidenced-based behavioral support systems. These recommended pilot model demonstration areas could be examined within such settings that are urban, rural, and/or metropolitan.

Rationale for Recommendations:

Chapter 394 of the Florida Statutes, known as “The Baker Act,” governs mental health services including voluntary admissions (Section 394.4625, F.S.), involuntary examination (Section 394.463, F.S.), and involuntary placement (Section 394.467, F.S.). Enacted in 1971, the law was

designed to protect the rights and liberty interests of citizens with mental illnesses and ensure public safety.

According to media reports from 1971, the Baker Act, named in honor of its sponsor, Representative Maxine Baker, strengthened the legal and civil rights of patients of state mental institutions. Perhaps more importantly, the Baker Act was designed to require the state Division of Mental Health to offer community services to most patients with mental illness and reserve confinement only if an individual is dangerous to himself or others. During legislative debate on the sweeping revision of Florida's then 97-year-old mental health laws, Representative Baker told her colleagues that "only nine percent of our patients are dangerous to themselves or others, yet 91 percent are under lock and key." She added that "for the 58 percent of our patients who are committed involuntarily, they lose all their civil rights and leave with an indelible stigma. In the name of mental health, we deprive them of their most precious possession—liberty." (See *Times-Miami Herald* Service report from May 11, 1971.) The problem is that ADRD is not a diagnosis of a mental illness.

In the "Judicial Administration of the Baker Act and Its Effect on Florida's Elders" report and recommendations, it was cited during hearings that one question raised was, "Are involuntary examinations being excessively and inappropriately used for elders who reside in nursing homes and assisted living facilities?"

The law is being misused in several ways concerning nursing home and assisted living facility residents.

**First**, the diagnosis of some elders with ADRD may be shown as mental illness, because Medicare and some private insurance companies will not reimburse treatment for persons with a diagnosis of dementia.

**Second**, when a Medicare patient is involuntarily examined or placed, the nursing home is eligible to receive reimbursement for holding the bed empty for a period of time, while providing no actual services. The financial incentive for abusing the Baker Act is compounded when there is a relationship between the nursing home and the Baker Act-receiving facility. Sometimes mental health beds are within the same facility as the nursing home, but the facility receives a higher rate of compensation for individuals hospitalized under the Baker Act than for ordinary nursing home residents.

**Third**, the *St. Petersburg Times* reported in 1995, based on a review of more than 4,000 cases and a statistical analysis of 3,151 petitions for involuntary examinations, that "about two-thirds of people forced into treatment in Pinellas County in 1993 and 1994 were 65 and over." Public testimony before the Florida Legislature indicated that many elders fared poorly and some even died during or shortly after their hospitalization under the Baker Act. While the Baker Act was overhauled in 1996 by the Florida Legislature in response to these allegations, according to a June 14, 1998, article in the *St. Petersburg Times*, "Some mental health advocates, and the state records, suggest the Baker Act still is being used to confine older people, many of whom may simply be confused or unable to care for themselves."

It is predictable that AD patients at some time during the disease process will exhibit stressful behaviors and under the right conditions and with specific “triggers,” they will demonstrate a psychotic behavior that could be interpreted as being at harm to themselves or others if there are no skilled and trained personnel to intervene. During those times if the Baker Act is instituted and an individual is hospitalized under the Baker Act, the cost for that act is expensive and the return on the investment for care is disappointing. The patient’s longevity is compromised considerably.

During the hearings, a general master suggested that Florida’s legal definition of mental illness be revised to exclude those persons whose primary diagnosis is some form of dementia.

The environment of a mental-health-receiving facility is not designed to accommodate a fragile, forgetful, highly agitated, and frightened person with ADRD who has no capacity to understand how he or she got to be institutionalized under the Baker Act. Also, to have to experience these anxieties in total isolation from their family members and in a room with complete strangers is not a skilled treatment for persons with ADRD. In addition, giving them a psychiatric medication that is supposed to calm them and make them “quiet,” may instead destabilize their medical condition spiraling them into a medical decline from which they may never recover.

A high percentage of persons with ADRD who are Baker Acted from their homes may never return. To the dismay of families, they generally do not realize the procedures or treatments administered through a receiving facility’s regulated plan with a mental illness treatment focus that is not dementia specific or medical, are psychiatric. Once discharged, patients’ charts contain a psychiatric disorder release order, hence the majority of times they do not return to their homes or communities or to their former long-term care residences. A disruptive and uncertain placement challenge emerges and becomes a major issue for the family. When a long-term care facility finally agrees to take them, many times it is at the physical and emotional expense of the caregiver because of the long distance they must travel to visit with their loved ones. Caregivers witness the physical and mental decline of their loved ones and ultimately an untimely death, an experience from which the caregivers may never recover.

#### Justification:

Over the next five years, it is anticipated that the behavioral health-operating environment will continue to experience increased psychiatric emergencies in the emergency rooms as well as more need for services for geriatric adults. It is also noted that the number of patients with co-occurring medical problems such as ADRD will increase.

This will most likely result in changes in the behavioral health-operating environment requiring providers to do the following:

- Address both the psychiatric and medical needs of the adult and older adult patient population; and

- Provide a continuum of care that includes both inpatient and outpatient services founded in sound and fiscally responsible operating standards.

Co-occurring physical and psychiatric needs are on the rise because it is estimated that by 2030 persons age 65 and older will comprise 20 percent of the population, up 13 percent. Currently, 35 million people age 65 and older reside in the United States of which 7 million (20%) have a psychiatric illness (Jeste et al., 1999; U.S. Census Bureau, 2000). This number is expected to double to 15 million over the coming three decades (Jeste et al, 1999).

Because we are seeing such significant growth in our older adult population, rapid changes are needed in how services are provided. Nearly twenty percent (19.8) of the population age 55 and older experience specific mental disorders unrelated to the aging process. Studies show that approximately 20.2 percent of these individuals will need inpatient treatment at some point. In addition, the prevalence rate of medical inpatients with a psychiatric co-morbidity ranges from 15 to 50 percent. A number of medical conditions accompany psychiatric needs. The most common chronic illnesses are hypertension, heart disease, stroke, diabetes, and pulmonary and respiratory disease. These medical co-morbidities extend lengths of stay in psychiatric facilities by 3.25 days. Likewise, when patients with primary medical and surgical issues have depressive disorders, the results have been similar.

#### Conclusion:

Due to the growth in the older adult population, better diagnosing practices, and more accurate predictions on the various stages of the disease process through research, it is expected there will be an increased demand for behavioral health care services at all levels of health care. Preparations need to be made so that organizations can provide for complex medical and psychiatric conditions presented by this population that suffers with ADRD.

Floridians with ADRD are regrettably underserved with regard to their behavioral health care needs. Presently, approximately 70 to 80 percent of America's nursing home residents suffer from a primary or secondary diagnosis of psychiatric illness caused by a progressive neurological disorder; however, few receive appropriate care. As a result, Medicare statistics reflect that 15 out of every 1,000 enrollees will experience at least one inpatient hospitalization per year for a psychiatric crisis.

A comprehensive behavioral health care model should incorporate partnerships that will provide a local innovative dementia-capable system with an Alzheimer's family focus. This focus will encompass a coordinated quality care dementia-specific set of best practices throughout the stages of the disease to diminish the risk of a psychotic episode. These acute psychotic symptoms caused by the progression of ADRD are commonly expressed in private homes, community settings, or long-term care environments. It is critical that families are equipped with coping strategies and life skills to strengthen their endurance during these episodic situations to insure that patients will return home or to their former residence with full understanding on what the triggers were that contributed to their behaviors. This positive outcome can only happen if there is a recovery-focused environment inclusive of an appropriate, dementia-specific trained staff

and medical practitioners that possess core mechanisms within the model that treat medical conditions as well as the ADRD simultaneously. This comprehensive and holistic approach versus the industry's standard of treating each need in a vacuum will reverse a negative outcome to positive by abating the physical and mental decline of the ADRD patients. This critical model of care allows the natural progression of the disease to progress to end stage with appropriate coordination of services through involvement with the family and, when acceptable, hospice resources that maintain everyone's dignity and quality of life.

#### Action Steps:

- The Legislature should fund an interdisciplinary study on the continued involuntary placement process.
- Judges and general masters should be adequately trained and educated on ADRD and elder issues, including community resources and issues identified by the AD Advisory Committee as they preside over Baker Act proceedings.
- The Florida Court Education Council should develop a model-training curriculum in this regard, including consideration of videos and other alternative teaching methods.
- The Legislature should consider amending the definition of mental illness to exclude ADRD and traumatic brain injury.
- The Legislature should fund a guardian advocate system that provides each geographical area with a readily available pool of guardian advocates who have training on ADRD issues and psychotropic pharmacology. These guardian advocates could serve on behalf of ADRD individuals for whom no family or friends are willing or able to serve or for whom the appointment of a friend or family member has been found by the court to be inappropriate.
- The Legislature should fund approval of a demonstration project for short-term acute care geropsych units at extended congregate care facilities, especially those with a limited mental health license. These would be used, with physician approval and referral, in place of the Baker Act for probable ADRD persons, eliminating recurring trips to the ER and local crisis stabilization unit for ADRD persons. These units within the community are inclusive of behavioral and clinical specialists on the symptoms of Alzheimer's disease or a related form of dementia and medical conditions. These units' treatments are time sensitive and on the specific needs of the family affected by ADRD with the ultimate goal that the person having ADRD is returned home with the appropriate wraparound services to mitigate reoccurrence of an acute crisis.

#### Timeline:

##### **2013/14**

- Create legislative action to establish an interdisciplinary task force inclusive of stakeholders to examine and evaluate the enactment of a behavioral health program that focuses on the evolution of local community comprehensive health care partnerships to provide innovative inpatient behavioral health care for persons having ADRD who are experiencing acute psychiatric symptoms.

## **2016/17**

- Implement the findings of the interdisciplinary task force's recommendations and required funding to establish several pilot demonstration projects that are local community-based comprehensive behavioral health care centers. These centers could be located within rural, urban, and metropolitan areas within the state of Florida as recommended by the task force. This process should take approximately six months of contractual and administrative exercises (RFPS, awards, etc.).

## **2020/21**

- Submit a detailed and comprehensive commissioned report to the Governor, Speaker of the House, and President of the Senate on the effectiveness, efficiency, and cost-savings measures that have evolved from the implementation of these comprehensive behavioral health care centers. Also, include ratings by families impacted by ADRD regarding their satisfaction with specialized services, indicating whether services helped them to sustain their quality of life during traumatic conditions and lessened the need for long-term care placement.

### Cost Considerations:

- Medicare billing has demonstrated these units are capable of sustaining themselves (Colorado and Texas reports).
- Cost savings may be compared to three admissions per year in the round robin scenario as opposed to getting accurate diagnosis and treatment, followed by in-home wraparound services including nursing, care management, counseling, and medication management.

### Recommendation:

#### **Develop an efficient and supportive Alzheimer's Disease Initiative (ADI).**

- Create the Office of Alzheimer's disease or a related form of dementia (ADRD) in statute under the Executive Office of the Governor (EOG) that will encompass the challenges, issues, funding, resources, information, research, and data that are associated with ADRD.
  - a. The Office would work directly with DOEA, FDLE, DCF, AHCA, DOH, DOVA, and the Emergency Operation Center (EOC) as the ADRD contact.
  - b. The Governor shall have authority to appoint the Executive Director.
  - c. The mission is to improve access to treatment, diagnosis, and services.
  - d. The Office would coordinate a research consortium for universities to obtain state and NIH funding
  - e. An annual ADRD conference would be hosted by the Office of ADRD.

- f. The Office would initiate training and certification for ADRD to encompass all industries and personnel (physicians, hospitals, therapists) in contact with persons having ADRD.
- Move the Alzheimer’s Disease Advisory Committee to the new Office of ADRD; restructure the membership; and update the purpose of ADAC.
  - a. The ADAC would be moved from DOEA to the Office of ADRD.
  - b. Increase the number of appointed positions to 18 members. These appointments may follow the Purple Ribbon composition: six members shall be appointed by the Governor, six members shall be appointed by the Senate President, and six members shall be appointed by the Speaker of the House of Representatives.
  - c. The ADAC would advise the Office of ADRD on policy issues and oversee the implementation of the State Plan developed by the Purple Ribbon Task Force.
  - d. The ADAC would approve requests for the designation of MDCs based on the needs of the State.

Rationale for Recommendation:

Florida is a leader and is proactive in addressing the challenges and issues associated with ADRD. The creation of an Office of ADRD under the Executive Office of the Governor is a trailblazing action that would change the paradigm of managing ADRD. Creating a position under the Department would be a bandage procedure for the attention and work that needs to be accomplished in the challenges and issues of ADRD. Florida must move to the next level to tackle the care, costs, treatment, research, and services of ADRD.

Florida has been a trendsetter for the research, care, treatment, and services that it has created for persons and caregivers with ADRD. Section 430.501-504, F. S., indicates the Florida Legislature found that “Alzheimer’s disease and similar major memory disorders affect an alarmingly high percentage of citizens, primarily those over 65 years of age, and yet little is known of the cause, prevention, or treatment of this disease,” and created the Alzheimer's Disease Initiative (ADI). It is imperative to open the Statute to advance its purpose in the great effort to provide care, quality of life, and contain the costs to the State.

The purpose of the ADI is to provide a continuum of services to meet the changing needs of individuals and families affected by Alzheimer’s disease or a related form of dementia (ADRD). The ADI is administratively housed within the Department of Elder Affairs (DOEA).

Legislators have approved the following ADI services: respite and MDC funding, ADRD training requirements and certifications, special waiver projects, Silver Alert, specialized AD adult day care license, and the Purple Ribbon Task force to tackle challenges and the costs to Florida that this disease incurs. There is still much work to be done legislatively to close gaps and initiate innovative and effective programs and protocols for the care of persons and caregivers with ADRD.

In Florida, there are very few resources available to support people with younger/early-onset Alzheimer's to support or care for themselves and their families. ADI funding is the only resource that is offered to persons under the age of 60. People with early or younger-onset AD develop symptoms as early as in their 30s. A significant number of people with Down syndrome also develop dementia in their 40s. At this young age, there is a different set of challenges, needs, and financial necessities that need to be dealt with outside of the traditional methods of care and services.

The creation of an Office of ADRD would be the epicenter to address the massive challenges that are associated with ADRD. Florida must develop a seamless and more efficient system that supports and assists persons with memory disorders and their caregivers. Without bold actions, caregivers will continue to be overworked, the health care system will be overwhelmed, and state programs will be unable to meet the demand for services.

The creation of an ADRD Office in the Executive Office of the Governor will not only emphasize the importance of ADRD, but also will create a more efficient and streamlined communication process across departments and better utilize all ADRD services: DOEA, FDLE, AHCA, DCF, DOH, DOVA, and EOC. The ADRD in EOG will give opportunity for promotion and better public relations for available services around the state. It will focus on services and communications to the underserved, minorities, and Floridians living in rural areas. It will coordinate public-private partnerships to ensure necessary services around the state, and will work with associations and organizations on services offered.

The Alzheimer's Disease Advisory Committee was legislatively established in 1985 prior to the enactment of the Department of Elder Affairs. It reported to the Governor and Legislators directly and had authority to make recommendations concerning ADRD. The Committee is comprised of 10 members selected by the Governor. The present function of the advisory committee is to advise DOEA in the performance of its duties under the ADI. The ADI Advisory Committee is under the DOEA and has no authority or influence in the development of Alzheimer's strategies. As appropriate, and with the approval of DOEA, the advisory committee may establish subcommittees to carry out the functions of the Committee.

The Committee can only recommend and report to the DOEA in the performance of its duties and findings; this includes legislative, programmatic, and administrative matters that relate to Alzheimer's disease patients and their caregivers. It is at the discretion of the DOEA, under the direction of the Governor, to take action on those recommendations.

Revolutionizing the ADAC to be effective in its legislative responsibilities is imperative. The advancements and changes in the methodologies of the care and treatment have changed dramatically from 1985. The number of reported ADRD cases in Florida alone is 452,000 according to the DOEA. The methods and delivery systems need an overhaul into the twenty-first century.

The Committee has the authority and the responsibility to consult with the Department in program and service policy development. The Committee also has the responsibility to evaluate

and make recommendations to the DOEA and the Florida Legislature concerning the need for additional memory disorder clinics in the state. However, there is no means to approve the designation of an MDC.

As mentioned in the Research recommendations, an annual ADRD conference has the opportunity to attract researchers, physicians, and others to present the current findings and treatments for ADRD. In addition, it is an opportunity for the newly created Office to generate revenues for operations or special projects.

### Action Steps:

1. The Legislature should develop language to create a new Office of ADRD in EOG.

- The Office should be created by Type 2 transfers from each agency, thereby creating a revenue and budget-neutral situation.
- The ADRD Office should work with departments who provide direct ADRD services or indirect services. These departments include, but not limited to the following:
  - a. DOEA: ADI respite, MDCs, Alzheimer training, ADRCs, Ombudsman
  - b. FDLE: Safe Return, law enforcement dementia-specific training, crimes targeting persons with dementia
  - c. AHCA: Managed care dementia-specific services, proper care in ALFs, SNFs, ADC, hospices
  - d. DCF: Medicaid eligibility, Adult Protective Services, exploitation, mental health facilities, Baker Act
  - e. DOH: Training county health departments, reaching out and promoting available services to underserved, BRFS survey, suicide prevention, assist with needs of Special Needs Shelters, promote such shelters
  - f. DOVA: Coordinating available services to veterans
  - g. Emergency Operation Center: Prepare facilities for manmade/natural disasters, promote preplanning to caregivers, contact at EOC during disaster, support all departments and ADRCs during recovery (post disaster). Maintain special needs registry.
- The Governor should have authority to appoint an Executive Director.
- The Office of ADRD should improve public awareness.
- The Office of ADRD should focus on services and communications to the underserved, minorities, and Floridians living in rural areas.
- The Office of ADRD should coordinate public-private partnerships to ensure necessary services around the state, and will work with associations and organizations on services offered.
- The Office of ADRD should develop a single unified state communication system that will ensure the most current and accurate information on ADRD and the access to services/programs.
- The Office of ADRD should create and market a clearinghouse of dementia curricula and practice recommendations for providers across the care continuum, including physicians,

nurses, social workers, psychologists, other health care professionals, direct-care workers, and informal caregivers.

2. The Legislature should develop language to restructure membership and redefine the purpose of the ADI Committee.
  - Increase the number of appointed positions to 18 members. These appointments may follow the Purple Ribbon composition.
    - Six members shall be appointed by the Governor; six members shall be appointed by the Senate President; and six members shall be appointed by the Speaker of the House of Representatives.
  - The ADAC would advise the Office on policy issues and oversee the implementation of the State Plan developed by the Purple Ribbon Task Force.
  - Retain the authority of the ADAC committee to make additional Memory Disorder Clinic approvals.
    - Model Day Care
  - There should be legislation to define the Model Day Care.
  - The legislation would eliminate the Model Adult Day Care. Pursuant to the provisions of Section 287.057, F.S., the Department of Elderly Affairs may contract for the provision of specialized Alzheimer's Services who are licensed under Section 694, F.S. and Chapter 58A- 6.0 F.A.C., programs in conjunction with the memory disorder clinics.
    - Allow current model day cares access to state ADI Respite funds or specialized ADC license to assist them with transitioning out of the model day care funding.

#### Timeline:

##### **2013**

- Draft legislation to enact the Office of Alzheimer's disease or a related form of dementia; secure sponsors; ensure Governor's support; work with stakeholders for support
- Include language in legislation that will open Section 430.501-504, F. S. to revise the Alzheimer's Disease Initiative Advisory Committee membership and purpose
- Include language in legislation that defines Model Day Care
- Explore the feasibility of a single-system communication and data collection that would be compatible with the State CIRTS system
- Report to legislators the progress of the Purple Ribbon Plan
- Draft Memorial to Congress; work with Congressional delegation and leaders

##### **2014**

- Prepare to host the first annual conference on ADRD
- Approve curriculum for the gaps in training of professionals and caregivers
- Increase funding for ADI services (during 2014 Legislative Session)

#### Cost Considerations:

- \$600,000 to establish the Office of Alzheimer’s Disease and Related Dementia subject to appropriation
- \$2,000,000 additional funding to increase services to ADRD through Model Adult Day Care centers subject to appropriation
- \$200,000 annually to support an ADRD conference subject to appropriation
- Funding increases depended on the services and waitlists

**Recommendation:**

- **Create regulations for respite programs that serve ADRD.**
- **Increase ADI funding for respite.**

**Rationale for Recommendation:**

Respite care is one of the services that Alzheimer’s caregivers say they need most. One study found that if respite care delays institutionalization of a person with Alzheimer’s disease by as little as a month, \$1.12 billion is saved annually (Leon, et al., 1998). A similar study in 1995 found that as respite use increased, the probability of nursing home placement decreased significantly (Kosloski, K. and Montgomery, R.J.V., 1995).

Investment up front for ADRD care can save Florida thousands of dollars in facility placement and caregiver burnout.

One of the three critical issues from the survey conducted on behalf of the Purple Ribbon Task Force states that there is a need for quality care for persons with ADRD. To validate quality care, there need to be measurable standards.

At the present time, there are no regulations or formal definition of “respite services.” There are many “respite programs” in Florida, none of which is regulated. The Brookdale Foundation Model has been the most successful and offers standards and guidelines to provide programs. There were 12 grants provided to Florida to start neighborhood respite programs.

**Action Steps:**

- ADAC should create an advisory group with multiple industry representation that will establish the definition of respite care and provide recommendations to the Office of ADRD for legislative agenda.
- The Legislature should draft legislation to define and regulate respite programs.

**Timeline:**

**2013-2014**

- ADAC to create an advisory group

## **2014-2015**

- Recommendations to the Office of ADRD for legislative agenda
- Draft bill; secure sponsors for 2015 Session

### Cost Considerations:

- \$25,000 to cover the costs of staff and travel for committee members subject to appropriation
- Bill analysis would be required during the legislative process
- Generation of revenues from application fees

### Recommendation:

#### **Eliminate and replace Model Day Care with the Alzheimer's Specialized Adult Day Care License Centers.**

- Allow current model day cares access to state ADI Respite funds or specialized Alzheimer's Day Care license to assist them with transitioning out of the model day care funding.

### Rationale for Recommendation:

In 1985, the Florida Legislature enacted Sections 430.501 – 430.504, Florida Statutes, which mandated Model Day Care. The day care centers are considered models because they are to provide specialized services for AD clients in addition to those functions provided at adult day care centers (i.e., supervision, social/therapeutic activities, and personal care services). There are only three locations: Alachua, Hillsborough, and Miami-Dade counties. Under ADI Model Day Care, there are specialized services that include, but are not limited to the following:

- Providing a natural laboratory for research conducted by Memory Disorder Clinics (MDCs);
- Training in the care of ADI clients for health care and social service personnel, as well as caregivers;
- Specialized activities that take into account the ADI client's diminished level of functioning;
- Providing stimulation to the ADI client; and
- Providing relief for the ADI client's primary caregiver.

In 2013, legislators increased the present level of funding for ADI services in the community, which was a testament of their commitment to care for persons with ADRD and their caregivers. The investment in these community and home-based services will pay dividends in the long run in keeping health and long-term costs caring for ADRD from escalating at alarming rates as Florida ages.

The increase of Model Adult Day Cares to address the special needs of persons with ADRD will improve the quality of care and life of ADRD individuals and their families as well as providing an avenue for research and treatment.

Action Steps:

- The Legislature should define the Model Adult Day Care, pursuant to the provisions of Section 430.501-504, F. S. , that are licensed under Chapter 429, Part III and Chapter 58A- 6.0 F.A.C. and those programs in conjunction with the MDCs.
- The Legislature should authorize the ADAC to define Model Adult Day Care.
- The Office of ADRD to accept applications and recommends centers to be designated as Model Adult Day Care Centers.
- The Department should designate new centers as Model Adult Day Care.
- Entities should advocate for increased ADI funding for Model Adult Day Care.
- Entities should promote the critical importance of meaningful activities that are specific for persons with ADRD that are available in model adult day care centers.
- The Department should allow current model day cares access to state ADI Respite funds or specialized ADC license to assist them with transitioning out of the model day care funding within a three-year period.

Timeline:

**2013-2014**

- ADI Advisory Committee defines Model Adult Day Care

**2014-2015**

- Legislative action to open Section 430.501-504, F. S. to amend the definition of Model Adult Day Care
- Transition current model day care from model DC funding to have access to state ADI Respite funds or specialized ADC license.

Cost Considerations:

- No additional cost for the ADI Advisory Committee task force
- Increase would be based on the number of new model adult day cares
- Additional cost to current model day care as they transition out of this specific line item.

**Recommendation:**

**Amend F.S. Chapter 429 Part III Adult Day Care Centers the exemption for assisted living facilities, hospices, and nursing homes to provide adult day services.**

Rationale for Recommendation:

Adult day services are not just centers. They are comprehensive programs that provide person-centered care, care planning, health and medical services, nutrition, social support, and education for both the participant and the caregiver. Adult Day Services are Leaders in Community-Based Care for Individuals with Alzheimer’s disease and other related dementias. Adult day services centers provide an interactive, safe, and secure environment to prevent behavioral episodes and prevent elopement for ADRD. In Florida, it is estimated that 70 percent of the participants in adult day services have some level of dementia.

Adult day services centers are a non-residential facility professionally staffed. Adult day services centers serve as an up-and-coming provider of transitional care and short-term rehabilitation following hospital discharge. Most centers operate 10 – 12 hours per day and provide meals, meaningful activities, health care, personal care, and general supervision. Florida F.S. Chapter 429, Part III and Chapter 58A-6.0 F.A.C, regulates the quality of care and standards that make adult day services the effective program in long-term and health care.

There is no issue for assisted living facilities or nursing homes to provide adult day services as long as they hold a license under F.S. Chapter 429, Part III, and comply with all the rules under Chapter 58 A-6.0.

The integrity and purpose of adult day services is being misrepresented by assisted living facilities and nursing homes designating space and staff, but not providing the entire comprehensive program. It is concerning for the adult day care industry with the Medicaid Managed Care organizations contracting for adult day services in assisted living facilities that do not hold a license and do not deliver the appropriate service as defined in Statute and Rule.

#### Action Steps:

- The Legislature should draft language to amend Chapter 429 to change present exemptions.

#### Timeline:

##### **2013-2014**

- Draft legislation for 2014 Session to amend Chapter 429, Part III Adult Day Care Centers to change the exemption for assisted living facilities, nursing homes and hospice to provide adult day centers without an adult day care license. Secure sponsors, stakeholders to advocate for legislation.

#### Cost Considerations:

- There is no cost to the State
- Florida Adult Day Services Association will assume the cost of time to prepare the request.

**Recommendation:**

**Provide demonstration funding to address the unique challenges faced by the young onset of Alzheimer’s disease.**

Rationale for Recommendation:

Florida needs to be proactive and address the young onset and mild cognitive impairments. Adult day services are recognizing the new trend and implementing early memory loss programs and services. Young-onset ADRD patients are challenged with young families and employment issues that the late-onset senior do not encounter. Early intervention can save the State millions of dollars in future long-term care.

Action Steps:

- The Office of ADRD, MDCs, researchers, and other service providers should evaluate and analyze the demographics and challenges, and do a needs assessment of early/young-onset ADRD.
- The Office of ADRD should research national practices that are successful and have positive outcomes, including the Alzheimer’s Association, which has conducted extensive research and has formed a national work group.
- The Office of ADRD should analyze the cost of providing care for young/early-onset patients.
- Existing pilot programs within the State of Florida shall be evaluated as part of the process.

Timeline:

**2015**

- The ADI Advisory Board forms a task force to begin the process of analyzing and evaluating early/young-onset ADRD.

Cost Considerations:

- \$75,000 for research and data collection

**Recommendation:**

**Update dementia-specific training requirements for employees in care settings.**

Rationale for Recommendation:

Dementia-specific training standards began exclusively within the Department with the Assisted Living Facilities in 1998. For the next seven years, the Legislature approved dementia-specific

training requirements across the continuum of care. The required hours vary, but employees can be transferred across care settings.

Assisted living has the longest required hours of a total of eight hours of training: Initial four hours within three months; additional four hours (direct care) within nine months; direct caregivers must participate in a minimum of four contact hours of continuing education each year.

During the 2001 Legislative Session, legislators passed sweeping nursing home reform, which included dementia-specific training for all nursing home employees. Spearheaded by the Alzheimer's Association, a total of four hours is required for training: initial one hour within three months of the hire date; an additional three hours within nine months of hire date. No continuing education is required.

During the 2003 Legislative Session, legislators passed legislation worked by the Alzheimer's Association that required dementia-specific training for employees in adult day care, hospice, and home health agencies. Adult day care and hospice employees are required a total of four hours of training: initial one hour within three months of the date of hire; an additional three hours within nine months of hire date. Home health agencies are required a two-hour training within nine months of hire date. No continuing education is required.

The basic training requirements are outlined in statute for each area. The standards of the basic training are basically identical in the different care settings

The Alzheimer's Association secured \$73,935 recurring in 2003 state budget to develop an effective training and certification process. The Department of Elder Affairs contracted with the University of South Florida Policy Exchange to establish and manage the certifications of trainers and trainees. USF has a clinical review process done by licensed clinicians.

To date, USF Policy Exchange has processed 1,162 curriculum applications and 5,694 training provider applications. Training provider approvals do not expire; curriculum approvals expire in three years to ensure updated information. Currently, 32 percent of approved curriculum is in home care, 28 percent in nursing homes, 7 percent in adult day cares, 14 percent in Assisted Living, and 19 percent in hospices. Fifty-two percent of training providers have a nursing home training provider number.

The Agency for Health Care Administration is charged with enforcing the required trainings. Assisted living and nursing homes can be cited for not complying with state rules. For the past four years, there has been no citation at the nursing home level for staff not complying. There have been a few citations for assisted living.

Action Steps:

- The Legislature should change standards of basic training in statute to be specific for different care settings. Each care setting provides services for persons in different stages of ADRD.
- The Legislature should insert language in statute that requires direct caregivers in nursing homes, adult day cares, hospices, and home health agencies to also participate in a minimum of two hours of continuing education each year.
- The Legislature should change lifetime certification to three-year certification of trainee.
- The Department should review enforcement procedures of AHCA.
- The Department should review the implementation of managed long-term care to ensure dementia-specific trained employees.
- The Department should develop a survey to be conducted by trainees for feedback on trainer and curriculum.
- The Department should review the continuing education requirements for each health care profession to ensure that ADRD is a component of continuing education requirements.

Timeline:

- 2013:
  - a. Work with DOEA and USF to develop care standards for each care setting and survey for trainee feedback on trainer and curriculum.
  - b. Task force request enforcement rational and procedures by AHCA and numbers of citations in all care settings.
- 2014:
  - a. Draft language for legislation to change standards of basic training; insert continuing education; change lifetime certification.
  - b. DOEA and AHCA to ensure dementia-specific training for managed long-term care employees.

Cost Considerations:

- Cost incurred by Alzheimer’s Association to draft language with DOEA and USF for basic care standards across care settings; minimal cost for DOEA and AHCA.
- Minimal cost to AHCA to report citation numbers and enforcement procedures.
- Minimal cost to AHCA and DOEA to review whether providers are following dementia-specific training requirements.
- Minimal cost to DOEA and USF to develop survey for feedback.

**Recommendation:**

**Develop a well-coordinated and dementia-capable emergency management system.**

Rationale for Recommendation:

A disaster can happen anytime, anywhere, to anyone. In order to prevent unnecessary hospitalization or nursing home placement, disaster preparation is critical for persons with ADRD, caregivers, and families taking care of loved ones with ADRD.

Currently, while Florida's emergency management system is the best in the nation, more of a focus needs to be placed on standard dementia-specific procedures and better coordination across the 67 counties. Since the 2004 active hurricane season, there has been a variety of programs to help make a better system for persons with special needs, i.e., DOH Special Needs Committee. However, more needs to be done with ensuring a dementia-capable local emergency management office. A well-coordinated and dementia capable system between state and local emergency offices and ADRCs will not only save lives but will also ensure that the special needs of individuals and caregivers are addressed during all phases of a disaster.

In addition, all special needs shelters, long-term care facilities, and dementia-specific services must be identified and recognized by local emergency management office and state EOC. This will help when preparing for an immediate disaster and recovery. For example, in 2004, Hurricane Charlie hit Charlotte County. Per the request of Senior Services, the Memory Mobile traveled to devastated areas, supporting caregivers in need of assistance.

#### Action Steps:

##### Pre disaster:

- The state should require all county emergency management offices to be dementia-specific capable; update information on website.
- The state should facilitate coordination among state and local emergency management offices and ADRCs.
- The state should provide specialized education on disaster preparedness to family caregivers.
- The state should review access to Special Needs Shelters and appropriate sources for such shelters.
- The state should promote locations of Special Needs Shelters.
- The state should ensure access to special needs registries identifying people who may need help before a disaster.
- The Department should provide dementia-specific training to first responders, law enforcement, emergency medical technicians, and firefighters.
- The state should work with all long-term care facilities to ensure disaster plan and preparation.

##### During disaster:

- Establish an ADRD contact within the Emergency Operation Center to coordinate assistance among departments and ADRCs.

##### Post disaster:

- Enact special needs registry to identify missing persons.

## Timeline:

2013:

- (ADRCs) Coordinate at local level.
- (DOEA) Work with Emergency Operation Center in Tallahassee to ensure dementia-specific capabilities for local EOCs.
- (Department of Health) Ensure access to Special Needs Shelters and appropriate sources.
- (ADRCs) Update special needs registry in each county
- Draft legislation for 2014 Session to create an Office of ADRD that will require Office representative to be contact in EOC during high-alert disaster

## Cost Considerations:

- ADRCs should be already coordinating at local level EOCs (within current cost).
- DOEA/EOC staff to work on coordination of dementia-specific services. Staff cost but should be included in Department's emergency management plan.
- DOH staff to focus on access to SN shelters and appropriate sources. Special committee continued work on plan.
- Alzheimer's Association to draft language to include ADRD contact person in state EOC or, if approved by the task force, draft language to create new ADRD Office. Cost assumed by Alzheimer's Association.

## **Recommendation:**

**Establish a statewide program that is standardized for prevention and recovery of ADRD persons who become "lost on foot." This is essential for the safety and wellbeing of Floridians with dementia.**

## Rationale for Recommendation:

The current Silver Alert program is geared toward older adults with ADRD who drive away from their residence and thus do not return as expected. To assist in locating the lost person, law enforcement may alert local media and activate electronic dynamic message signs to provide the community with a description of the vehicle and the person. According to the Florida Department of Law Enforcement's Missing Endangered Persons Information Clearinghouse, 13 percent of older drivers are found as a direct result of Silver Alert activations (Davenport, 2012). While the Silver Alert Program increases the recovery rate of those who meet its criteria, the prevalence of getting lost on foot is much greater than becoming lost while driving (e.g., Rowe & Glover, 2001).

As 80 percent of those with dementia live at home with a spouse or caregiver (Fineberg, 2008), the Local Silver Alert Program or "Lost on Foot" initiative is most likely to impact those ADRD adults. Those ADRD persons not living at home are in assisted living facilities or nursing homes, which are more likely to have secure locked units or safety procedures that minimize potentially

problematic behaviors such as wandering. For people living at home, becoming lost is not equivalent to wandering. Relative to wandering, becoming lost is a low frequency behavior. People with dementia may walk outside of their homes, become confused, and forget how to return home, or become lost in unfamiliar surroundings. Individuals who become lost on foot are typically within a short distance (1/4 mile) from home or the place of their last known location.

Based on the current research literature, recommendations for finding lost individuals include the following:

- **Predetermined Search Plans:** Each caregiver should have a search plan with implementable strategies to locate the person as soon as possible. Strategies may include a list of people to call who can assist with the search, knowledge of favored locations, and checking dangerous areas (e.g., bodies of water, highways, etc.).
- **Technology:** Current technologies include Safety Net by LoJack, Project Lifesaver, other global positioning systems, radio frequency identification and/or cell phone triangulation which can allow for convenient monitoring, improve recover times/rates, and relieve caregiver burden. Unfortunately, the cost of the equipment and monthly service fees may be prohibitive for many families.
- **Other Subscription Services:** Reverse 911 and other programs can be used to inform the public about the lost person. In some cases, the cost to subscribe to these services is covered by the community rather than the caregiver. Family members may wish to inquire at the county sheriff's office as well as their local memory disorder clinic about access.
- **Training and Education:** Caregivers, whether paid or unpaid family members, should receive instruction for modifying the environment. For example, recommendations include masking exit doors, establishing safe areas for wandering, and encouraging behaviors that are incompatible with wandering or elopement (e.g., socialization with others and/or engagement in personally meaningful activities).

### Conclusion:

Unfortunately, there is no cure predicted or slowing of the disease process for the next 20 years and the baby boomers for all sense and purposes are already affected. There are not enough nursing home beds, government funds, or state financial resources to care for the vast numbers of probable ADRD victims today, not to speak of what the statistics will be within the upcoming years in Florida. The need for preparing the community on how to meet these challenges is critical for securing the safety and security of our most vulnerable and endangered persons. Safety and security interventions for methods of prevention and methods of recovery that are accessible to law enforcement, community organizations, agencies, and ADRD families is essential for maintaining ADRD persons' dignity and integrity for all cultures, no matter their financial status.

### Action Steps:

- The Legislature should fund the next level of development for a “lost on foot” program to be implemented within every community throughout Florida.
- The Department of Law Enforcement should translate selected materials into Spanish for community outreach program, participation, and caregiver training.
- The Department of Law Enforcement should disseminate public service announcements and other training videos for raising the public awareness on the dangers to those who do wander as to why they are our most endangered and vulnerable persons.

Timeline:

**2013/14**

- To enlarge the funding to law enforcement and DOEA to establish a safety net using the resources of technology and other methods of prevention and recovery.
- Translate selected materials into Spanish for community outreach program, participation, and caregiver training.
- Create on appropriate websites a social media campaign for involving Facebook, Pinterest, and blog sources for creating more awareness on the safety and security needs of our ADRD persons whose safety and security is so relevant to their well-being.
- Research and seek federal funding for the expansion of the Florida Silver Alert Program that is also a national model and is another hallmark of its continued concern for the protection of its most vulnerable elders and those who are afflicted with Alzheimer’s disease or a related form of dementia.

**2014/15**

- Enact a commission to review and evaluate the effectiveness of the Florida Silver Alert Program inclusive of “Lost on Foot.”

Cost Considerations:

- Request funding from the Florida Legislature at \$150,000 upgrading its resources and simultaneously seek additional funding from private or federal government sources for the expansion of the program inclusive of the “lost on foot” program.
- Request funding from the Florida Legislature at \$100,000 for implementing a demonstration program for making available electronic monitoring bracelets on those ADRD persons who are at risk for wandering.

**Recommendation:**

**Raise the standard of care for assisted living facilities providing care and services to persons with Alzheimer’s disease or a related form of dementia.**

- Update and revise the training regulated requirements for Alzheimer’s Care units by four hours to include the additional topics:
  - a. Person-centered care focus including physical therapy
  - b. Palliative care, and end of life care
  - c. Recognizing pain as a behavior modifier and pain management
  - d. Preventing falls
  - e. Recognizing medical needs, signs and symptoms of illness
  - f. Nutrition and dining
  - g. Daily life skills including physical contact with Alzheimer’s resident
  - h. Non-pharmacologic intervention
  - i. Medication affects
  
- **Create an Alzheimer’s Care designation on the ALF license specifying Alzheimer’s specialized care standards are met. The Alzheimer’s Association has a “Foundations of Dementia Care” document, which is an example for guidance. The care designation would mandate/allow by regulation:**
  - a. Resident care staff to provide total help in activities of daily living
  - b. Wander risk assessments
  - c. Secured units depending on the stage of the Alzheimer’s resident
  - d. Hospice umbrella for medical care as needed to maintain Alzheimer’s resident in ALF needing a higher care due to end of life
  - e. Medication Management regulatory change to follow the Medication Administration regulations (Chapter 65G-7) as is allowed with the Persons with Disabilities which services children and adults.
  - f. Medical review by a physician at least yearly
  - g. Day care services have standards set so that the ALF provider has a minimum of a health assessment form 1823 completed, contract for services that will be provided, and information and referral to the family caregiver regarding community services and Alzheimer’s disease.
  
- **Develop a process/protocol to permit an ALF to continue residency of a person with dementia in their current living environment despite a change in their condition (such as challenging behaviors or other disease symptoms) that under existing regulations might otherwise promote their move to a different level of care.**
  - a. Allow psychiatric behavior management with the appropriate medical professionals to be done in the ALF, limiting the use of the hospital geriatric-psychiatric units and limiting the use of geriatric-psychiatric units to temporary stays.
  - b. Allow flexibility in physical plant regulations to encourage creativity in environment changing needs such as an additional room that may be used as a serenity room, a special palliative room or a temporary bedroom that is not restricted for one use continuously but can be changed as needed to accommodate

the need of the Alzheimer's resident without going through regulatory licensing survey as is required currently.

- **Enlist state and local government to facilitate Alzheimer's training for employees of government agencies that interface frequently with patients, families, adult day care centers, and assisted living facilities, such as the Department of Health, Department of Elder Affairs, Agency for Health Care Administration, Ombudsman, Division of Motor Vehicles, and Area Agencies on Aging.**

Partner with licensing boards to mandate continuing education on Alzheimer's and other dementias as a requirement for relicensing of nurses, physicians, and other health care professionals.

- **Seek ways to keep residential costs at affordable levels for the ALFs residents and the providers in order to maintain a viable option for home and community-based services saving the Government from increased expense of paying for nursing home care for the Alzheimer's resident.**
  - a. Tax credits for ALFs that are caring for those residents on Medicaid assistance such as waiver programs and long-term care diversion.
  - b. Increase Medicaid funding for ALF residency versus nursing home placement.

#### Rationale for Recommendation:

The epidemic of Alzheimer's disease or a related form of dementia has created the need for increased care options for the person with Alzheimer's. The prevalence of the disease and the growth of public awareness necessitate that caregivers be knowledgeable of how to "care." The need continues to grow for experienced, trained, and compassionate caregivers. Alzheimer's is not a disease old people get because they grow old, it is becoming one that is affecting individuals at a younger age, some as young as 40. The face of an Alzheimer's patient is truly changing and the standard of care must change as well allowing those caregiving to be able to change as rapidly as this disease demands. The Alzheimer's Association's Campaign for Quality Residential Care introduced Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes, mapping out the fundamentals of good dementia care.

The current education requirements need to be updated and enhanced as research and care needs increase in this population. Research finds that exercise enhances brain activity and pain is a contributing factor to behavior problems. Our resident care aides are in this care arena as professionals and need to be taught all aspects of caregiving to enhance quality of life. Instruction on fall prevention, nutrition, non-pharmacologic intervention, and medication effects will create a better awareness for the caregiver and will in turn increase the quality of life for the person with Alzheimer's. The more we can "protect" the Alzheimer's residents, the quality of life and their comfort is increased.

According to the Agency for Health Care Administration, there are 3,010 assisted living facilities in Florida licensed with 84,764 beds. Since 2003, we have seen growth of 32 percent. ALFs are

very diverse and range in size from two beds to 495 beds. (AHCA, 2012) Approximately 65 percent of ALFs are 17 beds and under. A small homelike environment is the desired residency for persons with Alzheimer's or related disorders. Small business is in the majority and needs the opportunity to keep costs down in order to continue serving and stay in business.

#### Action Steps:

- The Legislature should amend the DOEA training requirements for Alzheimer's training for Assisted Living Alzheimer's Level 1 and Level 2.
- Entities should create a workgroup of Alzheimer's specialists, including researchers, and physicians to determine protocols/processes in providing urgent care to Alzheimer's patients who experience an urgent behavioral crisis. Establish protocols for community-based services to help maintain or implement intervention in a behavioral crisis, limiting the need for hospitalization in a psychiatric hospital or at least limit the hospital stay.
- Entities should create a workgroup with Agency for Health Care Administration, Department of Elder Affairs, and Alzheimer's specialists to create Alzheimer's care unit designation requirements.

#### Timeline:

##### **2013-2014**

- DOEA training requirements become regulatory
- Create workgroup of Alzheimer's specialists to determine protocol and process for behavioral crisis intervention
- Create workgroup to design Alzheimer's care designation requirement

##### **January 2015**

- Training requirements for Level 1 and Level 2 changes are in place

#### Cost Considerations:

The cost to the industry is training time for the staff which in turn increases quality care maintaining residents in the ALF aging in place because care needs are better met with well trained staff.

The cost to the assisted living industry will stabilize. The aging in place component will keep the resident in the "home" and census will remain. Quality of life will be increased for the Alzheimer's patient due to the extra oversight of their physician (medication review). The flexibility of changing the environment to meet the needs of the resident will also increase their quality of life. The ability to maintain in the ALF a resident who may experience a behavior issue will help Medicare's budget and will create less trauma for the resident by allowing them to stay in the environment with which they are familiar.

#### Recommendation:

## **Fund Memory Disorder Clinics according to performance standards and benchmark goals.**

- The 15 statutorily designated Memory Disorder Clinics should receive a base level of annual funding contingent on minimum performance requirements.
- Memory Disorder Clinics should be eligible for incentive funding above the base level, for achieving established benchmarks.

### Rationale for Recommendation:

- Public dollars are used to fund Memory Disorder Clinics (MDCs). Public funds should be allocated according to consistency and equality in all regions of the state.
- Minimum standards insure that each resident in Florida receives the access to the same services, same clinical staff with the same frequency regardless of the region in which they reside and regardless of their income level or ability to pay for service.
- Establishing a base level of annual funding is consistent with current methodology of equal funding amounts.
- Incentive funding rewards those MDCs that maintain outstanding performance standards and achieve benchmark goals. This assures that MDCs continually provide residents of Florida with a higher level of services and public access.
- Each Memory Disorder Clinic that receives funds from the State should do the following:
  1. Meet minimum requirements associated with base level funds, including the following:
    - a. Staffing level: required levels of clinical and mental health staffing to be directly employed by the MDC with State funding. *Recommended base level:* two licensed clinical providers
    - b. Services: required clinical and mental health services to be directly provided by the MDC with State funding. *Recommended base level direct services:* Primary care/neurologist/and or psychiatrist service, social work/mental health service; caregiver education/training
    - c. Public access: required hours of operation and financial politics to allow better public access; *Recommended base level:* 24 hours a week, at least three days a week.
  2. Qualify for incentive funding for greater levels of performance including:
    - a. Volume of clinical services: thresholds of patient services should be established for existing and new patients. Recommend incentive for direct clinical services over 1,500 patients and/or 250 new patients annually
    - b. Public outreach to low-income and minority populations: Goals for minority patient participation should be established. Recommend incentive for minority and/or low-income patient percentages over 40 percent and/or 500 patients annually.

- c. Financial assistance and insurance policies: Providers that have low-income assistance policies and that accept all forms of Medicaid and Medicare should be rewarded. Recommend incentive for providers that accept 10 or more Medicaid HMOs and 10 Medicare HMOs;
- d. Institutional Financial Commitments; Providers that match state funds at least 2:1 or higher should be rewarded. Recommend incentives for providers that make dedicated financial commitment by providing 500,000 or more of institution funds to the MDCs.

Action Steps:

- Department staff should develop minimum requirements and desired goals after publically consulting with the ADAC and MDC subcommittee.
- Department staff should draft minimum requirements and incentive goals to be presented to the legislature for action;
- The Department should meet with stakeholders to develop accountability metrics.

Timeline:

- By December 1, 2013, provide minimum requirements and benchmark goals;
  - a. Through August 31, 2013, Department staff meets to draft guidelines.
  - b. By September 1, 2013, Department staff schedules a joint public meeting of the ADAC and ADI Committee in August to solely discuss this issue;
  - c. The Department makes recommendations at a public meeting in October 2013; input is collected and recommendations revised.
  - d. The Department makes recommendations to Governor and Legislature in its SFY 2014-15 budget request.

Cost Considerations:

- The current base budget level is \$3.4 million for the 15 MDCs. No impact to this base budget.
- The incentive funding will require an Agency budget request. The recommended budget increase is \$350,000.

**Recommendation:**

**Provide sustainable funding for the State of Florida Brain Bank. Funding reductions that occurred during the State financial crisis should be restored and statewide activities should be funded at increased, appropriate level.**

Rationale for Recommendation:

- Funding for the Brain Bank has not been restored to pre-financial crisis levels, a decrease of ~\$40,000 since 2005. Yet, funding was allocated for NEW funding considerations by the legislature for SFY 13-14.
- The enrollment and activity of the State of Florida Brain Bank has doubled in the last five years.
- The organizations that run the Brain Bank should receive funding at a level that is sustainable for their organizations and the statewide mission.
- The costs of the Brain Bank have not been adequately evaluated and need to be reviewed. The costs of administration, recruitment, and clinical aspects of brain transportation and diagnosis are significantly below a sustainable level, and far below market rates.

#### Action Steps:

- The Department should meet with stakeholders and discuss actual costs.
- The Department should propose restoring original funding and adding additional funding in their SFY 14-15 budget request.

#### Timeline:

- July 2013, Brain Bank stakeholders meet with agency staff.
- August 2013, Brain Bank stakeholders bring staff proposal to ADI committee.
- September 2013, Brain Bank stakeholders bring proposal to Elder Affairs Advisory Council.
- November 2013, Agency budget request formulated with restoration of previous funding and additional increase.

#### Cost Considerations:

- Restoration of Funding: Increase \$40,000.
- Additional Funding: \$145,000.
- There are three organizations that are main stakeholders and other organizations that discount rates as vendors. It is conservatively estimated that each of the main stakeholders lose at least \$75,000 per year average in increased expenses, uncompensated staff time, as well as lost opportunity costs. Restored and increased funding will go to all stakeholder organizations.

#### **Recommendation:**

##### **Design Domestic Violence Shelters for the older population.**

#### Rationale for Recommendation:

These situations are stressful enough for the older adult, but then when you place them in a shelter with young kids running around it can increase their stress or make it even harder to convince them to go to a shelter. In addition to the noise and activity level, there are the

additional physical/medical needs of some older adults that must be considered, and not all victims of senior DV are women. There is really no place for older men who are victims of DV to go.

Action Steps:

The DOEA would work in conjunction with the Florida Coalition Against Domestic Violence to establish best practices that could be reviewed at a subsequent legislative session.

Timeline:

Fall of 2013, with the expectation for the best management practices to be delivered to the legislature in 2014.

Cost Considerations

There would not be a cost associated.

## References

- AARP. (2008). Houser, A., et al., AARP Public Policy Institute, *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*, 2008. Retrieved from [http://www.aarp.org/relationships/caregiving/info-11-2008/i13\\_caregiving.html](http://www.aarp.org/relationships/caregiving/info-11-2008/i13_caregiving.html)
- ARCH National Resource Center. (2011). *National Respite Guidelines: Guiding Principles for Respite Models and Services*. Retrieved from [http://www.lifespanrespite.memberlodge.org/Resources/Documents/NationalRespite\\_Guidelines%20Final%20October%202011%201MB.pdf](http://www.lifespanrespite.memberlodge.org/Resources/Documents/NationalRespite_Guidelines%20Final%20October%202011%201MB.pdf)
- Agency for Health Care Administration. (2013). Assisted Living Directory. Retrieved from [http://ahca.myflorida.com/mchq/long\\_term\\_care/Assisted\\_living/pdf/Directory\\_ALF.pdf](http://ahca.myflorida.com/mchq/long_term_care/Assisted_living/pdf/Directory_ALF.pdf)
- Agency for Health Care Administration. (2012). Florida Statutes. Retrieved from [http://ahca.myflorida.com/mchq/long\\_term\\_care/Assisted\\_living/common\\_files/ADCC\\_ST\\_429.pdf](http://ahca.myflorida.com/mchq/long_term_care/Assisted_living/common_files/ADCC_ST_429.pdf)
- Agency for Health Care Administration (2012). Assisted Living Facilities. Retrieved from <http://ahca.myflorida.com/SCHS/CommitteesCouncils/ALWG/docs/2012-06-25/AHCA-Presentation.pdf>
- Agency for Health Care Administration (2011). Health Care Advance Directives. Retrieved from <http://www.floridahealthfinder.gov/reports-guides/advance-directives.aspx>
- Alzheimer's Association. (2013). *Alzheimer's Disease Facts and Figures*. Retrieved from [www.alz.org/downloads/facts\\_figures\\_2013.pdf](http://www.alz.org/downloads/facts_figures_2013.pdf)
- Alzheimer's Association. (2012). *Alzheimer's Disease Facts and Figures*. Retrieved from [http://www.alz.org/downloads/facts\\_figures\\_2012.pdf](http://www.alz.org/downloads/facts_figures_2012.pdf)
- Alzheimer's Association. (2012). *End of Life Decisions: Honoring the Wishes of the person with Alzheimer's Disease*. Retrieved from [http://www.alz.org/national/documents/brochure\\_endoflifedecisions.pdf](http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf)
- Alzheimer's Community Care. (2010). *The Publication for Alzheimer's Community Care, Inc.* Retrieved from <http://cache.trustedpartner.com/docs/library/CapitalGuardian2010/Winter%20Alzheimers%20Magazine.pdf>
- Alzheimer's Disease Deaths. (2013). *Florida Health Statistics and Community Health Data*. Retrieved from <http://www.floridacharts.com/charts/SearchResult.aspx>
- Barnes, Mary M. (2013). *Purple Ribbon Task Force Florida Baker Act Report*

Centers for Disease Control and Prevention. (2011). *Healthy Brain Initiative: Alzheimer's Disease - Aging*. Retrieved from <http://www.cdc.gov/aging/aginginfo/alzheimers.htm>

Centers for Medicare & Medicaid Services. (2012). Quality Measures. Retrieved from <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/NHQIQualityMeasures.html>

Chan, C.K., Lee, P. & Lieh-Mak, F. (2000). Coping with spinal cord injury: Personal and marital adjustment in the Hong Kong Chinese setting. *Spinal Cord*, 38, 687–696. Retrieved from <http://www.apa.org/pi/about/publications/caregivers/faq/cultural-diversity.aspx>

Department of Elder Affairs Alzheimer's Disease Initiative. (2011). *Memory Disorder Clinics & Brain Bank Summary of Year End Activities 2010-2011*. Retrieved from [http://elderaffairs.state.fl.us/doea/alz/2010\\_2011mdcYearEndSummary.pdf](http://elderaffairs.state.fl.us/doea/alz/2010_2011mdcYearEndSummary.pdf)

D. Hilfiker. (2012). A Memoir from Inside Alzheimer's Disease. Retrieved from <http://davidhilkier.blogspot.com/>

Facts and Figures 2006. (2006). *Value of Medicines*. Retrieved from <http://www.innovation.org/documents/Value%20of%20Medicine%20FINAL%200712061.pdf>

The Florida Legislature Office of Economic and Demographic Research (2011, April 20-21). Florida: Demographics. Retrieved from [edr.state.fl.us/Content/presentations/population-demographics/DemographicOverview\\_4-20-11.pdf](http://edr.state.fl.us/Content/presentations/population-demographics/DemographicOverview_4-20-11.pdf)

Florida Department of Elder Affairs. (2013). *Purple Ribbon Task Force Surveys on Alzheimer's Disease and Related Dementias*. Retrieved from [http://elderaffairs.state.fl.us/doea/purple\\_ribbon/PRTFAlzheimersSurveys-Report.pdf](http://elderaffairs.state.fl.us/doea/purple_ribbon/PRTFAlzheimersSurveys-Report.pdf)

Florida Department of Elder Affairs – Alzheimer's Disease Initiative. (2012). Memory Disorder Clinics. Retrieved from <http://elderaffairs.state.fl.us/doea/alz.php#memory>

Florida QuickFacts from the US Census Bureau. (2012). *State and County QuickFacts*. Retrieved from <http://quickfacts.census.gov/qfd/states/12000.html>

Gannett, A. K. (2013, February 21). Dementia affects companies even if their workers don't have it | DailyComet.com. *Thibodaux Daily Comet*. Retrieved from <http://www.dailycomet.com/article/20130221/WIRE/130229940>

Hebert, L.E., Scherr, P.A., Bienias, J.L., Bennett, D.A., & Evans, D.A. (2003). Alzheimer Disease in the U.S. Population: Prevalence Estimates Using the 2000 Census. *Archives of Neurology*, 60 (8), 1119 – 1122.

Jeste, D.V., Alexopoulos, G.S., Bartels, S.J., Cummings, J.L., Gallo, J.J., Gottlieb, G.L., et al. (1999). Consensus statement on the upcoming crisis in geriatric mental health: Research agenda for the next two decades. *Archives of General Psychiatry*, 56, 848-853.

MetLife. (August 2006). *The MetLife Study of Alzheimer's Disease*. Retrieved from <https://www.metlife.com/assets/cao/mmi/publications/studies/mmi-alzheimers-disease-caregiving-experience-study.pdf>

National Center for Assisted Living. (2013). *Assisted Living State Regulatory Review*. Retrieved from [http://www.ahcancal.org/ncal/resources/Documents/2013\\_reg\\_review.pdf](http://www.ahcancal.org/ncal/resources/Documents/2013_reg_review.pdf)

National Hospice and Palliative Care Organization. (2011, July 29). *The Medicare Regulations for Hospice Care, Including the Conditions of Participation for Hospice Care 42 CFR418*. Retrieved from [http://www.nhpco.org/sites/default/files/public/regulatory/Medicare\\_COPS\\_Updated\\_072911.pdf](http://www.nhpco.org/sites/default/files/public/regulatory/Medicare_COPS_Updated_072911.pdf)

National Institute on Aging Alzheimer's. (July 2012). Disease Fact Sheet. *National Institute on Aging*. Retrieved from [http://www.nia.nih.gov/sites/default/files/alzheimers\\_disease\\_fact\\_sheet\\_0.pdf](http://www.nia.nih.gov/sites/default/files/alzheimers_disease_fact_sheet_0.pdf)

National Institute on Aging. (2012, August 8). Legal and Financial Planning for People with Alzheimer's Disease Fact Sheet Retrieved from <http://www.nia.nih.gov/alzheimers/publication/legal-and-financial-planning-people-alzheimers-disease-fact-sheet>

National Institute on Aging. (2011, October 20). Understanding Alzheimer's Disease. Retrieved from <http://www.nia.nih.gov/alzheimers/publication/understanding-alzheimers-disease/are-there-treatments-alzheimers-disease>

National Institute on Aging. (2011, November 18). Understanding Alzheimer's Disease | Alzheimer's Disease Fact Sheet. | Retrieved from <http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet>

National Institutes of Health. (2013, April 3). NIH-supported study finds U.S. dementia care costs as high as \$215 billion in 2010. Retrieved from <http://www.nih.gov/news/health/apr2013/nia-03.htm>

Race, Ethnicity, and Alzheimer's Disease. (August 2012). Factsheet. Retrieved from [act.alz.org/site/DocServer/2012\\_Race\\_and\\_Ethnicity\\_Factsheet.pdf?docID=3761](http://act.alz.org/site/DocServer/2012_Race_and_Ethnicity_Factsheet.pdf?docID=3761)

Selected Caregiver Statistics. (2012). Fact Sheet. Retrieved from [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=439](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439)

Silverman, R. E. (2006, September 7). Who Will Mind Mom? Check Her Contract. *The Wall*

*Street Journal*. Retrieved from <http://online.wsj.com/article/SB115759786200356055.html>

Statutes & Constitution. (2012). *The 2012 Florida Statutes*. Retrieved from [http://www.leg.state.fl.us/statutes/index.cfm?App\\_mode=Display\\_Statute&URL=0700-0799/0736/0736PartVIContentsIndex.html&StatuteYear=2012&Title=%2D%3E2012%2D%3EChapter%20736%2D%3EPart%20VI](http://www.leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&URL=0700-0799/0736/0736PartVIContentsIndex.html&StatuteYear=2012&Title=%2D%3E2012%2D%3EChapter%20736%2D%3EPart%20VI)

Statutes & Constitution. (2012). *The 2012 Florida Statutes*. Retrieved from [http://www.leg.state.fl.us/statutes/index.cfm?App\\_mode=Display\\_Statute&Search\\_String=&URL=0700-0799/0744/Sections/0744.1012.html](http://www.leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=0700-0799/0744/Sections/0744.1012.html)

Statutes & Constitution. *The 2012 Florida Statutes*. (2013). Retrieved from [http://www.leg.state.fl.us/statutes/index.cfm?App\\_mode=Display\\_Statute&Search\\_String=&URL=0700-0799/0709/0709PARTIIContentsIndex.html](http://www.leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=0700-0799/0709/0709PARTIIContentsIndex.html)

U.S. Census Bureau. (2000). *Projections of the resident population by age, sex, race, and Hispanic origin: 1999-2100*. Retrieved from (<http://www.census.gov>)

US Department of Health & Human Services. (2011). National Alzheimer's Project Act. Retrieved from <http://aspe.hhs.gov/daltcp/napa/>

U.S. Department of Health and Human Services. (2012). *National Plan to Address Alzheimer's Disease*. Office of The Assistant Secretary for Planning and Evaluation. Retrieved from <http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>

## Purple Ribbon Task Force Members

**Representative Matt Hudson**

Member of the House of Representatives

**Senator Garrett Richter**

Member of the Senate

**Gloria Smith**

Representative from the Alzheimer's Association

**Albert Johnson**

Representative of persons having Alzheimer's disease or related form of dementia

**Ronald Davis**

Family caregiver or former caregiver

**Christine Powers**

Representative from Alzheimer's Disease Advisory Committee

**Stacey Payne**

Representative of law enforcement

**Mary Barnes**

Representative with Baker Act knowledge

**Natalie Kelly**

Expert of disaster preparedness

**Samira Beckwith**

Representative of health care facility or hospice

**Ted Wolfendale**

Representative of the adult day care services industry

**Stacy Kilroy**

Representative of health care practitioners

**Scott Solkoff**

Florida board-certified elder law attorney

**Linda Levin**

Representative of the AAA or ADRC

**Todd Golde, M.D.**

Alzheimer's disease researcher

**Neill Graff-Radford,**

Representative from a Memory Disorder Clinic

**Jamie Glavich**

Representative of the ALF community

**Darrin Brooks**

Representative of a skilled nursing facility

## **Florida Department of Elder Affairs Support Staff**

**Mary Hodges**

Bureau Chief

**Adam Lovejoy**

Legislative Affairs Director

**Darlene Heinrich**

Evaluation Unit Supervisor

**Sibylle Allendorff**

Evaluator

**Mindy Sollisch**

Manager of Strategic Initiatives

**Carol Waters**

Senior Management Analyst II

**Danielle Bist**

Administrative Assistant

**Stephanie Pollack**

Research Assistant

## **Appendix 1: Purple Ribbon Task Force Interim Report**



DEPARTMENT OF ELDER AFFAIRS



# **PURPLE RIBBON TASK FORCE**

*Division of Statewide Community-Based Services*

## 2013 INTERIM REPORT

---

A Comprehensive Plan for Addressing Alzheimer's  
Disease and Other Related Forms of Dementia

**RICK SCOTT**  
*Governor*

**DON GAETZ**  
*President of the Senate*

**WILL WEATHERFORD**  
*Speaker of the House of Representatives*

## Purple Ribbon Task Force Members

**Representative Matt Hudson**

Member of the House of Representatives

**Senator Garrett Richter**

Member of the Senate

**Gloria Smith**

Representative from the Alzheimer's Association

**Albert Johnson**

Representative of persons having Alzheimer's disease or related form of dementia

**Ronald Davis**

Family caregiver or former caregiver

**Christine Powers**

Representative from Alzheimer's Disease Advisory Committee

**Stacey Payne**

Representative of law enforcement

**Mary Barnes**

Representative with Baker Act knowledge

**Natalie Kelly**

Expert of disaster preparedness

**Samira Beckwith**

Representative of health care facility or hospice

**Ted Wolfendale**

Representative of the adult day care services industry

**Amy Perry**

Representative of health care practitioners

**Scott Solkoff**

Florida board-certified elder law attorney

**Linda Levin**

Representative of the AAA or ADRC

**Todd Golde, M.D.**

Alzheimer's disease researcher

**Neill Graff-Radford,**

Representative from a memory disorder clinic

**Jamie Glavich**

Representative of the ALF community

**Darrin Brooks**

Representative of a skilled nursing facility

## **Florida Department of Elder Affairs Support Staff**

**Mary Hodges**  
Bureau Chief

**Joshua Spagnola**  
Legislative Affairs Director (now former)

**Adam Lovejoy**  
Legislative Affairs Director (beginning January 2013)

**Mindy Sollisch**  
Manager of Strategic Initiatives

**Carol Waters**  
Senior Management Analyst II

**Cory Livingston**  
Certified Government Financial Manager

**Danielle Bist**  
Administrative Assistant II

**Kimberly DelVecchio**  
Operations and Management Consultant II

**Stephanie Pollack**  
Research Assistant

## **Executive Summary**

In 2012, the Florida Legislature passed HB 473 that created the Purple Ribbon Task Force (PRTF), housed within the Department of Elder Affairs. The legislation requires the Purple Ribbon Task Force to submit to the Governor, the President of the Senate, and the Speaker of the House of Representatives, an interim study regarding state trends with respect to persons having Alzheimer's disease and related dementia (ADRD) and their needs. Information regarding state trends includes a description of the role of the state in providing care and support to persons with ADRD and family caregivers, as well as state policy regarding persons with ADRD. The interim study provides information relative to the prevalence of ADRD in Floridians at the present and in future projections.

Additionally, in accordance with HB 473, the task force is to “assess the current and future impact of ADRD; examine existing industries, services, and resources addressing the needs of persons with ADRD and family caregivers; examine the needs of persons of all cultural backgrounds having ADRD and how their lives are affected by the disease at various stages; develop a strategy to mobilize a state response to this public health crisis; provide information regarding existing services, resources, and capacity, including type, cost, and availability of dementia-specific services statewide; provide information regarding policy requirements for training for professionals providing care; determine quality care measures of care providers; determine the capability of public safety workers and law enforcement workers to respond to persons with ADRD related to disappearance, search and rescue, abuse, elopement, exploitation, or suicide; determine availability of home and community-based services, and respite for persons with ADRD; conduct an inventory of long-term care facilities, and community-based services for persons with ADRD; determine adequacy and appropriateness of geriatric psychiatric units for persons having behavior disorders associated with ADRD; determine residential assisted living options for persons with ADRC; determine the level of preparedness of service providers before, during, and after a catastrophic emergency involving persons with ADRD, their caregivers and families; determine needed state policies or responses, for the provision of clear and coordinated care, services and support for persons with ADRD, caregivers and families, and determine strategies to address identified service gaps.”

In summary, this interim report lays out the assessment of the members of the task force concerning the needs and trends within the state of Florida regarding persons with ADRD and their caregivers, reflects the current and future impact of ADRD, delineates existing services and resources available to Florida's population, and identifies gaps and limitations.

## **Impact of ADRD**

In the “2012 Alzheimer’s Disease Facts and Figures” report, the Alzheimer’s Association states that Alzheimer’s disease is becoming a more common cause of death as the populations of the United States and other countries age. While deaths from other major causes continue to experience significant declines, those from Alzheimer’s disease have continued to rise. Between 2000 and 2008, deaths attributed to Alzheimer’s disease increased 66 percent, nationally while those attributed to the number one cause of death, heart disease, decreased 13 percent. The Alzheimer’s Association “2012 Alzheimer’s Disease Facts and Figures” report, indicates Alzheimer’s disease is the sixth leading cause of death in the United States and the fifth leading cause of death age 65 and older.

Section 430.501-504, F. S. indicates, the Florida Legislature found that “Alzheimer’s disease and similar major memory disorders affect an alarmingly high percentage of citizens, primarily those over 65 years of age, and yet little is known of the cause, prevention, or treatment of this disease,” and created the Alzheimer’s Disease Initiative (ADI). The purpose of the ADI is to provide a continuum of services to meet the changing needs of individuals and families affected by Alzheimer’s disease and related disorders (ADRD). The ADI is administratively housed within the Department of Elder Affairs (DOEA) and consists of the Alzheimer’s Disease Advisory Committee; 15 legislatively designated memory disorder clinics; three specialized model day care programs operating in Gainesville, Tampa, and Miami-Dade; statewide community-based respite care programs; Approval of Alzheimer’s disease training curricula to ensure statutory standards are met for certain health service providers; and the ADRD Research Brain Bank as the entity designated by DOEA to collect postmortem normal control brains and brains of individuals who were clinically diagnosed with Alzheimer’s disease for the purpose of conducting comparative research aimed at learning about, finding a cause, and developing a treatment or cure for the disease. The statute also provides for implementation of a Medicaid home and community-based waiver targeted to persons with Alzheimer’s disease to test the effectiveness of Alzheimer’s specific interventions to delay or to avoid institutional placement. Over the past two decades, the accomplishments of the Florida ADI have laid the foundation for Florida’s response to Alzheimer’s disease. In accordance with DOEA administrative rules for the ADI, 58D-1.003, F.A.C., to be eligible to receive services funded under the ADI that are included in the provider’s contract with the department or the area agency on aging, an individual must be 18 years of age or older and have a diagnosis of Alzheimer’s disease or related memory disorder, or be suspected of having Alzheimer’s disease or a related memory disorder. 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.

## **Introduction**

The Florida Purple Ribbon Task Force (PRTF) is established within the Department of Elder Affairs. The PRTF is tasked with developing a comprehensive state plan to address the needs of individuals with Alzheimer’s disease and their caregivers, and the task force must submit the plan with findings and date-specific recommendations to the Governor, the Speaker of the House

of Representatives, and the President of the Senate no later than August 1, 2013. The task force consists of 18 culturally diverse volunteer members appointed by the Governor, the Senate President, and the Speaker of the House of Representatives. Membership is comprised of the following:

- (a) A member of the Florida House of Representatives;
- (b) A member of the Florida Senate;
- (c) A representative from the Alzheimer's Association;
- (d) At least one person having Alzheimer's disease or ADRD;
- (e) At least one family caregiver or former family caregiver of a person having ADRD;
- (f) A representative from the Alzheimer's Disease Advisory Committee;
- (g) A representative of law enforcement with knowledge about the disappearance and recovery, self-neglect, abuse, exploitation, and suicide of persons with ADRD;
- (h) A representative who has knowledge of and experience with the Baker Act and its impact on persons with ADRD;
- (i) An expert on disaster preparedness and response for persons with ADRD;
- (j) A representative of a health care facility or hospice that serves persons with Alzheimer's disease;
- (k) A representative of the adult day care services industry;
- (l) A representative of health care practitioners specializing in the treatment of persons having Alzheimer's;
- (m) A Florida board-certified elder law attorney;
- (n) A representative of the Area Agencies on Aging (AAA) or Aging and Disability Resource Centers (ADRC);
- (o) A person who is an Alzheimer's disease researcher;
- (p) A representative from a memory disorder clinic;
- (q) A representative of the assisted living facility industry; and
- (r) A representative of the skilled nursing facility industry.

Specialized committees of the task force completed an inventory of the state's needs and available resources for individuals with ADRD and their caregivers. This "state of the state" is provided in the following interim study report.

### **State Trends**

The Purple Ribbon Task Force researched state trends with respect to persons having ADRD and their needs.

## **Role of the State and Development of State Policy**

The state plays a significant role in the development of state policy and in providing community-based care, long-term care, and family caregiver support, including respite, education, and assistance to persons who are in the early stages of Alzheimer's disease, those who have younger-onset Alzheimer's disease, or those who have a related form of dementia. The role is firmly supported in state statute.

Section 430.02, F. S. indicates that the intent of the Legislature is to:

- (1) Advise, assist, and protect the state's elderly citizens to the fullest extent.
- (2) Ensure that programs and services are developed and implemented to be accessible to all elderly citizens to assist them in the achievement or maintenance of maximum independence and quality of life and minimum levels of social dependence.
- (3) Support and promote the efforts of families and other caregivers in assisting elderly persons.
- (4) Promote intergenerational activities that will provide citizens of all ages opportunities to enjoy the enriching benefits of interaction and that will promote unity and support for one another.
- (5) Ensure that state government functions effectively and efficiently in serving the elderly through coordination of policy development, planning, and service delivery by all state agencies relating to the elderly population of the state.
- (6) Ensure that elderly citizens are able to secure prompt, adequate, and accurate information and assistance regarding, but not limited to, health, social welfare, long-term care, protective services, consumer protection, education and training, housing, employment, recreation, transportation, insurance, and retirement.
- (7) Organize the Department of Elderly Affairs as the state agency that has lead responsibility for administering human service programs for the elderly and for developing policy recommendations for long-term care.

In accordance with Section 430.03, the purposes of the Department of Elder Affairs are to:

- (1) Serve as the primary state agency responsible for administering human services programs for the elderly and for developing policy recommendations for long-term care.
- (2) Combat ageism and create public awareness and understanding of the potentials and needs of elderly persons.
- (3) Study and plan for programs and services to meet identified and projected needs and to provide opportunities for personal development and achievement of persons aged 60 years and older.
- (4) Advocate quality programs and services for the state's elderly population and on behalf of the individual citizen's needs.

- (5) Coordinate interdepartmental policy development and program planning for all state agencies that provide services for the elderly population in order to prevent duplicative efforts, to maximize utilization of resources, and to ensure cooperation, communication, and departmental linkages.
- (6) Recommend state and local level organizational models for the planning, coordination, implementation, and evaluation of programs serving the elderly population.
- (7) Oversee implementation of federally funded and state-funded programs and services for the state's elderly population.
- (8) Recommend legislative budget requests for programs and services for the state's elderly population.
- (9) Serve as a state-level information clearinghouse and encourage the development of local-level identifiable points of information and referral regarding all federal, state, and local resources of assistance to elderly citizens.
- (10) Assist elderly persons to secure needed services in accordance with personal choice and in a manner that achieves or maintains autonomy and prevents, reduces, or eliminates dependency.
- (11) Promote the maintenance and improvement of the physical well-being and mental health of elderly persons.
- (12) Promote opportunities for volunteerism among the elderly population.
- (13) Promote the prevention of neglect, abuse, or exploitation of elderly persons unable to protect their own interests.
- (14) Eliminate and prevent inappropriate institutionalization of elderly persons by promoting community-based care, home-based care, or other forms of less intensive care.
- (15) Aid in the support of families and other caregivers of elderly persons.
- (16) Promote intergenerational relationships.
- (17) Oversee aging research conducted or funded by any state agency to ensure that such activities are coordinated and directed to fulfill the intent and purposes of this act.

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

## **Number of Persons Affected by ADRD**

Relative to the prevalence of ADRD in Floridians at the present and in future projections, the Alzheimer's Association's "2012 Alzheimer's Disease Facts and Figures" report states that one in eight people aged 65 and older (13 percent) has Alzheimer's disease. The estimated numbers for people over 65 come from the Chicago Health and Aging Project (CHAP), a population-based study of chronic health diseases of older people. The report indicates in the year of 2000, the estimated number of Floridians with Alzheimer's disease was 360,000. The estimated number in 2010 was 450,000, and the estimated number for 2025 is 590,000. The study indicates the percentage of change in the number of people with Alzheimer's disease from 2000 to 2010 was 25 percent. The percentage of change in number of people with Alzheimer's disease from 2000 to 2025 is projected to be 64 percent.

## **Research**

Much more is known about ADRD today than 25 years ago. The major demographic risk for development of AD is age with risk approximately doubling every 5 years after age 65. Thus, by the age of 85 one's chances of having dementia due to AD may be 40% or more. Largely due to a predicted increase in the average expected life span, the prevalence of AD is predicted to double every 20 year. Based on estimates that 35 million people worldwide have AD today, over 125 million individuals are predicted to have AD in 2050 (<http://download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012000325.pdf>). If nothing is done, the personal, economic and societal toll of the ongoing and growing AD epidemic will be immense (1).

Effective therapy for Alzheimer's disease (AD) is a major unmet medical need (2-3) (<http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>). For the typical AD patient, current symptomatic therapies (acetylcholinesterase inhibitors and memantine) demonstrate limited symptomatic benefit that is not sustained. Moreover, there is virtually no evidence that either of these types of treatments alter disease progression. AD is among the 10 most prevalent diseases in the US. Despite tremendous advances in understanding certain aspects of AD pathogenesis, there are no therapies that significantly impact the disease. Though many other prevalent diseases still cause tremendous morbidity and mortality, for almost all of them, scientific and medical advances have led to novel therapies that alter disease course, reduce mortality, or at least significantly relieve symptoms for some period of time. Typically, these therapies are not panaceas, or true cures, but nevertheless significant therapeutic inroads have been made.

There is hope. Scientific advances over the last 25 years have provided sound rationale for the development of potentially disease-modifying AD therapies (3). These therapies primarily target the suspected trigger or triggers of the disease (proteins called A $\beta$  and tau). Thus, therapeutic advances coupled with advances in premorbid detection of underlying AD pathology in non-demented individuals, suggest that concerted translational research efforts focusing on prevention or early intervention could dramatically reduce the incidence and prevalence of AD. Indeed, it is now well recognized that AD actually begins 15-20 years before it is clinically diagnosed, providing a window for intervention prior to a patient becoming symptomatic.

Moreover, as researchers illuminate the downstream pathways that contribute to the degenerative process there is also hope that we can better intervene and slow or even reverse the progression in those with clinically diagnosed AD.

### **Infrastructure to Support AD Research**

Many Florida institutions have independently invested in both infrastructure and intellectual capital to support AD and related dementia research. The state previously invested in the Byrd Alzheimer's Institute that is now part of USF, and currently funds 13 of the legislatively designated 15 regional ADI Memory Disorder Clinics (MDCs). Large research investments in Scripps, Torrey Pines, and Burnham have added to our general research capabilities, but only a few scientists at these institutes focus on Alzheimer's disease and other dementias. Though the latter largely have a service mission, it is our general belief that these MDCs provide access to diverse patient populations that could be leveraged further to enhance statewide patient-oriented research efforts. Overall, there are dozens of laboratories focusing on AD research in the state of Florida, with focused efforts at Mayo Clinic Florida, USF, UF, UM, and Mount Sinai Medical Center. However, virtually all of the academic institutions in Florida have some investigators with active AD research programs. Currently yearly funding from the National Institute of Health to investigators studying varying aspects of AD and related dementias is less than \$25 million (<http://projectreporter.nih.gov/reporter.cfm> text search Florida, year 2011, State of Florida, does not capture subcontracts). Other non-state funding sources likely bring in an additional \$10 million to support research efforts.

Notably, preeminent scientists in the ADI and broader neurodegenerative field are based in Florida. They have a history of research breakthroughs, as well as commercialization of their discoveries. Several Florida scientists have won international prizes in recognition of their contributions to AD research advances. Examples of their contribution to the scientific advances in AD are:

- Florida Scientists played major roles in defining the genetic underpinnings of AD and related dementias (4-13)
- Florida Scientists established key therapeutic targets for prevention or treatment of AD (9, 14-16)
- Florida Scientists developed of best-in-class models that are used by virtually all companies engaged in development of AD therapeutics (17-19)
- Florida Scientists developed novel diagnostic tests for AD (20-21)
- Florida Scientists identified therapies that advanced to late stage human clinical trials (22-23)

### **Existing Industries, Services and Resources**

#### **Diagnosis, Treatment, and Care**

In an aging population, especially with the tsunami of the baby boomers, Alzheimer's disease and other related dementias can have a significant financial impact on Florida's Medicaid, medical insurance, long-term care programs, and other senior care systems.

Alzheimer's disease and other related dementias diminish a person's ability to manage their health care and drain the wellness out of their caregivers. Early diagnosis, treatment, and coordination of care for dementia, starting at the primary care point of entry, can mitigate the growing social and financial burdens on health care systems, Medicaid, Medicare, and caregivers.

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

Families and professionals often face challenges in finding medical care and resources for people with dementia. There is no single comprehensive list or single entry access point that identifies health care providers who have experience treating dementia or resources for other caring for this special population. Also, rural communities face additional barriers to services, including the finding and accessibility of providers with the appropriate expertise. The use of technology could bridge that gap by allowing health care providers, their patients, and even community leaders to consult with health care providers in other parts of the state.

Efficiency and quality of care is further negatively affected by poor understanding of common medical conditions that elevate risk for dementia, cultural disparities in health care delivery, and lack of communication among consumers, their families, and their providers.

Florida has invested into the diagnosis and treatment of ADRD with the establishment of the Memory Disorder Clinics (MDCs) throughout the state. There are 15 legislatively designated MDCs, including two unfunded. In addition, the location of many centers does not allow easy access for seniors who are unable to drive or travel long distances. (Transportation issues in Florida severely hinder its seniors to accessing resources.)

Florida has many excellent physicians who are highly experienced in recognizing Alzheimer's and helping their patients/caregivers manage the physical, health, and emotional challenges related to the disease. Physicians and other primary care providers are presently not reimbursed to deliver appropriate preventive measures. Under current reimbursement methods, physicians and other primary care providers are paid for episodic treatment. The current reimbursement policy effectively discourages valuable between-visit care and support for people with dementia and their family caregivers.

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

“Medical technology has exponentially increased lifespan during the 20th century, from 46 to 78 years at present. Advances in medicine have led to cures and treatments of many diseases, such as cancer, heart disease, and tuberculosis. These diseases were not survivable a century ago. Yet, Alzheimer's disease and other dementias create problems on a scale never before imagined. A person's physical health can now easily outlast his or her cognitive and mental abilities.

Advancing age presents a classic paradox: people want to live as long as they can, but do not want to experience a decline in their cognitive abilities.” (*AARP’s Educator Community*).

Early identification of a dementia enables a person and their family to receive help in understanding and adjusting to the diagnosis and to prepare for the future. This might include making legal and financial arrangements, making changes to living arrangements, and researching assistance and services that will enhance quality of life. Early diagnosis enables the individual to have an active role in decision making and planning.

Every person is entitled to a timely diagnosis. The need for autonomy is imperative to persons who are diagnosed to make their wants, desires, or needs known to their caregivers and health professionals.

The impact of a dementia diagnosis depends greatly upon how it is made and imparted. Evidence suggests that when individuals with dementia and their families are well prepared and supported, initial feelings of shock, anger, and grief are balanced by a sense of reassurance and empowerment. (Alzheimer’s disease International, “World Alzheimer’s Report 2011”)

Most people with early stage dementia would wish to be told of their diagnosis. Improving the likelihood of an earlier diagnosis can be enhanced through: a) medical practice-based educational programs in primary care, b) the introduction of accessible diagnostic and early stage dementia care services (for example, memory clinics), and c) promoting effective interaction between different components of the health system. (“World Alzheimer’s Report 2011”)

### **Needs of Persons of all Cultural Backgrounds Affected by ADRD**

The Alzheimer’s Association’s report estimated that 5.4 million Americans of all ages were living with Alzheimer’s disease in 2012. The number includes 5.2 million age 65 and older and 200,000 individuals under age 65 who have younger-onset Alzheimer’s disease. For persons diagnosed with ADRD, the amount of and level of care and assistance with activities of daily living increases as the disease progresses. Alzheimer’s disease and related disorders is a disease experienced by the entire family. Regarding the needs of persons of all cultural backgrounds having ADRD and how their lives are affected by the disease at various stages, the task force suggests cultural competence includes understanding languages, understanding differences in culture and beliefs, and being respectful and attentive to differences in behavior and outlook. Cultural diversity is a significant consideration in addressing the caregiver burden. The “2012 Alzheimer’s Disease Facts and Figures” report cited that older African Americans and Hispanics are proportionately more likely than older Caucasians to have Alzheimer’s disease and other related dementias.

### **Existing Services, Resources, and Capability**

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

The Department of Elder Affairs administers the Alzheimer’s Disease Initiative (ADI). To be eligible to receive services funded under the Alzheimer’s Disease Initiative, an individual must

be 18 years of age or older and have a diagnosis of Alzheimer's disease or related memory disorder, or they must be suspected of having Alzheimer's disease or a related form of dementia (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.

In the ADI, 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 State Fiscal Year (SFY) 2010-2011 was \$350,050.62.

The current total (2012-2013 SFY) State General Revenue Budget for the ADI is \$12,639,878. In accordance with Section 430.501 – 503 F. S., the ADI consists of the following components:

1) The Alzheimer's Disease Advisory Committee is comprised of 10 members selected by the Governor. The Committee advises the DOEA in the performance of its duties, including legislative, programmatic, and administrative matters that relate to Alzheimer's disease patients and their caregivers. The Committee has the authority and the responsibility to consult with the Department in program and service policy development. The Committee also has the responsibility to evaluate and make recommendations to the DOEA and the Florida Legislature concerning the need for additional memory disorder clinics in the state. The members of the Committee and subcommittees receive no salary, but they do receive reimbursement for travel and per diem expenses. DOEA uses existing staff to provide support to assist the Committee in the performance of its duties.

2) Memory Disorder Clinics (MDCs) provide diagnostic and referral services, conduct basic and service-related multidisciplinary research, and develop training materials and educational opportunities for lay and professional caregivers of individuals with Alzheimer's disease. The MDCs provide in-service training annually to model day care and respite care providers in the designated service areas, and they annually contact each model day care and respite care provider in the designated service areas to plan and develop service-related research projects. During SFY 2011-2012, the total training hours for the MDCs was 3,942 hours, and the total number of trainees was 34,784, including 14,000 medical health professionals, 3,000 students, and 6,975 general public. The MDCs had 10,105 office visits and served 6,723 unduplicated persons. They provided telephone counseling, information, and support 12,570 times. The MDCs routinely conduct community memory screening events that are free to the public. Individuals are screened for problems with cognition, provided a screening score with an explanation of the results, and advised to follow up with their own physicians, if necessary. A total of 1,573 memory screens were recorded during SFY 2011-2012, and 13,678 referrals were made on the behalf of clients and caregivers for respite care, support groups, long-term care placement, counseling, medical care, and other social services. The MDCs provide research opportunities and information about research studies to patients, caregivers, and family members. These research studies may be conducted at an MDC or outside of the MDC. Research referrals include genetic studies with the specific aim to improve understanding genetics, clinical drug trials with the specific aim of studying drugs/medications, other studies that have a genetic

component but are not primarily genetic studies, and referrals to the Florida Brain Bank. The Memory Disorder Clinics contracts totaled \$2,968,081 in SFY 2011-2012.

The University of Florida (UF) and Mayo Clinic Jacksonville Memory Disorder Clinics play a crucial role in the training of Behavioral Neurology Fellows who are subspecialists able to care expertly for dementia patients. To date UF has trained 81 fellows, and Mayo Clinic Jacksonville has trained 9 fellows.

3) The Florida Brain Bank is the entity designated by the DOEA to collect postmortem normal (control) brains and brains of individuals who were clinically diagnosed as having Alzheimer's disease for the purpose of conducting comparative research aimed at learning about, finding a cause, and developing a treatment or cure for the disease. Brain Bank Activity during SFY 2011 - 2012 was as follows:

- The number of donors enrolled: 129
- The number of brains received: 119
- The number of autopsies performed: 127
- The number of diagnoses completed: 90
- The number of reports sent to families: 90

The Brain Bank contract totaled \$117,535.00, with subcontracts to Alzheimer's and Dementia Resource Center in Orlando for \$35,000 and Mayo Clinic Jacksonville for \$17,000. The Brain Bank has performed 1,515 autopsies to date.

These autopsies have been included in many publications (included in the reference list) during the last 7 years (2005-2012). It is important to highlight a few crucial discoveries:

- The Florida ADI has contributed to the discovery of the Late Onset Alzheimer Disease risk genes;
- There has been a discovery that there are at least three types of Alzheimer's patterns of pathology, suggesting different pathogenesis. Treatment may be specific for each type;
- There are a number of diseases, such as hippocampal sclerosis, that doctors diagnose as Alzheimer's disease but have other causes; and
- New genes causing frontotemporal dementia have been discovered.

4) Specialized model day care programs in Florida provide service delivery to persons suffering from ADRD and training for health care and social service personnel in the care of persons having ADRD. Model Day Care services are funded in three planning and service areas (PSAs 3 - Gainesville, 6 - Tampa, and 11 - Miami-Dade). Examples of activities implemented at model day care centers may include:

- Exercise Program of Tai Chi, balance, and muscle strengthening activities;

- Active and passive range of motion exercises;
- Daily walks, independently and with one and two person assistance;
- Music Therapy, including sing along, playing musical instruments, reminiscing, musical story-telling, educational presentations, inter-generational music in groups and individually, and dancing. The participants in the early and moderate stages engage in musical presentations during special holidays for the families; and
- Therapeutic Art, including visual art programmed for different cognitive abilities. A professional therapeutic visual artist works with participants in the early and moderate stages. Through cues participants make replicas of other art works.

The total amount of the three specialized model day care centers was \$340,065 for SFY 2011-2012. The amount of \$113,355 is included in each Area Agency on Aging (AAA) respite contract.

5) Respite care and supportive services are provided through direct contracts with the 11 Area Agencies on Aging (AAAs). Funds are contracted according to an allocation formula, which includes the number and proportion of the county population of individuals who are 75 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 following is the statewide breakdown by Planning and Service Area (PSA) by County of current service and ADI allocation data:

PSA 1 (7/1/2011 – 6/30/2012 ADI Allocation – \$323,326 – 108 clients and caregivers served)

- Escambia County - \$193,841.00 - Services provided: respite; case management; education and training; and specialized medical equipment, services, and supplies
- Okaloosa County – \$58,057.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies
- Santa Rosa County – \$38,856.00 - Services provided: respite; case management; education and training, and specialized medical equipment, services, and supplies
- Walton County – \$32,572.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies

PSA 2 (7/1/2011 – 6/30/2012 ADI Allocation – \$401,341 – 176 clients and caregivers served)

- Bay County – \$96,508.00 - Services provided: respite and case management
- Calhoun County – \$12,840.00 - Services provided: respite and case management
- Franklin County – \$5,650.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies
- Gadsden County – \$34,077.00 - Services provided: respite and case management
- Gulf County – \$11,201.00 - Services provided: respite and case management
- Holmes County – \$16,591.00 - Services provided: respite and case management
- Jackson County – \$39,894.00 - Services provided: respite and case management

- Jefferson County – \$11,937.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies
- Leon County – \$97,629.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies
- Liberty County – \$8,597.00 - Services provided: respite and case management
- Madison County – \$16,135.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies
- Taylor County – \$15,301.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies
- Wakulla County – \$12,607.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies
- Washington County – \$22,374.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies

PSA 3 (7/1/2011 – 6/30/2012 ADI Allocation – \$744,551 – 360 clients and caregivers served)

- Alachua County – \$157,677.17 - Services provided: respite care, model day care, and case management
- Bradford County – \$27,032.16 - Services provided: respite care
- Citrus County – \$59,199.36 - Services provided: respite care
- Columbia County – \$35,772.64 - Services provided: respite care
- Dixie County – \$26,552.12 - Services provided: respite care
- Gilchrist County – \$26,462.29 - Services provided: respite care
- Hamilton County – \$30,201.13 - Services provided: respite care
- Hernando County – \$57,604.30 - Services provided: respite care
- Lafayette County – \$26,224.10 - Services provided: respite care
- Lake County – \$70,679.83 - Services provided: respite care
- Levy County – \$31,809.96 - Services provided: respite care
- Marion County – \$70,232.68 - Services provided: respite care
- Putnam County – \$36,314.63 - Services provided: respite care
- Sumter County – \$34,531.95 - Services provided: respite care
- Suwannee County – \$28,153.07 - Services provided: respite care
- Union County – \$26,103.61 - Services provided: respite care

PSA 4 (7/1/2011 – 6/30/2012 ADI Allocation – \$518,172 – 152 clients and caregivers served)

- Baker County – \$43,812.61 - Services provided: respite care
- Clay County – \$53,831.50 - Services provided: respite care
- Duval County – \$129,339.41 - Services provided: respite care
- Flagler County – \$48,175.54 - Services provided: respite care
- Nassau County – \$44,785.94 - Services provided: respite care
- Saint Johns County – \$65,733.00 - Services provided: respite care
- Volusia County – \$132,494.00 - Services provided: respite care

PSA 5 (7/1/2011 – 6/30/2012 ADI Allocation – \$695,953 – 140 clients and caregivers served)

- Pasco County – \$261,961.00 - Services provided: respite; case management; and specialized medical equipment, services, and supplies

- Pinellas County – \$433,992.00 - Services provided: respite; counseling; case management; and specialized medical equipment, services, and supplies

PSA 6 (7/1/2011 – 6/30/2012 ADI Allocation – \$736,642 – 182 clients and caregivers served)

- Hardee County – \$6,647.00 - Services provided: respite care
- Highlands County – \$59,467.00 - Services provided: respite care
- Hillsborough County – \$360,372.00 - Services provided: respite care, model day care, and case management
- Manatee County – \$130,027.00 - Services provided: respite and case management
- Polk County – \$180,129.00 - Services provided: respite care

PSA 7 (7/1/2011 – 6/30/2012 ADI Allocation – \$549,983 – 698 clients and caregivers served)

- Brevard County – \$191,212.00 - Services provided: respite care
- Orange County – \$232,243.00 - Services provided: respite and case management
- Osceola County – \$47,033.00 - Services provided: respite and case management
- Seminole County – \$79,495.00 - Services provided: respite and case management

PSA 8 (7/1/2011 – 6/30/2012 ADI Allocation – \$644,661- 246 clients and caregivers served)

- Charlotte County – \$90,901.00 - Services provided: respite and case management
- Collier County – \$109,004.00 - Services provided: respite and case management
- Desoto County – \$33,043.00 - Services provided: respite care
- Glades County – \$28,602.00 - Services provided: respite care
- Hendry County- \$30,974.00 - Services provided: respite care
- Lee County – \$182,634.00 - Services provided: respite and case management
- Sarasota County – \$169,503.00 - Services provided: respite care

PSA 9 (7/1/2011 – 6/30/2012 ADI Allocation – \$2,374,450 – 692 clients and caregivers served)

- Indian River County - \$60,780.00 - Services provided: respite and case management
- Martin County – \$67,157.00 - Services provided: respite and case management
- Okeechobee County – \$12,026.00 - Services provided: respite care
- Palm Beach County – \$2,159,289.00 - Services provided: respite and case management
- Saint Lucie County – \$75,198.00 - Services provided: respite and case management

PSA 10 (7/1/2011 – 6/30/2012 ADI Allocation – \$1,350,512.03 – 414 clients and caregivers served)

- Broward County - \$1,350,512.03 - Services provided: respite, caregiver training, and case management

PSA 11 (7/1/2011 – 6/30/2012 ADI Allocation – \$874,397 – 504 clients and caregivers served)

- Dade County – \$817,651.00 - Services provided: respite, caregiver training, counseling, model daycare, and case management
- Monroe County – \$56,746.00 - Services provided: respite care

In-facility respite care (adult day care) services are provided to individuals throughout the state in adult day care centers, funded through programs other than ADI. Just over 80 percent of the

individuals who received these services require supervision due to cognitive decline. Although other programs, such as Community Care for the Elderly (CCE) and Older Americans Act programs, provide adult day care services, eligibility is not restricted to Alzheimer's disease or related disorders. Other programs providing support to caregivers not specific to ADRD include RELIEF, Home Care for the Elderly, and National Caregiver Support Program.

### **Policy Requirements for Dementia-Specific Training for Professions Providing Care**

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

The requirements are as follows:

Assisted Living Facility employees who have regular contact with residents who have ADRD must complete up to four hours of initial Alzheimer's disease training approved by the Department of Elder Affairs (DOEA) within three months of employment. Any assisted living facility employee who provides direct care to residents who have ADRD must complete four additional hours of approved training. The additional four-hour training for a direct caregiver employee must be completed within nine months of employment. Assisted living facility employees who provide direct care are required to complete four hours of continuing education annually.

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

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

### **Quality Care Measures**

Individual statutes address quality measures employed by providers of care, including providers of respite, adult daycare, assisted living facilities, skilled nursing facilities, and hospice services. Florida Statutes indicate the following:

Assisted Living Facilities – Section 429.23 F. S., indicates, “Every facility licensed under this part may, as part of its administrative functions, voluntarily establish a risk management and quality assurance program, the purpose of which is to assess resident care practices, facility incident reports, deficiencies cited by the agency, adverse incident reports, and resident grievances and develop plans of action to correct and respond quickly to identify quality differences.

Adult Day Care – Section 429.929, F. S. indicates, “The agency shall develop the key quality-of-care standards, taking into consideration the comments and recommendations of the Department of Elderly Affairs and of provider groups. These standards shall be included in rules adopted by the Department of Elderly Affairs.

Nursing Facilities – Section 400.147, F. S., indicates “Every facility shall, as part of its administrative functions, establish an internal risk management and quality assurance program, the purpose of which is to assess resident care practices; review facility quality indicators, facility incident reports, deficiencies cited by the agency, and resident grievances; and develop plans of action to correct and respond quickly to identified quality deficiencies.

Hospices – Section 400.605, F.S. indicates, “The agency, in consultation with the department, may adopt rules to administer the requirements of part II of chapter 408. The department, in consultation with the agency, shall by rule establish minimum standards and procedures for a hospice pursuant to this part.

Section 400.60501, Florida Statutes, requires the Department of Elder Affairs, in conjunction with the Agency for Health Care Administration (AHCA), to develop outcome measures to determine the quality and effectiveness of hospice care for hospices licensed in Florida. This statute, along with Rule 58A-2.005, defines the outcome measures, as well as demographic and diagnostic information hospices are required to submit to the Department of Elder Affairs annually. Hospices are also required to conduct patient surveys using the National Hospice and Palliative Care Organization (NHPCO) Patient/Family Satisfaction Survey or a similar survey. Two of the three hospice outcome measures were promulgated on August 11, 2008. The 2011 calendar year was the third year for which a full year’s results for all three outcome measures were available. Please visit <http://elderaffairs.state.fl.us/doea/evaluations.php> to view the full report.

Since it is necessary to determine the standards and measures in place for each service provider type, the task force continues its review in the area of quality measures.

### **Capability of Public Safety Workers and Law Enforcement Officers to Respond**

In 2008, Governor Charlie Crist, signed an Executive Order enacting the Florida Silver Alert Plan. The purpose of the statewide Silver Alert is to help law enforcement officers rescue missing seniors with Alzheimer’s disease or a related dementia disorder who became lost while driving a car. The Silver Alert allows widespread broadcast of information to the public that a person is

missing through the use of dynamic message signs on highways that note the color, make, and tag number of the vehicle the missing person is driving. In addition to these dynamic message signs, the public is notified through the media and neighborhood telephone alerts. Florida Silver Alert became state law during the 2011 Florida legislative session, and Governor Scott signed it into law June 24, 2011. Section 937.0201, F. S. which addresses missing persons, was amended to include Silver Alert. The term “missing endangered person” includes missing adults who meet the criteria for Silver Alert. Persons providing information related to a missing person, when acting in good faith, are provided immunity from civil liability. Agencies, including both law enforcement and service providers may communicate information about an endangered missing person among themselves, and to the media. In 2011, the Silver Alert was expanded to include persons with ADRD who “lost on foot.”

The statistical information below exhibits the effectiveness of the Silver Alert initiative.

**State Silver Alert Stats Overview 2008-2012**

Total Activations:	598
Total Denials:	240
Total Recoveries Prior to Activation:	221

Outcome	Total/Percentage
State Silver Alert Recoveries	74 (12%)
Direct Recoveries	50 (8%)
Indirect Recoveries	24 (4%)
*Recovered Deceased	15 (3%)

**Activations by Year:**

State Silver Alert Activations 2008	32
State Silver Alert Activations 2009	105
State Silver Alert Activations 2010	124
State Silver Alert Activations 2011	162
State Silver Alert Activations 2012	175

\*Recoveries: In the first 81 cases (2008-2009) that were analyzed, 8% were found deceased.

Florida is unique in that it is the only state that has a formal program for prevention and recidivism of persons with ADRD becoming missing. Florida Silver Alert provides information regarding the difficult decision of when a loved one or family member with ADRD is no longer safe to drive. The program also promotes prevention by giving training and support to caregivers of persons with ADRD that have been found through Silver Alert to decrease the chance of recidivism.

Florida Silver Alert training is provided to law enforcement focusing on defining ADRD, interacting with individuals who have ADRD, as well as how to properly enact the Silver Alert Program in the event a person with ADRD is missing. Community training is offered in the form of on-going community education seminars throughout the state. Florida utilizes the senior network to provide training and services to families of persons with ADRD. The public can

choose to sign up to receive Silver Alerts, allowing them to be notified when an individual with ADRD is found missing.

Memory Disorder Clinics (MDCs) have specific protocol in response to a Silver Alert.

1. MDCs are notified through the FDLE list service of all Silver Alerts enacted throughout the state of Florida.
2. When notification of a Silver Alert is received by the MDC, the Clinic Coordinator reviews the information to determine:
  - a. From where the person is missing, and
  - b. The law enforcement agency reporting the Silver Alert.
3. The MDC that provides services in the county of the reporting law enforcement agency is responsible for following up on all Silver Alerts in that county.
4. After receiving notification of a local Silver Alert, the MDC calls the reporting law enforcement agency to obtain the name, address, and phone number of the caregiver.
5. The MDC calls the caregiver/family to inform them that services are available to the endangered person and caregiver at the MDC when the person is recovered and returned home.
6. The MDC provides the caregiver with a contact name and the phone number of the MDC and asks the caregiver to call when the endangered person returns home.

Upon recovery of an endangered person, MDCs initiate services through a referral process to the Aging and Disability Resource Center (ADRC) in the county of residence. In accordance with the Silver Alert protocols, the ADRC then initiates contact with the caregiver and provides community referrals and resources for both the caregiver and endangered person.

### **Response to Abuse, Exploitation, and Suicide**

Persons with ADRD are among Florida's vulnerable population. This population is at higher risk for self-neglect, abuse, exploitation, and suicide. In accordance with Section 430.205, F. S., DOEA collaborates with the Department of Children and Families' (DCF) Adult Protective Services (APS), to protect individuals with ADRD from harmful situations. Section 430.205 F.S. mandates, "Those elderly persons who are determined by protective investigations to be vulnerable adults in need of services, pursuant to s. 415.104(3)(b), or to be victims of abuse, neglect, or exploitation who are in need of immediate services to prevent further harm and are referred by the adult protective services program, shall be given primary consideration for receiving community-care-for-the-elderly services. As used in this paragraph, "primary consideration" means that an assessment and services must commence within 72 hours after referral to the department or as established in accordance with department contracts by local protocols developed between department service providers and the adult protective services program."

In 2004, to facilitate compliance and improve operations, DOEA partnered with DCF to design the Adult Protective Services (APS) Referral Tracking Tool (ARTT). The purpose of (the

ARTT) is to track DCF APS referrals for individuals 60 and older, made to Area Agencies on Aging (AAAs) and Community Care for the Elderly (CCE) lead agencies. The ARTT makes APS referral notification quick and simple and allows referral information to be quickly viewed and printed.

APS staff refers elders in need of home and community-based services to CCE lead agencies. APS staff enters information about each APS referral into the ARTT. The ARTT automatically send emails to the designated staff in the aging network, notifying them that a new referral has been made. The aging network acknowledges in the ARTT that the referral was received and documents the action taken, which automatically causes emails to be sent to the appropriate DCF staff. Both DCF staff and aging network staff are able to review referral information in the ARTT for individuals in their specified geographic regions at any time. The ARTT ensures APS referrals make it to their destination, and all necessary parties are able to access appropriate APS referral information.

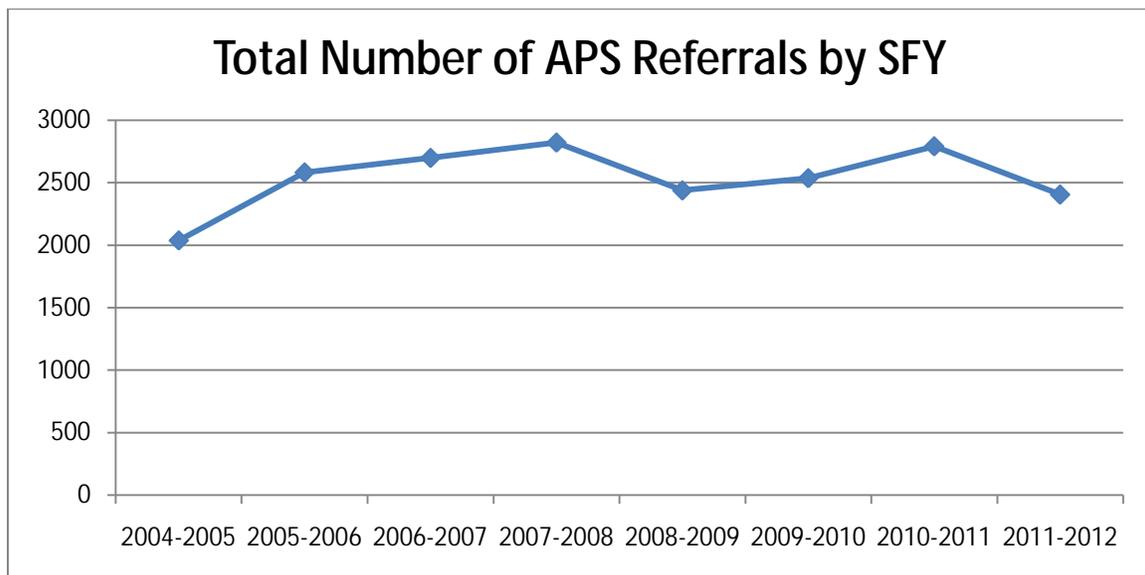
The chart below provides statistical data of APS referrals. During 2011-2012, the aging network received 1,436 APS high-risk referrals that were prioritized for immediate assessments and services. 33 percent of the individuals referred had dementia.

Number Clients Referred by Risk Level and Year									
State Fiscal Year									
Risk Level	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011	2011-2012	2012-2013 (as of Nov 2012)
Low	208	278	319	259	257	235	282	237	92
Medium	751	884	1030	991	851	916	1047	732	328
High	1079	1420	1349	1571	1330	1385	1462	1436	585
<b>Total</b>	<b>2038</b>	<b>2582</b>	<b>2698</b>	<b>2821</b>	<b>2438</b>	<b>2536</b>	<b>2791</b>	<b>2405</b>	<b>1005</b>

% Referrals By Risk Level and Year									
State Fiscal Year									
Risk Level	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011	2011-2012	2012-2013 (as of Nov 2012)
Low	10%	11%	12%	9%	11%	9%	10%	10%	9%
Medium	37%	34%	38%	35%	35%	36%	38%	30%	33%

High	53%	55%	50%	56%	55%	55%	52%	60%	58%
Total	<b>100%</b>								

% Change - Number Referrals Compared to Previous Year								
State Fiscal Year								
	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011	2010-2012
% Change	NA	27%	4%	5%	-14%	4%	10%	-14%



### Available Home and Community-Based Services to Assist Persons with ADRD and Caregivers

According to the Alzheimer’s Association’s “2012 Alzheimer’s Disease Fact and Figures” report, over 15 million Americans provide unpaid care for a person with Alzheimer’s disease or other dementias. Unpaid caregivers are primarily family members, but they also may be other relatives and friends. In 2011, these people provided an estimated 17.4 billion hours of unpaid care, a contribution to the nation valued at over \$210 billion. Caregivers of people with Alzheimer’s and other dementias provide care for a longer time, on average, than caregivers of older adults with other conditions. For example, among caregivers of people with Alzheimer’s disease, 23 percent had been caregivers for less than one year, 43 percent for one to four years, and 32 percent for five years or more. In contrast, more of their non-Alzheimer’s disease

caregiver counterparts had been caregiving for less than one year (34 percent), and fewer of them had been caregiving for one to four years (33 percent) or longer (28 percent). According to the Alzheimer's Association's "2012 Alzheimer's Disease Fact and Figures" report, in 2011, 998,684 Alzheimer's and dementia caregivers in Florida provided 1,137,301,634 hours of unpaid care. These unpaid hours are valued at \$13,784,095,810.

### **Adult Day Care Services**

Adult day care services differ from other forms of long-term care in its unique focus on the strengths and abilities of a person rather than on his or her illness or loss of functional abilities. The program monitors medical conditions to prevent unnecessary hospitalization and increase or maintain optimal functional abilities. The strengths of adult day care services provide an extraordinary range of benefits designed to:

- Stabilize medical conditions;
- Reduce crisis episodes of emergency rooms through preventive monitoring and early intervention;
- Prevent secondary disabilities caused by inactivity;
- Improve functional ability through therapeutic and meaningful activities;
- Prevent or delay unnecessary institutionalization;
- Provide an alternative setting of health care to an aging population;
- Increase health and wellness programs/services;
- Improve or stabilize cognitive functioning;
- Increase socialization opportunities decreasing isolation and loneliness;
- Promote better nutrition;
- Educate caregivers;
- Provide respite to caregivers;
- Improve the quality of life;
- Increase the ability to access services and information; and
- Increase self-esteem and dignity

There are 213 licensed adult day care centers under the Agency for Health Care Administration (AHCA) with a total capacity to serve 10,801 individuals age 18 years and older. These figures do not reflect centers that might be exempt from licensure under Chapter 429 F.S. These include assisted living facilities, free standing hospice, federal government entities, and nursing homes.

The number of ADRD participants that attend adult day care centers may not be reflected in the DOEA statistics. This is due to private operations/corporations that do not receive funding from the DOEA. These corporations are not mandated to complete or submit paperwork that could be entered into the DOEA data systems. Centers that accept private pay participants are not mandated to collect or submit data. These include organizations such as Easter Seals, Sarah Care, Catholic Charities, and hospital systems. Centers accept participants with multiple challenges, including Alzheimer's disease and related dementias. The majority of attendees in the centers have some form of dementia.

There are several centers that target the population specific to ADRD. A large majority of the population that is served has some form of cognitive impairment. Approximately 70 percent of

the participants at the adult day care have some form of dementia. In 2012, the Florida legislators passed the “Specialized Alzheimer’s Services Adult Day Care Act.” An adult day care center may not claim to be licensed or designated to provide specialized Alzheimer’s services unless the adult day care center’s license has been designated as such pursuant to Section 429.918 F.S. “Specialized Alzheimer’s services” means therapeutic, behavioral, health, safety, and security interventions; clinical care; support services; and educational services that are customized for the specialized needs of a participant’s caregiver and the participant who is affected by Alzheimer’s disease or an irreversible, degenerative condition resulting in dementia. Within this statute are specific requirements to the delivery of services to persons with ADRD.

There are a limited amount of Early Memory Loss or Mild Cognitive Impairment programs. Few adult day care centers provide specialized programming for persons with young-onset Alzheimer’s or individuals who are under the age of 70 years old.

### **Residential Assisted Living Options**

Assisted living provides housing, meals, and one or more personal services for a period exceeding 24 hours to one or more adults who are not relatives of the owner or administrator. According to the Agency for Health Care Administration, there are 3,010 assisted living facilities (ALFs) in Florida licensed with 84,764 beds. Since 2003, we have seen growth of 32 percent. ALFs are very diverse and range in size from 2 beds to 495 beds.<sup>1</sup>

Assisted living facilities licensed to operate by the Agency for Health Care Administration receive a standard license. In addition, those wishing to offer specialty services may apply for a Limited Nursing Services (LNS) license, an Extended Congregate Care (ECC) license or a Limited Mental Health (LMH) license. The first two specialty licenses allow the ALF to offer additional nursing services not otherwise allowed under a standard license. Nurses are limited to the actual services that they may perform in the ALF according to the license that the ALF holds. Unlike any other setting, a nurse may not operate to the full scope of her/his license in an ALF unless the ALF holds one of these specialty licenses.

In addition to admission criteria for residents, there are also statutory and regulatory limitations for continued residency. The ECC specialty license was created specifically to address the aging-in-place concept, which allows the ALF to provide additional nursing services for a more frail resident to be able to remain in place.

The third specialty license is required when an ALF has 3 or more residents meeting the statutory definition of a mental health resident. There are additional training requirements for ALFs holding this specialty license.

While there is no specialty license for ALFs that care for residents with Alzheimer’s disease, a facility that claims it provides special care for persons with Alzheimer’s disease or other related

---

<sup>1</sup> Senate Children & Families Committee report from AHCA, January 15, 2013

disorders must disclose those services in its advertisements or in a separate document. There are also statutory standards for training, staff, activities, and physical environment that must be met. The statute also provides direction for individuals conducting Alzheimer's training. Examples of the special care standards include; if a facility has 17 or more residents, the facility must have awake staff at all times, and if a facility has fewer than 17 residents, the facility must have awake staff on duty at all hours or have mechanisms in place to monitor and ensure the safety of the facility's residents; offering activities specifically designed for persons who are cognitively impaired; having a physical environment that provides for the safety and welfare of the resident; and that training includes 8 hours of specific Alzheimer's care and a required 4 hours of continuing education yearly after that. (F.S. 429.178)

With the growing numbers of individuals that are afflicted with this disease, there are a number of ALFs that do have memory care units and some that designate the entire facility as memory care. While there is no special licensure designation, an ALF will advertise these services in their literature and by other means.

### **Inventory of Long-Term Care Facilities**

Regarding the availability of long-term care to persons with ADRD, as of January 2013, the state of Florida had 279 nursing facilities. Please view <http://apps.ahca.myflorida.com/nhcguide/RegionMap.aspx> to access the list and specific information on each facility.

### **Adequacy and Appropriateness of Geriatric-Psychiatric Units and Legal Issues Affecting Floridians with Dementia**

One area of note is Florida's "Baker Act," residing at Chapter 394 of the Florida Statutes. As with all 50 states and the District of Columbia, Florida has laws dealing with the voluntary or involuntary commitment of people whose cognitive function actually creates a danger to themselves or others. Among other goals, the Florida Legislature created Chapter 394 with the intent to provide a safe haven for people who needed emergent care in a setting which is clinically appropriate and "most likely to facilitate the person's return to the community as soon as possible" with a guarantee of "individual dignity and human rights."<sup>2</sup> There is a vital balance between protecting people from harm and being too quick for government to intercede. The Task Force perceives opportunities to strengthen Chapter 394 to better ensure that people who need intervention get it even when the dangerous behaviors may not be immediately apparent to first responders and hearing officers while, at the same time, preserving human rights and the dignity of all involved. Sometimes voluntary or involuntary commitment proceedings are initiated by assisted living or skilled nursing facilities where the person resides. It may be possible to provide resources, regulation, and tools to better ensure that, whenever possible,

---

<sup>2</sup> 394.453, Fla. Stat.

residents receive “treatment in place” rather than being transferred by involuntary commitment to a mental health facility.

Another legal issue affecting the independence and dignity of people with Alzheimer’s disease and related dementias is Florida’s guardianship system. Chapter 744 of the Florida Statutes provides for different types of guardianships including an “involuntary guardianship.” The purpose of an involuntary guardianship is to protect people who are incapacitated, often from their own actions and vulnerability. The court determines whether the person is incapacitated and, if so, to what degree. The court can then appoint a “guardian” to exercise certain rights of the incapacitated person or “ward.” It is the legislative intent that guardianship not take place if a less restrictive alternative is available, and any guardianship should be designed and monitored by the court to best maintain the dignity and independence of the ward.<sup>3</sup> The Task Force sees opportunities to lessen the burden on the courts and allow more people to avoid guardianship through better education on less restrictive alternatives to guardianship, including greater awareness of powers of attorney, advance health care directives, and other planning. When guardianship is necessary, the Task Force sees the opportunity to further protect individuals and have better information available to the courts through properly trained and selected examining committees, the people dispatched by the courts to examine the alleged incapacitated persons.

Family caregiving contracts are also an important tool to avoid the need for guardianship and to allow family members to help keep their loved ones independent and safe. Unlike some other states, children are not legally responsible to care for a parent in Florida. Family caregivers often miss work and lose significant income in addition to the psychosocial consequences that may accompany caregiving. Many family members provide services out of love and responsibility, but many cannot afford to do so. If an elder just gives the child money to care for them, that could cause ineligibility for need-based assistance like Medicaid. A family caregiving contract allows family members to create clear responsibilities and to receive fair compensation. According to the *Wall Street Journal*, “the contracts simply help reward the significant amounts of time, effort, and money that family members often spend watching over and taking care of an elderly relative.”<sup>4</sup> The Task Force sees family caregiving agreements as another tool to enable families to better cope with the average of 21 hours per week spent on caregiving for a family member.<sup>5</sup> Here too, better education can prevent exploitation and abuse while empowering families to better cope with caregiving.

People with dementia often require long-term care at costs few can afford without becoming impoverished. Most people have no insurance to cover long-term care. Medicare does not cover long-term care and the new health insurance law (the Affordable Care Act) does not provide payment for long-term care. Medicaid is a state and federal partnership program that helps

---

<sup>3</sup> 744.1012 et seq., Fla. Stat.

<sup>4</sup> “Who will mind Mom?” Rachel Silverman, *The Wall Street Journal* (Sept. 7, 2006)

<sup>5</sup> National Alliance for Caregiving and AARP, 2004 study.

finance long-term care for Florida's indigent elderly. Because Medicaid is the number one payment source for long-term care in Florida, the fairness and viability of the program is of great importance to Floridians with dementia. It has been demonstrated that government can realize significant savings and people will have a higher quality of life by using Medicaid to finance more home and community-based care, and this should be an aspiration reached by cash-flow analysis and greater utilization of such programs as Florida's Long Term Care Diversion Waiver and other programs designed to allow people to "age in place."

Florida does a good job of protecting spouses from becoming impoverished due to the care costs of the first spouse to become ill; otherwise creating a significant public policy conundrum which makes the well spouse a dependent. Florida should continue its practice, in place since 1999, of allowing a "well spouse" to refuse the obligation to spend-down assets on the care costs of the ill spouse.

The Task Force continues to identify and seek input on other legal issues affecting Floridians with Alzheimer's disease and related dementias.

### **Disaster Preparedness**

Disaster preparedness continues to be a significant issue for Florida's elder population. Lessons learned from the previous hurricane seasons have revealed the need for improved planning and coordination in each community. Persons with ADRD and their caregivers may be at greater risk of unfavorable health outcomes and loss of independence if there is a disruption to their support network and continuity of care. Persons with ADRD depend on their family, friends, and caregivers for assistance with their activities of daily living, such as bathing, preparing meals, transportation, and taking medications. Factors such as the cognitive impairment of ADRD, along with diminished sensory awareness, and social and economic limitations affect the ability to prepare for, respond to, and recover from a disaster.

Issues such as insurance fraud and regulation, post-disaster construction, and damage recovery are all concerns that arise following disasters. The financial impacts of hurricanes and other events are regulated and overseen by these agencies (DOEA, 2012).

Education and increased public awareness are both key components to a successful disaster preparedness plan for Floridians with ADRD and their caregivers. There is great diversity and disparity in Florida county emergency and disaster preparedness websites. Several counties have instructions in Spanish. Many websites include links to special needs information. But many websites are difficult to navigate, and an individual would have to have computer access, be proactive, be fairly knowledgeable about using various Internet tools in their search, and have other methods to gather the information.

DOEA performs a key role in disaster preparedness and response for elders. Through partnerships with other state agencies, DOEA coordinates resources and services available to elders throughout Florida during hurricanes and other disasters. Other Florida agencies involved

in preparations, response, and recovery efforts for Florida seniors include the Agency for Health Care Administration, Department of Health, Department of Veterans' Affairs, Agency for Persons with Disabilities, Department of Children and Families, Department of Economic Opportunity, Department of Education, and Department of Military Affairs. The Department of Financial Services' Office of Insurance Regulation and the Department of Business and Professional Regulation also play key roles in assisting Florida residents in the event of a disaster.

DOEA's Secretary is required to convene Multiagency Special Needs Shelter Discharge Planning Response Teams, at any time that he or she deems appropriate and necessary, or as requested by ESF 8 at the State Emergency Operations Center, to assist local areas that are severely impacted by a natural or manmade disaster that requires the use of special needs shelters. The teams are activated to provide resource and logistical support to local jurisdictions to assist with discharge planning and transition of clients to appropriate services and resources within the community (Multiagency Response Teams Standard Operating Procedure, 2006).

## References

- Algom AA, Dickson D. Dementia with Lewy bodies (DLB), Parkinson's disease dementia (PDD) and Alzheimer dementia (AD): A retrospective clinical comparison and quantitative neuropathologic study. *Neurology* 70(Suppl 1):A276, 2008.
- Allen M, Vlachantoni D, Bisceglia G, Carrasquillo M, Tulloch B, Wilcox S, Hayward C, Dickson D, Alan Wright A, Younkin S. Investigation of mitochondrial DNA damage in late onset Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* 4:T719-720, 2008.
- Allen M, Zou F, Chai HS, et al. Glutathione S-transferase omega genes in Alzheimer and Parkinson disease risk, age-at-diagnosis and brain gene expression: an association study with mechanistic implications. *Mol Neurodegener.* 2012 Apr 11; 7:13. PMID: PMC3393625.
- Allen M, Zou F, Chai HS, et al. Novel late-onset Alzheimer disease loci variants associate with brain gene expression. *Neurology.* 2012 Jul 17; 79(3):221-8.
- Alzheimer's Association (2012). 2012 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 8(2). Source: [http://www.alz.org/downloads/facts\\_figures\\_2012.pdf](http://www.alz.org/downloads/facts_figures_2012.pdf), and <http://download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012000325.pdf>. Retrieved: January 3, 2013.
- Amador-Ortiz C, Lin WL, Ahmed Z, et al. TDP-43 immunoreactivity in hippocampal sclerosis and Alzheimer's disease. *Annals of Neurology* 61:435-445, 2007.
- Bieniek KF, Murray ME, Rutherford NJ, et al. Tau pathology in frontotemporal lobar degeneration with C9ORF72 hexanucleotide repeat expansion. *Acta Neuropathol.* 2012 Sep 28. [Epub ahead of print] PubMed PMID: 23053135.
- Borchelt DR, Thinakaran G, Eckman CB, Lee MK, Davenport F, Ratovitsky T, et al. Familial Alzheimer's disease-linked presenilin 1 variants elevate Abeta1-42/1-40 ratio in vitro and in vivo. *Neuron.* 1996;17(5):1005-13.
- Carrasquillo MM, Belbin O, Hunter TA, et al. Replication of CLU, CR1, and PICALM Associations With Alzheimer Disease. *Arch Neurol.* 2010 Jun 14. [Epub ahead of print] PubMed PMID: 20554627.
- Chartier-Harlin M-C, Crawford F, Houlden H, Warren A, Hughes D, Fidani L, et al. Early-onset Alzheimer's Disease caused by mutations at codon 717 of the  $\beta$ -amyloid precursor protein gene. *Nature.* 1991;353:844-6.
- Duff K, Eckman C, Zehr C, Yu X, Prada CM, Perez-tur J, et al. Increased amyloid-beta42(43) in brains of mice expressing mutant presenilin 1. *Nature.* 1996;383(6602):710-3.

Eckman CB, Mehta ND, Crook R, Perez-tur J, Prihar G, Pfeiffer E, et al. A new pathogenic mutation in the APP gene (I716V) increases the relative proportion of A beta 42(43). *Human Molecular Genetics*. 1997;6(12):2087-9.

Eriksen JL, Sagi SA, Smith TE, Weggen S, Das P, McLendon DC, et al. NSAIDs and enantiomers of flurbiprofen target gamma-secretase and lower Abeta 42 in vivo. *J Clin Invest*. 2003;112(3):440-9.

FCA, 2005: Family Caregiver Alliance, Fact Sheet: Selected Caregiver Statistics, 2005. Available: [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=439](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439)

Feinberg, L., Reinhard, S.C., Houser, A., & Choula, R. (2011). Valuing the invaluable (2011 update): The growing contributions and costs of family caregiving. AARP Public Policy Institute.

Florida Department of Elder Affairs (2012). State plan on aging: 2013 – 2012. Source: [http://elderaffairs.state.fl.us/doea/StatePlan/2013\\_2016StatePlan.pdf](http://elderaffairs.state.fl.us/doea/StatePlan/2013_2016StatePlan.pdf). Retrieved: January 3, 2013.

Florida Department of Elder Affairs (2012). Florida county profiles projections: 2012. Source: [http://elderaffairs.state.fl.us/doea/pubs/stats/County\\_2012Projections/Florida\\_Map.html](http://elderaffairs.state.fl.us/doea/pubs/stats/County_2012Projections/Florida_Map.html). Retrieved: January 3, 2013.

Florida Department of Elder Affairs (2012). Silver Alert Program. Source: [http://elderaffairs.state.fl.us/doea/silver\\_alert.php](http://elderaffairs.state.fl.us/doea/silver_alert.php). Retrieved: January 16, 2013.

Florida Department of Elder Affairs (2012). Summary of Programs and Services: 2012. Source: [http://elderaffairs.state.fl.us/doea/pubs/pubs/sops2012/2012\\_SOPS\\_D\\_web.pdf](http://elderaffairs.state.fl.us/doea/pubs/pubs/sops2012/2012_SOPS_D_web.pdf). Retrieved: January 16, 2013.

Florida Health Care Association (2013). Facts about long-term care in Florida. Source: [http://www.fhca.org/media\\_center/long\\_term\\_health\\_care\\_facts/](http://www.fhca.org/media_center/long_term_health_care_facts/). Retrieved: January 3, 2013.

Florida Office on Disability and Health, University of Florida (UF) (2007). Characteristics of Caregivers in Florida. Source: <http://fodh.phhp.ufl.edu/files/2011/05/Caregiving-Policy-Brief.pdf>. Retrieved: December 28, 2012.

Goate A, Chartier-Harlin M-C, Mullan M, Brown J, Crawford F, Fidani L, et al. Segregation of a missense mutation in the amyloid precursor gene with familial Alzheimer's disease. *Nature*. 1991;349:704-6.

Golde TE, Petrucelli L, Lewis J. Targeting Abeta and tau in Alzheimer's disease, an early interim report. *Exp Neurol*. 2010;223(2):252-66. PMID: 2864363.

Golde TE, Schneider LS, Koo EH. Anti-abeta therapeutics in Alzheimer's disease: the need for a paradigm shift. *Neuron*. 2011;69(2):203-13. PMID: 3058906.

Graff-Radford NR, Crook JE, Lucas J, Boeve BF, Knopman DS, Ivnik RJ, et al. Association of low plasma Abeta42/Abeta40 ratios with increased imminent risk for mild cognitive impairment and Alzheimer disease. *Arch Neurol*. 2007;64(3):354-62.

Hardy JA, Higgins GA. Alzheimer's disease: the amyloid cascade hypothesis. *Science*. 1992;256(5054):184-5.

Hardy J. New insights into the genetics of Alzheimer's disease. *Annals of Medicine*. 1996;28(3):255-8.

Hsiao K, Chapman P, Nilsen S, Eckman C, Harigaya Y, Younkin S, et al. Correlative memory deficits, Abeta elevation, and amyloid plaques in transgenic mice [see comments]. *Science*. 1996;274(5284):99-102.

Hutton M, Lendon CL, Rizzu P, Baker M, Froelich S, Houlden H, et al. Association of missense and 5'-splice-site mutations in tau with the inherited dementia FTDP-17. *Nature*. 1998;393(6686):702-5.

Hutton M. Molecular genetics of chromosome 17 tauopathies. *Ann N Y Acad Sci*. 2000;920:63-73.

Lewis J, Dickson DW, Lin WL, Chisholm L, Corral A, Jones G, et al. Enhanced neurofibrillary degeneration in transgenic mice expressing mutant tau and APP. *Science*. 2001;293(5534):1487-91.

Lewis J, McGowan E, Rockwood J, Melrose H, Nacharaju P, Van Slegtenhorst M, et al. Neurofibrillary tangles, amyotrophy and progressive motor disturbance in mice expressing mutant (P301L) tau protein. *Nat Genet*. 2000;25(4):402-5.

Mace, N. & P.V. Rabins (1999). *The 36-hour day: A family guide to caring for persons with Alzheimer disease, related dementing illnesses, and memory loss in later life*. Johns Hopkins Press.

Mullan M, Crawford F, Axelman K, Houlden H, Lilius L, Winblad B, et al. A pathogenic mutation for probable Alzheimer's disease in the APP gene at the N-terminus of  $\beta$ -amyloid. *Nature genetics*. 1992;1:345-7.

Murray ME, Graff-Radford NR, Ross OA, et al. Neuropathologically defined subtypes of Alzheimer's disease with distinct clinical characteristics: a retrospective study. *Lancet Neurol*. 2011;10(9):785-96.

Pao WC, Dickson DW, Crook JE, et al. Hippocampal Sclerosis in the elderly: genetic and pathologic findings, some mimicking Alzheimer disease clinically. *Alzheimer Disease and Associated Disorder* 2011; Feb 22. [Epub ahead of print]

Reddy MM, Wilson R, Wilson J, Connell S, Gocke A, Hynan L, et al. Identification of candidate IgG biomarkers for Alzheimer's disease via combinatorial library screening. *Cell*. 2011;144(1):132-42. PMID: 3066439.

Scheuner D, Eckman C, Jensen M, Song X, Citron M, Suzuki N, et al. Secreted amyloid beta-protein similar to that in the senile plaques of Alzheimer's disease is increased in vivo by the presenilin 1 and 2 and APP mutations linked to familial Alzheimer's disease [see comments]. *Nature Medicine*. 1996;2(8):864-70.

Shoji M, Golde TE, Ghiso J, Cheung TT, Estus S, Shaffer LM, et al. Production of the Alzheimer amyloid beta protein by normal proteolytic processing. *Science*. 1992;258(5079):126-9.

United States Department of Health and Human Services, (2011). Cognitive impairment: The impact on health in Florida. Source: [http://www.cdc.gov/aging/pdf/cognitive\\_impairment/cogimp\\_fl\\_final.pdf](http://www.cdc.gov/aging/pdf/cognitive_impairment/cogimp_fl_final.pdf). Retrieved: December 21, 2012.

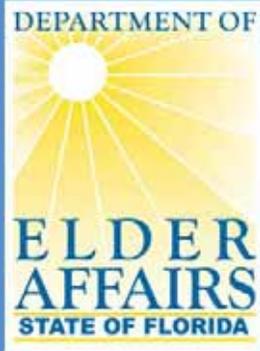
Van Broeckhoven C, Haan J, Bakker E, Hardy JA, Van Hul W, Wehnert A, et al. Amyloid beta protein precursor gene and hereditary cerebral hemorrhage with amyloidosis (Dutch). *Science*. 1990;248(4959):1120-2.

Weggen S, Eriksen JL, Das P, Sagi SA, Wang R, Pietrzik CU, et al. A subset of NSAIDs lower amyloidogenic Abeta42 independently of cyclooxygenase activity. *Nature*. 2001;414(6860):212-6.

Wilcox S, Carrasquillo M, Younkin S, et al. Identification of late-onset Alzheimer's disease (LOAD) susceptibility alleles in the PAI gene. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* 4: T144, 2008.

Wimo A, Winblad B, Jonsson L. The worldwide societal costs of dementia: Estimates for 2009. *Alzheimer's Dement*. 2010;6(2):98-103.

**Appendix 2: 2013 Purple Ribbon Task Force Surveys on Alzheimer's Disease  
and Related Dementias**



**RICK SCOTT**  
*GOVERNOR*

**CHARLES T. CORLEY**  
*SECRETARY*

## 2013 Purple Ribbon Task Force Surveys on Alzheimer's Disease and Related Dementias

## Table of Contents

Executive Summary.....	1
Background.....	4
Methodology.....	5
Survey.....	5
Survey Procedures.....	5
Analysis.....	6
Survey Findings.....	6
Characteristics of Respondents and Their Experience With ADRD.....	6
Diagnoses of Persons With ADRD.....	7
Caregiver Support and Areas of Needed Help.....	9
Help Needed by the Person With ADRD.....	9
Types of Services Accessed by Caregivers to Take Care of Person With ADRD.....	10
Support Services Needed For Persons With ADRD.....	11
Barriers, Challenges, and Difficulties for Caregivers and Families.....	12
Issues That Are Most Challenging For Persons With ADRD.....	13
Issues Affecting Persons with ADRD That Are Most Challenging for Caregivers and Their Families...	13
Most Important Critical Issues State Government Should Address.....	20
APPENDIX A: Response Tables.....	20
APPENDIX B: Survey Instruments.....	34

## Executive Summary

In 2012, the Florida State Legislature created the Purple Ribbon Task Force (PRTF) to address the growing epidemic of Alzheimer's disease and related dementias (ADRD). The major responsibilities of the Task Force include the development of a comprehensive state plan recommending state policy and strategies to mobilize a state response. To support this effort, the Department of Elder Affairs conducted five surveys developed in collaboration with the PRTF. The surveys addressed the experiences of five groups of stakeholders: persons with ADRD; family caregivers of persons with ADRD; concerned families and friends of persons with ADRD; healthcare providers and paid caregivers of persons with ADRD; and policy, legal, education, and other professionals. A total 840 people responded to the surveys.

The surveys included questions that identify various characteristics of the respondents and their experiences with Alzheimer's disease and related dementias. Respondents were asked a common set of questions to identify: the greatest challenges for persons with ADRD and their caregivers, the critical issues the State of Florida needs to address in the next few years, and the best ways to increase the public's awareness and understanding of the disease.

### Challenges for Persons With ADRD

Persons with ADRD were most concerned about being a burden on others and reported that the loss of the ability to drive, anxiety, and depression were the most challenging issues they faced.

### Challenges for Families and Caregivers

Caregivers and family and friends reported that losing control over their lifestyle, difficulty communicating with the person with ADRD, and changing family relationships were the most challenging issues for caregivers or families of persons with ADRD. Families and friends as well as healthcare providers and paid caregivers were also concerned about caregiver depression and anxiety. In contrast, healthcare providers and paid caregivers and other professionals considered paying for services the number one issue. Becoming a financial burden on children of families with a person with ADRD and dealing with financial, legal, and insurance issues were perceived as further major concerns for families involved with ADRD by respondents in the professional group.

### Support Services Needed by Persons With ADRD to Stay at Home

Caregivers indicated several areas of help needed by persons with ADRD who wish to remain in their homes. These included respite for the caregiver (65%), personal care (58%), financial assistance (52%), medical care (41%), and legal advice (36%).

## Barriers and Challenges for Caregivers, and Families

The main barriers that prevented caregivers from receiving the services or resources they needed were the inability to afford them (46%), lack of knowledge about where to find them (40%), lack of time (26%), and lack of availability (24%).

Respondents identified the following as the seven most challenging issues for caregivers and families of persons with ADRD:

- Communication with the person with ADRD,
- Changing relationships in the family,
- Feeling depressed or anxious,
- Losing control of lifestyle,
- Dealing with financial, legal, and insurance issues,
- Paying for services, and
- Becoming a financial burden on children.

While 39 percent of caregivers reported that they were employed, 49 percent of these respondents said their caregiving responsibilities affected their employment, often causing them to cut back on hours of work or leave their job.

## Most Helpful Resources for Information

Caregivers and persons with ADRD were asked to indicate the most helpful ways of getting information about ADRD. They responded that they considered the best ways of getting information about ADRD to be Internet or web-based information and trainings, in-person support groups, one-on-one counseling, community education and training, toll-free 24-hour telephone help lines, case management, and seminars.

## Best Ways to Raise General Awareness of ADRD in Florida

Respondents identified the following methods as best for increasing public awareness of ADRD: service announcements on radio and TV, websites with updated information, aging services and senior centers, physicians, and churches and faith communities. In addition, they considered the Veterans Administration, law enforcement, hospitals, nursing schools, and employers and the workplace as effective sources for raising ADRD awareness.

## Most Important Critical Issues State Government Should Address

Most respondents identified access to affordable and appropriate dementia-specific care as a major critical issue state government should address. In addition, they recommended the following critical issues as “very important” for consideration: ensuring quality of care, research

on prevention and treatment with clinical trials, education and training for caregivers, having an educated and trained workforce assisting persons with ADRD, and assistance for families in paying for care.

## Background

Alzheimer's disease is the sixth leading cause of death in the United States. More than five million Americans currently have the disease.<sup>1</sup> An estimated 14.7 percent of persons 70 years of age and older were afflicted with dementia in the United States in 2010. Research projects a threefold or greater increase in the total number of persons with Alzheimer's disease between 2000 and 2050, indicating it will continue to be a major public health problem during the coming decades.<sup>2</sup>

ADRD has a significant impact on the person suffering from the disease, their caregivers, families, and friends. Symptoms vary significantly by stage and type of ADRD, ranging from mild cognitive decline to the loss of ability to respond to the environment, control movement, and communicate, resulting in high reliance on help with daily personal care, eating, and using the toilet.<sup>3</sup>

Dementia presents an economic burden on individuals and society. For example, in 2010, the annual cost of care for a person with ADRD ranged from an estimated \$41,689 to \$56,290, depending on the method used to value informal care. Medicare paid approximately \$11 billion of the total cost of dementia care, estimated to be between \$157 and \$215 billion in 2010.<sup>4</sup> The main contributors to the costs attributable to dementia identified in this research were the costs of institutional and home-based long-term care rather than the costs of medical services.<sup>5</sup>

Currently, more than 40 states have developed or are developing an Alzheimer's Disease Plan.<sup>6</sup> In April 2012, the Florida Legislature established the Purple Ribbon Task Force (PRTF) to develop a comprehensive state plan to address the needs of individuals with Alzheimer's disease and their caregivers. The Task Force members were appointed to assess the current and future impact of Alzheimer's disease and related forms of dementia (ADRD) on the state; examine the existing industries, services, and resources in place that address the needs of individuals with Alzheimer's disease; develop a strategy to mobilize a state response to the Alzheimer's disease epidemic; and provide information regarding the development of state policy with respect to individuals with Alzheimer's disease, the role of the state in providing care to those with ADRD, and the number of people with ADRD in the state.

The task force consists of 18 volunteers who include six legislative staff members appointed by the Governor, at least one person having ADRD, one family caregiver of a person with

---

<sup>1</sup> [http://www.alz.org/alzheimers\\_disease\\_facts\\_and\\_figures.asp#quickFacts](http://www.alz.org/alzheimers_disease_facts_and_figures.asp#quickFacts)

<sup>2</sup> Zimmerman, S. PD, Suchindran C., Reed P, Wang L, Boustani M, and Sudha S. The public health impact of Alzheimer's disease, 2000-2050: potential implication of treatment advances. *Annu Rev Public Health*. 2002;23:213-31. Epub 2001 Oct 25.

<sup>3</sup> [http://www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp?type=alzFooter](http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp?type=alzFooter)

<sup>4</sup> <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>.

<sup>5</sup> <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629#t=articleBackground>

<sup>6</sup> [http://act.alz.org/site/PageNavigator/state\\_plans.html](http://act.alz.org/site/PageNavigator/state_plans.html)

ADRD, and representatives of various entities involved with ADRD.

To support the PRTF in developing a Florida state plan addressing the growing public health impact of ADRD, the Department of Elder Affairs conducted surveys of major stakeholders in the state. These stakeholders included people with ADRD; family caregivers; concerned families and friends; healthcare providers; paid caregivers of people with ADRD; and policy, legal, education, and other professionals.

## Methodology

### Survey

The Florida PRTF prepared five web-based surveys designed for specific groups of individuals having expertise and/or experience with ADRD. These instruments, based in part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force, were developed for the following populations:

- People with ADRD;
- Family caregivers of people with ADRD;
- Concerned families and friends;
- Healthcare providers and paid caregivers of people with ADRD; and
- Policy, legal, education, and other professionals.

The number of questions varied among surveys, ranging from 12 questions for persons with ADRD and policy, legal, educational, and other professionals, to 41 questions in the survey for family caregivers.

Some questions overlapped across surveys, whereas others were specific to the knowledge and experience of the respondent group. Common questions included those identifying challenging issues for the individual with ADRD, the family, and caregivers; ways to increase public awareness; and critical issues related to ADRD for Florida state government to address.

The survey instruments are included in Appendix B.

### Survey Procedures

The surveys were made available on the Department of Elder Affairs website April 15 through May 5, 2013. Respondents had the option of completing a survey electronically or printing and completing a survey on paper and mailing it to the Department.

840 people responded to the survey:

- 71 people with ADRD;
- 421 family caregivers;

- 143 concerned family and friends;
- 160 healthcare providers and paid caregivers; and
- 45 policy, legal, education, and other professionals.

## Analysis

The Department analyzed the five surveys individually and identified characteristics of participants. Questions that were common across survey groups were analyzed in terms of the strongest response option chosen (e.g. most important, most challenging, strongly agree) to highlight aspects of highest concern for respondents. Please see Appendix A for detailed tables containing percentages of all survey responses.

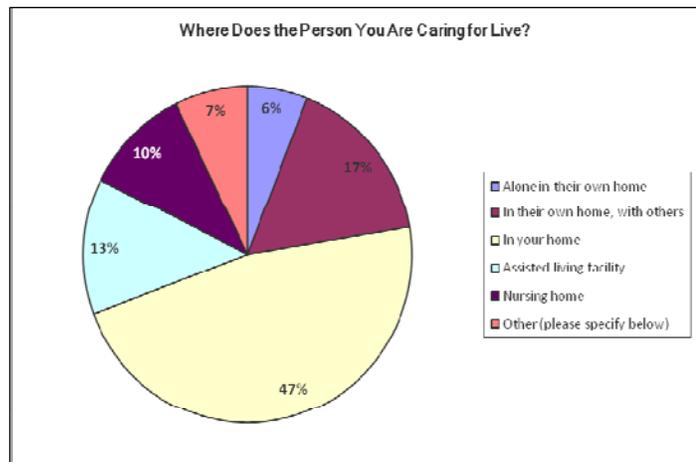
## Survey Findings

### Characteristics of Respondents and Their Experience With ADRD

#### Caregivers

The typical family caregiver responding to the survey was a 62-year-old white, non-Hispanic female. In general, a respondent was the primary caregiver. The majority of caregiving respondents (85%) lived in close proximity to the person with ADRD. Persons with ADRD receiving care from these caregivers were most frequently over 75 years of age and had Alzheimer’s disease for more than 4 years.

Caregivers provided care an average of 69 hours per week. Over 40 percent took care of a spouse, while 39 percent took care of a parent. Approximately one-quarter (24%) have helped more than one person with ADRD.



Furthermore, more than one-third of the family caregivers were in the “sandwich generation” caring for younger loved ones, such as children, as well as elder parents or other elder family members. Caregivers said that the majority of persons with ADRD they were taking care of lived in the home of the caregivers (47%), 17 percent lived with others in their own home, 14 percent lived in an assisted living facility, 10 percent in a nursing home, and six percent lived alone in the home of the caregiver.

The estimated annual household income for 37 percent of responding caregivers was over \$46,000, while 17 percent estimated their income to be below \$25,000.

## Persons With ADRD

The typical respondent with ADRD was a 69-year-old white, non-Hispanic female who had ADRD between one and five years.

While 46 percent of persons with ADRD who responded have an estimated annual income greater than \$46,000, 34 percent live on less than \$25,000 a year.

## Concerned Families and Friends

The typical respondent in the family and friends survey category was a 57-year-old white, non-Hispanic female family member who cared for someone with ADRD an average of 23 hours a week.

## Healthcare Providers and Paid Caregivers

The typical respondent in the healthcare provider and paid caregiver survey category was a 51-year-old white, non-Hispanic female. The majority (62%) said they had a training certificate or license. Forty-one percent had been providing care for persons with ADRD between six and 15 years. Respondents worked in a wide variety of settings caring for persons with ADRD including assisted living facilities (37%), private residences (21%), adult day or family care homes (19%), nursing facilities (12%), and hospice (8%). Sixty-five percent of the facilities employing the respondents offered cognitive assessments or screening.

## Policy, Legal, Education, and Other Professionals

The typical respondent in the policy, legal, education, and other professionals survey category was a 51-year-old white, non-Hispanic female who was an educator, trainer, or academician. Forty-nine percent of the respondents had personal experience as a primary caregiver for someone with ADRD.

## Diagnoses of Persons With ADRD

Reflecting national trends, caregivers as well as persons with ADRD reported that the most prevalent diagnosis was Alzheimer's disease (74% and 34%, respectively). However, as shown in the table below, the most frequent response of persons with ADRD was that they had not yet been diagnosed (38%). Family caregivers of persons with ADRD and respondents with ADRD reported that 28 percent and 19 percent of ADRD diagnoses, respectively, were dementia. An additional 15 and 24 percent reported memory loss. Eighteen percent of persons with ADRD reported a diagnosis with mild cognitive impairment compared to only four percent of persons with ADRD for whom family caregivers provide services. "Other" diagnoses included memory

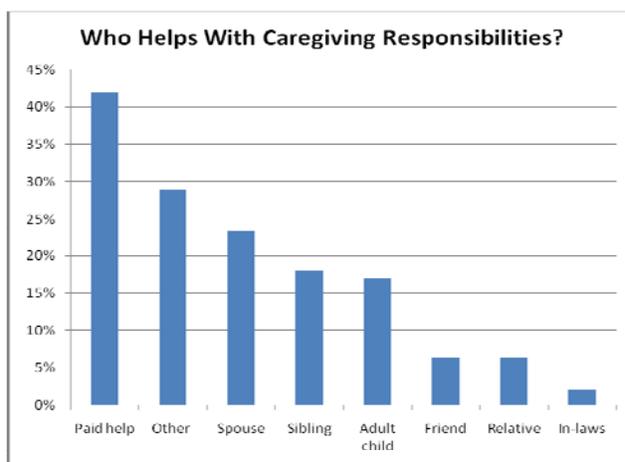
disorders that are complications of other diseases such as diabetes, Huntington's disease, reduplicative paramnesia, and muscular dystrophy.

Diagnosis	Response Percent	
	Family Caregiver	Respondent With ADRD
Alzheimer's Disease	74%	34%
Dementia	28%	19%
Memory loss	15%	24%
Vascular Dementia	9%	3%
Frontotemporal Dementia	5%	2%
Mild Cognitive Impairment	4%	18%
Stroke	4%	3%
Lewy Body Dementia	3%	2%
Parkinson's Disease	3%	0%
Other (please specify below)	3%	9%
Not diagnosed	1%	38%
Don't know	1%	2%

Family caregivers said that the majority of persons with ADRD were diagnosed by a neurologist (53%), followed by a family doctor or primary care physician (24%), a memory disorder clinic (9%), and a geriatrician (7%).

Who diagnosed the person you are caring for?	Response Percent
Neurologist	53.6%
Family doctor/Primary care physician	23.8%
(Florida) Memory Disorder Clinic	9.2%
Geriatrician	6.7%
Other	5.7%
Don't know	1.0%

## Caregiver Support and Areas of Needed Help



### Help for Caregivers

The majority of caregivers (73%) received some help from others in their caregiving responsibilities. The greatest sources of assistance were paid help (42%), spouses (29%), siblings (18%), and adult children (17%). “Other” sources of help consisted mostly of staff in nursing homes, hospices, assisted living facilities, and adult day care settings.

An open-ended question asked caregivers who provided routine assistance to the person with ADRD when the caregiver was absent. The largest percentage of respondents (34%) said that a family member, spouse, or friend would help. Twenty-two percent said there was no additional help, and, of these, one-fifth said they provided care 24/7.

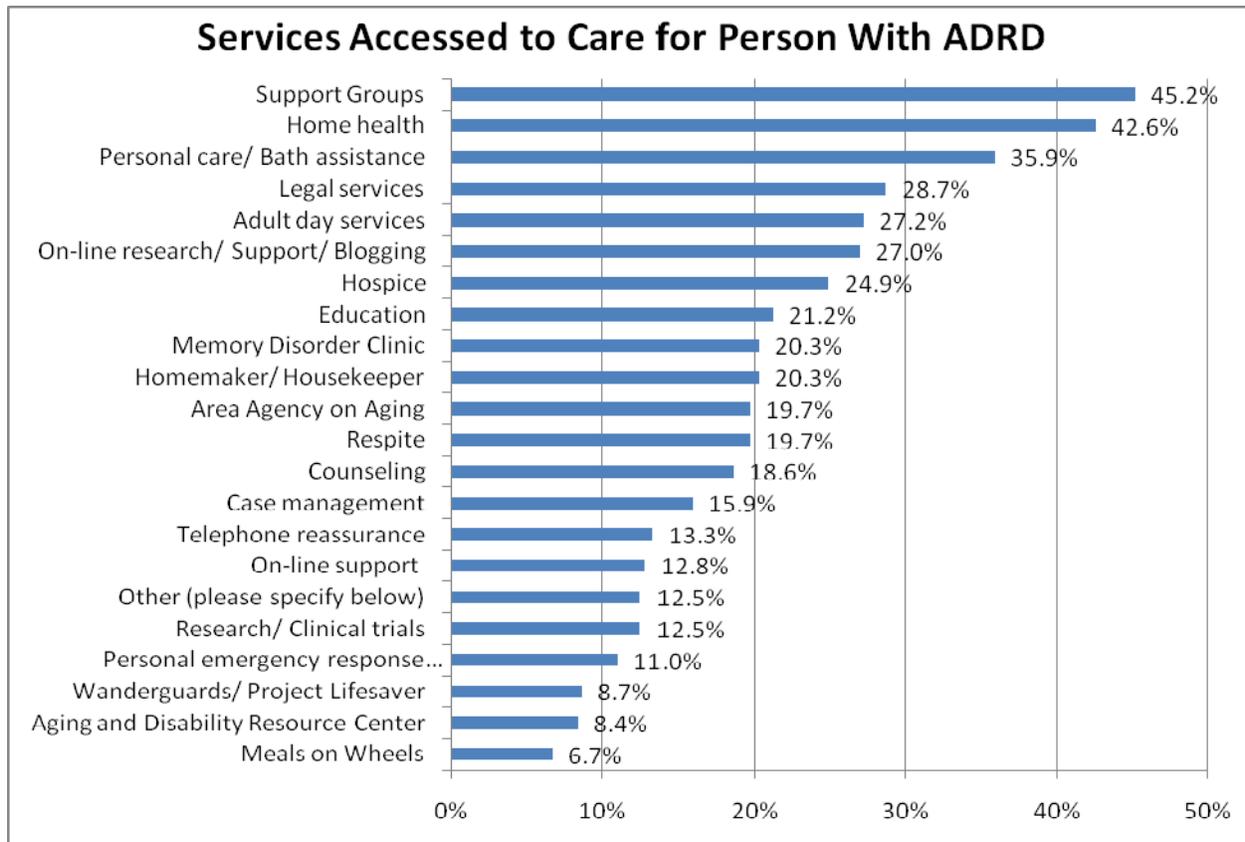
### Help Needed by the Person With ADRD

Caregivers were asked to indicate the areas in which the person they care for needed “a lot of help.” The predominant area of help needed was transportation outside the home (78%); taking care of the person’s residence and personal living space (76%); and helping the person with activities such as eating, dressing, or bathing (41%). Sixty-nine percent of respondents said that care recipients needed help in “other” areas, consisting mostly of medication management, toileting, issues related to disorientation and confusion, unpredictable behavior, and communication issues.

Help Needed by the Person With ADRD	No Help	A Little Help	Some Help	Quite a Bit of Help	A Lot of Help
Transportation outside the home	6.2%	4.9%	4.1%	6.9%	77.9%
Taking care of residence, personal living spaces	3.0%	2.3%	5.5%	12.8%	76.3%
Other	11.3%	1.3%	3.8%	15.0%	68.8%
Taking care of himself/herself (eating, dressing, bathing)	11.0%	11.0%	16.5%	20.5%	41.0%
Communicating	9.0%	13.3%	23.4%	22.1%	32.2%
Relieving/decreasing anxiety or depression	8.5%	15.0%	23.0%	26.9%	26.6%
Moving around within the house	26.2%	17.0%	18.3%	14.8%	23.7%
Getting along with people	27.7%	19.5%	25.4%	13.8%	13.6%
Seeing or hearing	31.9%	18.1%	24.2%	12.5%	13.3%

## Types of Services Accessed by Caregivers to Take Care of Person With ADRD

Caregivers reported that they mostly accessed services such as support groups (45%), home health (43%), personal care/bath assistance (36%), legal services (29%), adult day services (27%), and hospice services (25%) to care for persons with ADRD.



The majority of caregivers reported that services accessed were mostly private pay, either by the caregiver (74%) or by other family members (12%). Medicaid paid for 18 percent of service costs. Medicare was the most prevalent source of "other" payments (32%).

### Source of Payment for Services

Source of Payment for Services	Response Percent
Private pay/ Out of pocket of person	73.6%
Medicaid	18.3%
Other (please specify below)	14.9%
Family supported	12.1%
Long-term care insurance	11.8%
Veterans Administration	8.7%
Government funding	8.4%
Nursing Home Diversion Medicaid Waiver	6.8%
Trust funds	4.3%
County/ City funding	4.0%
Employee Assistance Program	0.3%

### Support Services Needed For Persons With ADRD

Caregivers reported several areas of help needed to keep the care recipient at home. The main types of support needed to help keep persons with ADRD at home included respite (65%), personal care (58%), financial assistance (52%), medical care (41%), and legal advice (36%).

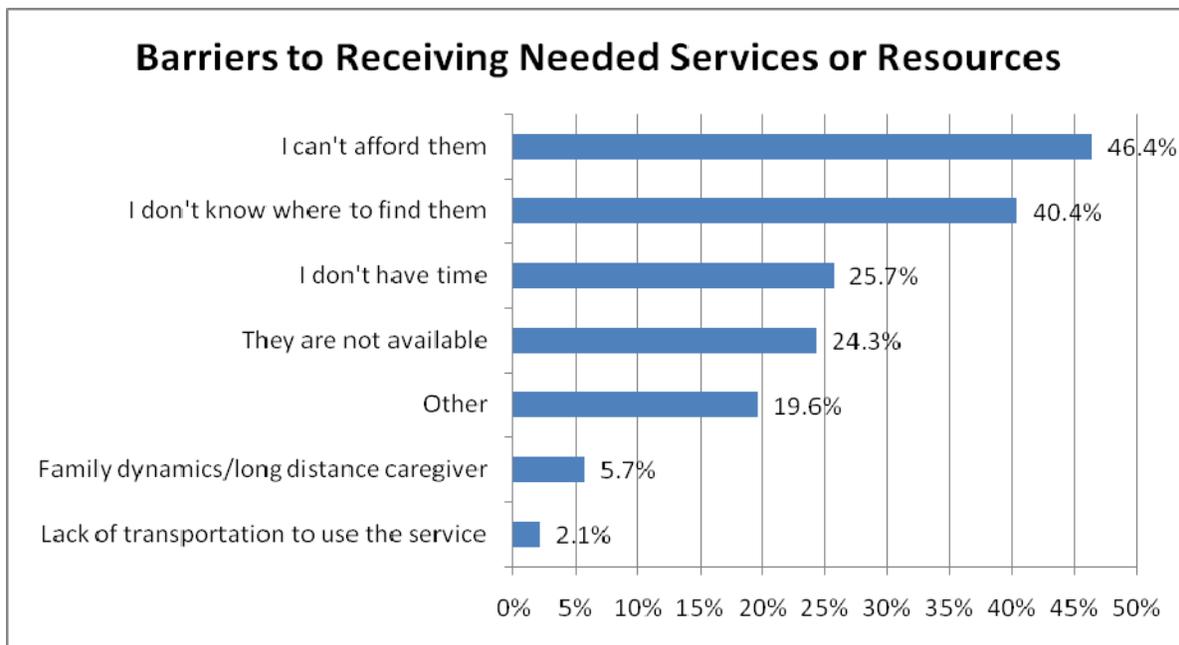
#### Type of Support Needed to Keep Person With ADRD at Home

Support Needed	Response Percent
Respite	64.6%
Personal care	57.9%
Financial assistance	52.4%
Medical care	40.5%
Legal advice	36.0%
Transportation	27.1%
Meals	26.2%
Education	18.0%
Other (please specify below)	16.8%

Forty-eight percent of caregiver respondents said they had not made any plans or other preparations for a natural disaster such as a hurricane. Only seven percent had registered with their local emergency management agency for assistance in evacuating to a special-needs shelter. This would indicate the need for intensified public-service efforts educating caregivers and persons with ADRD on how to plan and prepare for natural and man-made disasters.

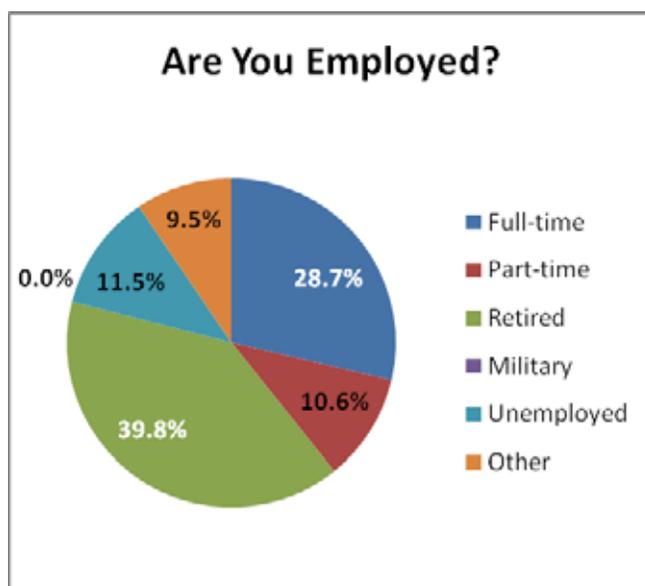
## Barriers, Challenges, and Difficulties for Caregivers and Families

The main barriers that prevented caregivers from receiving the services or resources they needed were lack of affordability (46%), knowledge of where to find them (40%), insufficient amount of time (26%), and availability of the services (24%).



## Employment Status and Impact of ADRD on Caregiver Employment

Forty percent of caregiver respondents said they were retired. Thirty-nine percent of caregivers reported that they were employed, of which 29 percent were employed full-time.



The ability to remain employed poses another challenge for caregivers. Forty-nine percent of respondents said that caregiving responsibilities affected their employment. Of those who said that caretaking responsibilities affected their employment, 47 percent indicated that they had to cut back on hours of work, while 33 percent reported that they had left their job.

## Issues That Are Most Challenging For Persons With ADRD

Persons with ADRD were most concerned about being a burden on others and reported that the loss of ability to drive, anxiety, and depression were the most challenging issues they faced.

Examples of “other” challenges included getting an exact diagnosis, difficulty of the family to accept the situation, and finding support groups.

Answer Options	How challenging are the following issues for you?					
	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Worrying about being a burden on others	11.1%	13.3%	8.9%	13.3%	48.9%	4.4%
Loss of ability to drive	28.3%	10.9%	4.3%	6.5%	41.3%	8.7%
Other (please specify below)	25.0%	0.0%	0.0%	12.5%	37.5%	25.0%
Depression or anxiety	17.8%	13.3%	17.8%	13.3%	35.6%	2.2%
Paying for services	33.3%	6.7%	17.8%	6.7%	28.9%	6.7%
Changing relationships in the family	26.7%	11.1%	13.3%	15.6%	26.7%	6.7%
Dealing with financial, legal and insurance issues	17.8%	13.3%	28.9%	11.1%	24.4%	4.4%
Communication with family and friends	28.3%	10.9%	17.4%	17.4%	21.7%	4.3%
Access to medical care for yourself	36.2%	17.0%	21.3%	10.6%	10.6%	4.3%
Access to support groups	30.4%	26.1%	15.2%	6.5%	8.7%	13.0%
Getting helpful information on Alzheimer's disease and related dementias	37.0%	30.4%	19.6%	8.7%	2.2%	2.2%

## Issues Affecting Persons with ADRD That Are Most Challenging for Caregivers and Their Families

In addition to asking persons with ADRD to indicate the most challenging issues for them, the other survey respondents were asked to report what they considered the most challenging issues related to ADRD for persons with ADRD, their caregivers, and their families. Some of the response categories for this question overlapped with those for the previous question addressed to persons with ADRD.

Issues Affecting ADRD Persons	"Very" Challenging Issues Affecting ADRD Individuals, Caregivers and Families			
	Caregiver	Families and Friends	Health Care Providers/Paid Caregivers	Professionals
Other	55.4%	51.9%	33.3%	66.7%
Losing control over lifestyle	49.3%	62.8%	55.2%	52.5%
Difficult behaviors	37.6%	59.3%	62.1%	58.5%
Loss of ability to drive	36.1%	48.8%	55.7%	58.5%
Depression or anxiety of the person with Alzheimer's disease or related dementia	34.8%	49.2%	54.3%	51.2%
Becoming a financial burden	26.8%	48.0%	54.0%	53.7%
Wandering or safety	25.7%	55.3%	53.6%	56.1%

Of the issues presented, family caregivers considered the care receiver's loss of control over his/her lifestyle (49%), difficult behaviors (38%), and the loss of the ability to drive (36%) as most challenging. More than half of respondents in the caregiver, family and friends, and professional survey categories included an "other" response. These comments were varied and described the challenges of coping with the depression and anxiety of the loved one (e.g., "watching the fear of dementia appear in her eyes"), hallucinations, or the person's inability to find things. In addition, survey respondents commented on the complete dependency of the person with ADRD on others, and the challenge this poses to caregivers and families. Caregivers reported that symptoms associated with ADRD have a detrimental impact on relationships in the family or between spouses, described in terms of the loss of a companion or friend. These symptoms also negatively affected families' ability to raise their children.

Respondents in the families and friends survey category considered loss of control by the person with ADRD over lifestyle (63%), difficult behaviors (59%), and wandering or safety (55%) as most challenging to persons with ADRD. Among the "other" issues added by respondents were difficulties communicating with, and changes in the personality of, the person with ADRD.

Healthcare providers and paid caregivers viewed difficult behaviors of persons with ADRD (62%) as a major challenge, followed by the loss of ability to drive (56%), and losing control over lifestyle (55%). "Other" issues described by these respondents were the loss of independence and identity, and getting expert help.

Survey participants in the policy, legal, education and other professionals survey category perceived the greatest challenges for persons with ADRD to be difficult behaviors and the loss of driving ability (59% each) with wandering and safety closely following at 56 percent.

Professionals identifying “other” issues affecting individuals with ADRD reported that their loss of independence, stress related to anticipating disease progression, and finding needed support and knowledgeable health professionals were major challenges.

### Challenging Issues for Caregivers and Families Involved With ADRD

Respondents in the family caregivers and families and friends survey categories reported that the most challenging issues for them were loss of control over lifestyle (45% and 47%, respectively), communication with the person with ADRD (40% and 53%), and changing relationships in the family (38% and 50%). Caregivers who included “other” issues as most challenging (53%) identified mental issues such as depression, anxiety, and stress; not living close to the person with ADRD; and not being able to get enough support to perform caregiving functions.

Most Challenging Issues for Caregivers and Families	Caregiver	Families and Friends	Health Care Providers/Paid Caregivers	Professionals
Other	52.6%	40.7%	66.7%	53.3%
Losing control of lifestyle	45.1%	47.2%	47.9%	51.2%
Communication with the person with ADRD	40.2%	53.3%	47.9%	53.7%
Changing relationships in the family	37.9%	50.4%	48.9%	40.0%
Paying for services	32.1%	44.9%	55.7%	62.5%
Dealing with financial, legal, and insurance issues	29.0%	45.1%	48.2%	60.0%
Dying before the person with ADRD	24.2%	24.0%	32.1%	34.1%
Access to respite care, adult day care, etc.	24.1%	23.3%	27.5%	36.6%
Loss of employment	18.7%	25.0%	35.3%	31.7%
Getting information about community resources	14.7%	18.7%	23.6%	22.0%
Access to support groups	12.1%	13.9%	10.1%	7.3%
Access to medical care for caregivers	11.9%	17.9%	21.3%	22.5%
Getting an appropriate diagnosis	11.1%	23.8%	31.7%	26.8%
Access to medical care for people with ADRD	10.2%	21.3%	24.1%	29.3%
Getting helpful information on ADRD	5.9%	11.4%	8.5%	7.3%
Becoming a financial burden on children	N.A.	36.1%	N.A.	62.5%
Caregivers feeling depressed or anxious	N.A.	48.4%	54.0%	46.3%
Understanding the disease	N.A.	23.5%	35.8%	23.1%
Caregivers feeling resentful	N.A.	20.7%	30.5%	17.1%

N/A: not applicable – question was not included in particular survey.

A table including responses to all response options is included in Appendix A.

Similar to the family caregiver survey category, respondents in the families and friends survey category also considered the most challenging issues to be the loss of control over lifestyle, communication with the person with ADRD, and changing relationships in the family. In addition, paying for services was a major challenge for caregivers and families. Forty-one percent of families and friends respondents reported “other” challenges, which included the lack of resources, refusal of caregivers to accept outside help, and living too far away from the person needing help.

In contrast to the caregiver and family and friends survey categories, respondents in the health care providers and paid caregivers survey category identified the following as the top three challenging issues for caregivers and families: paying for services (56%), depression and anxiety of caregivers (54%), and changing relationships in the family (49%). In addition, 54% identified depression and anxiety of caregivers as a major concern. Sixty-seven percent identified “other” issues as most challenging including coping with grief, the loss of friends, isolation, and finding appropriate resources for help.

The top three challenging issues reported by respondents from the professionals survey category were different from those for the other respondent groups. They included paying for services (63%); becoming a financial burden on children (63%); and dealing with financial, legal, and insurance issues (60%). “Other” issues (53%) included coping with feelings of frustration and guilt, communicating with health professionals, planning for disease progression, and the impact on children.

## The Impact of Caretaking on Caregivers

Caregivers were asked about the specific difficulties they experienced as a consequence of their caregiving. The highest rated difficulties reported were lack of time for themselves(53%); anxiety and depression (47%); “other” difficulties (46%); and to an equal extent financial burdens, difficult behaviors, and not enough time for oneself and family (39% each). “Other” difficulties reported by caregivers included understanding ADRD, the challenge of communicating with family and friends who are not educated about ADRD, loss of friends and feelings of social isolation, and feeling guilty about placing the person with ADRD outside of the home.

Difficulties experienced by caregivers	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree	N/A
Doesn't leave enough time for yourself	52.8%	27.8%	12.9%	3.0%	2.4%	1.1%
Creates anxiety or depression	47.0%	39.5%	7.6%	1.6%	2.2%	2.2%
Other	45.7%	4.3%	0.0%	0.0%	4.3%	45.7%
Creates a financial burden	39.1%	31.0%	15.1%	4.3%	5.9%	4.6%
Difficult behaviors	39.1%	39.1%	11.1%	2.4%	3.5%	4.9%
Doesn't leave enough time for your family	39.0%	26.9%	18.3%	6.2%	3.0%	6.7%
Affects family relationships	31.5%	41.2%	14.3%	5.4%	4.9%	2.7%
Interferes with your work	28.9%	26.5%	12.4%	3.2%	2.4%	26.5%
Wandering or safety	28.7%	31.7%	17.8%	3.8%	5.7%	12.3%
Creates or aggravates health problems	26.2%	36.2%	22.4%	7.6%	4.3%	3.2%
Interferes with employment/loss of employment	26.2%	18.9%	14.6%	3.8%	2.4%	34.1%
Understanding the disease	21.6%	37.4%	18.9%	9.8%	7.7%	4.6%
Feeling resentful	21.2%	26.6%	27.4%	12.6%	9.7%	2.4%

N/A: not applicable

## Helpful Resources for Information

Caregivers and persons with ADRD were asked how best to disseminate information about dementia. Caregivers responded that the most helpful ways were Internet or web-based information and trainings (74%), in-person support groups (55%), one-on-one counseling (44%), community education and training (42%), toll-free 24-hour telephone helplines (33%), case management (35%), and seminars (34%). Respondents with ADRD considered the Internet and in-person support groups the most helpful (64% each), followed by community education and training (44%), one-on-one counseling (38%), and toll-free 24 hour telephone helplines (22%).

Answer Options	Caregivers	Persons With ADRD
Internet or web-based information and training	74.3%	64.4%
In-person support groups	55.4%	64.4%
One-on-one counseling	43.5%	37.8 %
Community education and training	42.1%	44.4%
Toll-free 24-hr telephone helpline	32.8%	22.2 %
Case management	34.7%	N.A.
Seminars	33.9%	N.A.
Employers	7.9%	13.3%
Other (please specify below)	9.0%	N.A.

## Best Ways to Raise General Awareness of ADRD in Florida

All respondents, except persons with ADRD, were asked to identify the best ways to raise public awareness of ADRD in the community. Public service announcements on radio and TV were the highest rated way to raise public awareness, ranging from 71 percent for professionals to 77 percent for families and friends of persons with ADRD. In addition, 65 percent or more of respondents considered the following among the best means of increasing public awareness: website with updated information, aging services and senior centers, physicians, and churches and faith communities. Between 63 and 76 percent of healthcare providers and paid caregivers considered the Veterans Administration, law enforcement, hospitals, nursing schools, and employers and the workplace as optimal venues for raising ADRD awareness. Seventy percent of healthcare providers and paid caregivers chose nursing schools as an optimal venue for raising public awareness of ADRD issues.

Best Ways to Raise Public Awareness of ADRD	Caregiver	Families and Friends	Health Care Providers/Paid Caregivers	Professionals
Public service announcements on radio and TV	72.1%	76.9%	75.0%	70.7%
Website with updated information	69.1%	68.6%	69.3%	63.4%
Aging services and senior centers	68.8%	76.9%	82.1%	68.3%
Physicians	67.4%	69.4%	77.9%	70.7%
Churches and faith communities	64.9%	68.6%	77.9%	70.7%
Employers and workplaces	55.7%	69.4%	76.4%	61.0%
Hospitals	45.7%	54.5%	66.4%	56.1%
Medical training schools	44.0%	65.3%	58.6%	61.0%
Nursing schools	43.7%	54.5%	70.0%	51.2%
Veterans Administration	42.6%	52.9%	62.9%	51.2%
Religious organization	42.3%	52.9%	55.7%	51.2%
Law enforcement	37.9%	53.7%	62.9%	46.3%
Other	10.9%	16.5%	14.3%	26.8%

## Most Important Critical Issues State Government Should Address

All respondent groups were asked to identify the most critical ADRD issues state government should address. The majority of family caregivers indicated that access to affordable and appropriate dementia-specific care (85%), ensuring quality of care (80%), research on prevention, treatment, and clinical trials (77%), education and training for caregivers (75%), having an ADRD educated and trained workforce (75%), and assisting families in paying for care (72%) were “very important” issues for state government to address. The other survey response groups rated these issues similarly in importance, ranging from 56 to 85 percent.

Some of the “other” critical issues recommended were fostering quality nursing homes that accept Medicaid, promoting caregiver support, better coordination of fragmented ADRD services, implementing a centralized informational resource for answering questions about service and payment availability, and offering more services.

“Very Important” Critical Issues State Government Should Address	Caregiver	Families and Friends	ADRD	Health Care Providers/Paid Caregivers	Professionals
Access to affordable and appropriate dementia-specific care	84.5%	77.6%	61.9%	81.8%	85.0%
Ensuring quality of care	80.3%	82.9%	71.4%	77.4%	77.5%
Research on prevention, treatment, and clinical trials	76.6%	78.4%	76.7%	62.3%	66.7%
Education and training for caregivers	75.4%	70.1%	60.5%	77.5%	64.1%
Having an educated and trained workforce on Alzheimer's disease and related dementias	74.6%	73.3%	66.7%	76.6%	70.0%
Assisting families in paying for care	71.8%	62.1%	55.8%	75.5%	70.7%
Protecting people with Alzheimer's disease and related dementias	69.7%	65.8%	58.1%	68.6%	55.0%
Economic impact of ADRD on communities, workplaces, and citizens	68.0%	59.8%	47.6%	61.3%	63.4%
Specialized care facilities	67.3%	68.1%	56.1%	54.8%	60.0%
Tax credits for caregivers	67.2%	54.8%	52.4%	53.0%	62.5%
Clinical assessment, diagnosis, and testing	66.3%	69.0	74.4%	56.9%	52.6%
Medical care	65.9%	53.5%	52.4%	52.2%	43.6%
Mental health/depression	65.1%	64.3%	48.8%	58.8%	66.7%
Other (please specify below)	61.8%	38.1%	57.1%	63.6%	50.0%
Emergency management/disaster preparedness	46.7%	40.4%	50.0%	42.1%	47.5%
Transportation	41.2%	35.7%	42.9%	46.2%	51.2%
Access to non-dementia-specific services	34.0%	26.8%	37.8%	32.1%	37.5%
Employment	28.6%	19.6%	19.5%	28.2%	33.3%

## APPENDIX A: Response Tables

The following tables include detailed response options for those questions addressed in this report.

## Persons With ADRD: Issues of People With Alzheimer’s Disease and Related Dementias.

### Persons With ADRD Survey

#### 4. How challenging are the following issues for you?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Worrying about being a burden on others	11.1%	13.3%	8.9%	13.3%	48.9%	4.4%	3.62	45
Loss of ability to drive	28.3%	10.9%	4.3%	6.5%	41.3%	8.7%	2.96	46
Other (please specify below)	25.0%	0.0%	0.0%	12.5%	37.5%	25.0%	2.63	8
Depression or anxiety	17.8%	13.3%	17.8%	13.3%	35.6%	2.2%	3.29	45
Paying for services	33.3%	6.7%	17.8%	6.7%	28.9%	6.7%	2.71	45
Changing relationships in the family	26.7%	11.1%	13.3%	15.6%	26.7%	6.7%	2.84	45
Dealing with financial, legal and insurance issues	17.8%	13.3%	28.9%	11.1%	24.4%	4.4%	2.98	45
Communication with family and friends	28.3%	10.9%	17.4%	17.4%	21.7%	4.3%	2.80	46
Access to medical care for yourself	36.2%	17.0%	21.3%	10.6%	10.6%	4.3%	2.30	47
Access to support groups	30.4%	26.1%	15.2%	6.5%	8.7%	13.0%	1.98	46
Getting helpful information on Alzheimer’s disease and related dementias	37.0%	30.4%	19.6%	8.7%	2.2%	2.2%	2.02	46

## How Challenging Are Issues Affecting the Persons With ADRD For Persons With ADRD; Family Caregivers; and Their Families?

### Caregivers Survey

18. Please indicate how challenging the following issues affecting the person with Alzheimer's disease or related dementia have been for you and your family. Check N/A if the topic is not applicable to you.

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	N/A	Rating Average	Response Count
Loss of ability to drive	14.5%	8.9%	16.1%	10.5%	36.1%	13.9%	3.52	380
Depression or anxiety of the person with Alzheimer's disease or related dementia	6.3%	15.6%	19.3%	21.9%	34.8%	2.1%	3.65	379
Difficult behaviors	7.0%	12.5%	22.2%	18.5%	37.6%	2.1%	3.69	383
Wandering or safety	18.9%	17.6%	15.0%	14.2%	25.7%	8.7%	3.11	381
Becoming a financial burden	27.0%	15.2%	16.0%	9.2%	26.8%	5.8%	2.93	381
Losing control over lifestyle	3.4%	8.5%	13.3%	20.2%	49.3%	5.3%	4.09	377
Other (please specify below)	2.7%	1.4%	5.4%	12.2%	55.4%	23.0%	4.51	74
Other (please specify)								79

### Concerned Family and Friends Survey

5. How challenging do you feel the following issues are for individuals with Alzheimer's disease and related dementias and their families?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Loss of ability to drive	4.9%	4.1%	9.8%	26.8%	48.8%	5.7%	3.93	123
Depression or anxiety of the person with Alzheimer's disease or related dementia	1.6%	4.1%	9.8%	32.0%	49.2%	3.3%	4.13	122
Difficult behaviors	0.0%	4.1%	10.6%	25.2%	59.3%	0.8%	4.37	123
Wandering or safety	2.4%	6.5%	8.1%	25.2%	55.3%	2.4%	4.17	123
Becoming a financial burden	7.3%	3.3%	13.8%	18.7%	48.0%	8.9%	3.70	123
Losing control over lifestyle	0.8%	5.0%	8.3%	19.8%	62.8%	3.3%	4.29	121
Other (please specify below)	3.7%	3.7%	3.7%	0.0%	51.9%	37.0%	2.81	27
Other (please specify)								14

## Healthcare Providers and Paid Caregivers Survey

9. How challenging do you feel the following issues are for individuals with Alzheimer's disease or related dementia and their families?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Loss of ability to drive	1.4%	4.3%	7.9%	27.1%	55.7%	3.6%	4.21	140
Depression or anxiety of the person with Alzheimer's disease or related dementia	1.4%	3.6%	10.0%	30.0%	54.3%	0.7%	4.30	140
Difficult behaviors	0.0%	3.6%	9.3%	23.6%	62.1%	1.4%	4.40	140
Wandering or safety	1.4%	4.3%	9.3%	29.3%	53.6%	2.1%	4.23	140
Becoming a financial burden	1.4%	4.3%	10.8%	25.9%	54.0%	3.6%	4.16	139
Losing control over lifestyle	1.5%	1.5%	10.4%	29.9%	55.2%	1.5%	4.31	134
Other (please specify below)	11.1%	11.1%	0.0%	11.1%	33.3%	33.3%	2.44	9
Other (please specify)								9
<i>answered question</i>								140

## Policy, Legal, Education and Other Professionals Survey

5. How challenging do you feel the following issues are for individuals with Alzheimer's disease or related dementia and their families?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Loss of ability to drive	2.4%	4.9%	7.3%	26.8%	58.5%	0.0%	4.34	41
Depression or anxiety of the person with Alzheimer's disease or related dementia	0.0%	7.3%	7.3%	34.1%	51.2%	0.0%	4.29	41
Difficult behaviors	0.0%	4.9%	12.2%	24.4%	58.5%	0.0%	4.37	41
Wandering or safety	0.0%	0.0%	14.6%	29.3%	56.1%	0.0%	4.41	41
Becoming a financial burden	4.9%	4.9%	14.6%	22.0%	53.7%	0.0%	4.15	41
Losing control over lifestyle	2.5%	2.5%	10.0%	30.0%	52.5%	2.5%	4.20	40
Other (please specify below)	0.0%	0.0%	0.0%	0.0%	66.7%	33.3%	3.33	12
Other (please specify)								8

## Challenging Issues for Caregivers of People with Alzheimer’s Disease and Related Dementias.

### Family Caregivers Survey

19. Please indicate how challenging the following issues are (or have been) to you as a caregiver.								
Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	N/A	Rating Average	Response Count
Getting helpful information on Alzheimer's disease and related dementias	38.8%	21.8%	25.3%	7.7%	5.9%	0.5%	2.20	376
Getting information about community resources	24.5%	20.5%	22.1%	16.0%	14.7%	2.1%	2.75	375
Access to medical care for yourself	50.1%	14.9%	10.9%	5.8%	11.9%	6.4%	2.09	377
Access to medical care for your family member with Alzheimer's disease or related dementia	38.8%	22.5%	15.5%	10.2%	10.2%	2.9%	2.28	374
Dealing with financial, legal, and insurance issues	14.8%	19.9%	18.5%	15.6%	29.0%	2.2%	3.25	372
Access to support groups	35.2%	20.7%	14.5%	10.2%	12.1%	7.3%	2.39	372
Access to respite care, adult day care, and other services	19.3%	13.7%	15.8%	11.0%	24.1%	16.1%	3.08	373
Paying for services	17.0%	14.8%	14.0%	14.8%	32.1%	7.3%	3.33	371
Changing relationships in the family	9.5%	14.4%	17.1%	16.5%	37.9%	4.6%	3.62	369
Communication with the person with Alzheimer's disease or related dementia	4.0%	12.4%	19.7%	19.4%	40.2%	4.3%	3.83	371
Dying before the person with Alzheimer's disease or related dementia	23.4%	8.2%	11.1%	6.8%	24.2%	26.4%	3.00	368
Losing control of lifestyle	4.3%	12.8%	20.1%	13.0%	45.1%	4.9%	3.86	369
Loss of employment	28.4%	6.9%	7.2%	5.0%	18.7%	33.9%	2.68	363
Getting an appropriate diagnosis	35.3%	18.3%	14.7%	10.6%	11.1%	10.0%	2.38	360
Other (please specify below)	12.3%	0.0%	5.3%	1.8%	52.6%	28.1%	4.15	57
Other (please specify)								49

## Challenging Issues for Families of People with Alzheimer's Disease and Related Dementias

### Concerned Family and Friends Survey

#### 4. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Getting helpful information on Alzheimer's disease and related dementias	20.3%	21.1%	29.3%	17.1%	11.4%	0.8%	2.76	123
Getting information about community resources	8.1%	16.3%	31.7%	20.3%	18.7%	4.9%	3.11	123
Caregivers feeling depressed or anxious	0.8%	6.6%	12.3%	27.9%	48.4%	4.1%	4.04	122
Caregivers feeling resentful	9.1%	14.9%	19.0%	26.4%	20.7%	9.9%	3.05	121
Access to medical care for caregivers	14.6%	13.8%	20.3%	20.3%	17.9%	13.0%	2.74	123
Access to medical care for people with Alzheimer's disease and related dementias	11.5%	18.0%	18.9%	23.8%	21.3%	6.6%	3.06	122
Dealing with financial, legal, and insurance issues	4.1%	8.2%	14.8%	22.1%	45.1%	5.7%	3.79	122
Access to support groups	18.0%	17.2%	22.1%	16.4%	13.9%	12.3%	2.54	122
Access to respite care, adult day care, and other services	5.8%	15.8%	19.2%	22.5%	23.3%	13.3%	3.02	120
Paying for services	5.9%	5.9%	12.7%	14.4%	44.9%	16.1%	3.38	118
Changing relationships in the family	0.8%	6.6%	11.6%	24.8%	50.4%	5.8%	4.00	121
Communication with the person with Alzheimer's disease or related dementia	2.5%	5.7%	13.9%	21.3%	53.3%	3.3%	4.07	122
Becoming a financial burden on children	12.3%	7.4%	11.5%	22.1%	36.1%	10.7%	3.30	122
Dying before the person with Alzheimer's disease or related dementia	12.4%	7.4%	15.7%	18.2%	24.0%	22.3%	2.67	121
Losing control of lifestyle	3.3%	8.9%	16.3%	17.9%	47.2%	6.5%	3.77	123
Loss of employment	24.2%	9.2%	5.8%	17.5%	25.0%	18.3%	2.55	120
Getting an appropriate diagnosis	9.8%	11.5%	15.6%	24.6%	23.8%	14.8%	2.97	122
Understanding the disease	10.1%	13.4%	23.5%	24.4%	23.5%	5.0%	3.23	119
Other (please specify below)	7.4%	3.7%	7.4%	3.7%	40.7%	37.0%	2.56	27
Other (please specify)								18

## Healthcare Providers and Paid Caregivers Survey

### 8. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Getting helpful information on Alzheimer's disease and related dementias	10.6%	24.8%	<b>34.0%</b>	21.3%	8.5%	0.7%	2.90	141
Getting information on community resources	7.9%	12.9%	25.7%	<b>29.3%</b>	23.6%	0.7%	3.46	140
Caregivers feeling depressed or anxious	3.6%	4.3%	7.9%	28.1%	<b>54.0%</b>	2.2%	4.18	139
Caregivers feeling resentful	5.0%	12.1%	12.8%	<b>36.2%</b>	30.5%	3.5%	3.65	141
Access to medical care for caregivers	9.9%	14.2%	<b>26.2%</b>	25.5%	21.3%	2.8%	3.26	141
Access to medical care for people with Alzheimer's disease and related dementias	9.9%	15.6%	<b>25.5%</b>	23.4%	24.1%	1.4%	3.32	141
Dealing with financial, legal, and insurance issues	0.7%	6.4%	10.6%	28.4%	<b>48.2%</b>	5.7%	4.00	141
Access to support groups	13.7%	21.6%	<b>33.8%</b>	19.4%	10.1%	1.4%	2.86	139
Access to respite care, adult day care, and other services	10.9%	15.9%	21.0%	22.5%	<b>27.5%</b>	2.2%	3.33	138
Paying for services	1.4%	6.4%	9.3%	20.7%	<b>55.7%</b>	6.4%	4.04	140
Changing relationships in the family	1.4%	5.8%	12.2%	28.1%	<b>48.9%</b>	3.6%	4.06	139
Communication with the person with Alzheimer's disease or related dementia	2.1%	7.9%	11.4%	29.3%	<b>47.9%</b>	1.4%	4.09	140
Dying before the person with Alzheimer's disease or related dementia	2.9%	11.4%	14.3%	27.1%	<b>32.1%</b>	12.1%	3.38	140
Losing control of lifestyle	3.6%	8.6%	9.3%	27.9%	<b>47.9%</b>	2.9%	3.99	140
Loss of employment	6.5%	8.6%	14.4%	28.1%	<b>35.3%</b>	7.2%	3.55	139
Getting an appropriate diagnosis	3.6%	10.1%	24.5%	27.3%	<b>31.7%</b>	0.0%	3.65	139
Understanding the disease	5.1%	8.8%	16.8%	32.8%	<b>35.8%</b>	0.7%	3.83	137
Other (please specify below)	4.8%	4.8%	0.0%	0.0%	<b>66.7%</b>	23.8%	3.48	21
Other (please specify)								18

## Policy, Legal, Education and Other Professionals

### 4. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Getting helpful information on Alzheimer's disease and related dementias	12.2%	17.1%	<b>48.8%</b>	14.6%	7.3%	0.0%	2.88	41
Getting information about community resources	4.9%	9.8%	<b>31.7%</b>	31.7%	22.0%	0.0%	3.56	41
Caregivers feeling depressed or anxious	2.4%	2.4%	12.2%	36.6%	<b>46.3%</b>	0.0%	4.22	41
Caregivers feeling resentful	4.9%	12.2%	29.3%	<b>36.6%</b>	17.1%	0.0%	3.49	41
Access to medical care for caregivers	2.5%	17.5%	<b>30.0%</b>	25.0%	22.5%	2.5%	3.40	40
Access to medical care for people with Alzheimer's disease and related dementias	9.8%	14.6%	19.5%	26.8%	<b>29.3%</b>	0.0%	3.51	41
Dealing with financial, legal, and insurance issues	0.0%	7.5%	5.0%	25.0%	<b>60.0%</b>	2.5%	4.30	40
Access to support groups	9.8%	17.1%	<b>41.5%</b>	24.4%	7.3%	0.0%	3.02	41
Access to respite care, adult day care, and other services	4.9%	19.5%	19.5%	14.6%	<b>36.6%</b>	4.9%	3.44	41
Paying for services	0.0%	0.0%	20.0%	17.5%	<b>62.5%</b>	0.0%	4.43	40
Changing relationships in the family	0.0%	2.5%	27.5%	30.0%	<b>40.0%</b>	0.0%	4.08	40
Communication with the person with Alzheimer's disease or related dementia	0.0%	2.4%	17.1%	24.4%	<b>53.7%</b>	2.4%	4.22	41
Becoming a financial burden on children	2.5%	0.0%	25.0%	10.0%	<b>62.5%</b>	0.0%	4.30	40
Dying before the person with Alzheimer's disease or related dementia	2.4%	14.6%	12.2%	29.3%	<b>34.1%</b>	7.3%	3.56	41
Losing control of lifestyle	4.9%	2.4%	7.3%	31.7%	<b>51.2%</b>	2.4%	4.15	41
Loss of employment	2.4%	12.2%	17.1%	<b>34.1%</b>	31.7%	2.4%	3.73	41
Getting an appropriate diagnosis	4.9%	9.8%	<b>31.7%</b>	22.0%	26.8%	4.9%	3.41	41
Understanding the disease	2.6%	10.3%	30.8%	<b>33.3%</b>	23.1%	0.0%	3.64	39
Other (please specify below)	0.0%	0.0%	6.7%	6.7%	<b>53.3%</b>	33.3%	3.13	15
Other (please specify)								10

## Critical Issues that Florida Should Address in the Next Few Years

### Family Caregivers Survey

28. In your opinion, what are the most critical issues that the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	2.0%	1.1%	4.9%	14.3%	76.6%	1.1%	4.59	350
Clinical assessment, diagnosis, and testing	1.4%	2.3%	5.7%	22.3%	66.3%	2.0%	4.44	350
Assisting families in paying for care	0.8%	1.1%	6.2%	17.8%	71.8%	2.3%	4.52	354
Protecting people with Alzheimer's disease and related dementias	0.9%	1.2%	6.9%	19.9%	69.7%	1.4%	4.52	347
Ensuring quality of care	0.6%	0.3%	3.4%	14.0%	80.3%	1.4%	4.69	351
Education and training for caregivers	0.6%	0.0%	5.7%	17.4%	75.4%	0.9%	4.65	350
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	0.9%	2.3%	8.6%	18.0%	68.0%	2.3%	4.43	350
Access to affordable and appropriate dementia-specific care	0.6%	0.3%	1.7%	11.5%	84.5%	1.4%	4.75	355
Having an educated and trained workforce on Alzheimer's disease and related dementias	0.6%	0.6%	4.0%	18.4%	74.6%	1.7%	4.61	347
Transportation	1.5%	5.3%	23.4%	24.0%	41.2%	4.5%	3.85	337
Employment	9.9%	8.1%	22.7%	12.4%	28.6%	18.3%	2.87	322
Tax credits for caregivers	3.5%	1.8%	7.6%	14.4%	67.2%	5.6%	4.23	341
Access to non-dementia-specific services	5.3%	10.3%	20.2%	16.8%	34.0%	13.4%	3.24	321
Specialized care facilities	0.6%	1.8%	8.8%	18.1%	67.3%	1.8%	4.39	342
Emergency management/disaster preparedness	2.1%	6.8%	18.6%	23.7%	46.7%	2.1%	4.00	338
Medical care	0.9%	1.5%	12.0%	18.4%	65.9%	1.5%	4.43	343
Mental health/depression	1.5%	1.2%	9.6%	20.8%	65.1%	1.8%	4.41	332
Other (please specify below)	2.9%	0.0%	2.9%	0.0%	61.8%	32.4%	3.21	34
Other (please specify)								32

## Concerned Family and Friends Survey

7. In your opinion, what are the most critical issues the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	0.0%	0.9%	4.3%	15.5%	78.4%	0.9%	4.69	116
Clinical assessment, diagnosis, and testing	0.0%	1.7%	8.6%	19.8%	69.0%	0.9%	4.53	116
Assisting families in paying for care	0.0%	5.2%	10.3%	22.4%	62.1%	0.0%	4.41	116
Protecting people with Alzheimer's disease and related dementias	0.0%	0.9%	9.4%	23.9%	65.8%	0.0%	4.55	117
Ensuring quality of care	0.0%	0.9%	4.3%	12.0%	82.9%	0.0%	4.77	117
Education and training for caregivers	0.0%	0.0%	7.7%	22.2%	70.1%	0.0%	4.62	117
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	0.0%	2.6%	10.3%	23.1%	59.8%	4.3%	4.27	117
Access to affordable and appropriate dementia-specific care	0.0%	0.0%	6.9%	14.7%	77.6%	0.9%	4.67	116
Having an educated and trained workforce on Alzheimer's disease and related dementias	0.0%	0.0%	5.2%	20.7%	73.3%	0.9%	4.65	116
Transportation	2.6%	2.6%	21.7%	33.9%	35.7%	3.5%	3.87	115
Employment	8.0%	9.8%	29.5%	22.3%	19.6%	10.7%	3.04	112
Tax credits for caregivers	1.7%	4.3%	10.4%	26.1%	54.8%	2.6%	4.20	115
Access to non-dementia-specific services	6.3%	6.3%	25.9%	26.8%	26.8%	8.0%	3.38	112
Specialized care facilities	0.9%	2.6%	8.6%	18.1%	68.1%	1.7%	4.45	116
Emergency Management/ Disaster Preparedness	4.4%	6.1%	18.4%	27.2%	40.4%	3.5%	3.82	114
Medical care	1.8%	4.4%	11.4%	27.2%	53.5%	1.8%	4.21	114
Mental health/ Depression	0.0%	1.7%	12.2%	21.7%	64.3%	0.0%	4.49	115
Other (please specify below)	4.8%	0.0%	4.8%	14.3%	38.1%	38.1%	2.67	21
Other (please specify)								10

## People with Alzheimer’s Disease and Related Dementias Survey

6. In your opinion, what are the most critical issues the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	0.0%	2.3%	11.6%	9.3%	76.7%	0.0%	4.60	43
Clinical assessment, diagnosis, and testing	0.0%	2.3%	7.0%	16.3%	74.4%	0.0%	4.63	43
Assisting families in paying for care	2.3%	0.0%	11.6%	27.9%	55.8%	2.3%	4.28	43
Protecting people with Alzheimer’s disease and related dementias	2.3%	2.3%	7.0%	23.3%	58.1%	2.4%	4.12	43
Ensuring quality of care	0.0%	0.0%	2.4%	26.2%	71.4%	0.0%	4.69	42
Education and training for caregivers	0.0%	4.7%	11.6%	23.3%	60.5%	0.0%	4.40	43
Economic impact of Alzheimer’s disease and related dementias on communities, workplaces, and citizens	0.0%	7.1%	11.9%	26.2%	47.6%	7.1%	3.93	42
Access to affordable and appropriate dementia-specific care	2.4%	0.0%	4.8%	26.2%	61.9%	4.8%	4.31	42
Having an educated and trained workforce on Alzheimer’s disease and related dementias	0.0%	2.4%	2.4%	21.4%	66.7%	7.1%	4.31	42
Transportation	2.4%	14.3%	7.1%	23.8%	42.9%	9.5%	3.62	42
Employment	9.8%	12.2%	<b>29.3%</b>	14.6%	19.5%	14.6%	2.78	41
Tax credits for caregivers	2.4%	7.1%	9.5%	23.8%	52.4%	4.8%	4.02	42
Access to non-dementia-specific services	2.7%	10.8%	13.5%	18.9%	37.8%	16.2%	3.30	37
Specialized care facilities	0.0%	7.3%	4.9%	26.8%	56.1%	4.9%	4.17	41
Emergency management/ Disaster preparedness	0.0%	14.3%	14.3%	19.0%	50.0%	2.4%	3.98	42
Medical care	0.0%	9.5%	9.5%	23.8%	52.4%	4.8%	4.05	42
Mental health/ Depression	0.0%	4.9%	17.1%	26.8%	48.8%	2.4%	4.12	41
Other (please specify below)	0.0%	14.3%	0.0%	0.0%	57.1%	28.6%	3.14	7
Other (please specify)								2

## Healthcare Providers and Paid Caregivers Survey

12. In your opinion, what are the most critical issues that the state government of Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	0.0%	4.3%	8.0%	25.4%	62.3%	0.0%	4.46	138
Clinical assessment, diagnosis, and testing	0.7%	2.2%	7.3%	32.8%	56.9%	0.0%	4.43	137
Assisting families in paying for care	0.0%	0.7%	6.5%	16.5%	75.5%	0.7%	4.65	139
Protecting people with Alzheimer's disease and related dementias	0.0%	2.9%	8.0%	19.7%	68.6%	0.7%	4.52	137
Ensuring quality of care	0.0%	1.5%	3.6%	16.8%	77.4%	0.7%	4.68	137
Education and training for caregivers	0.0%	0.0%	2.2%	20.3%	77.5%	0.0%	4.75	138
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	0.0%	1.5%	11.7%	24.1%	61.3%	1.5%	4.41	137
Access to affordable and appropriate dementia-specific care	0.0%	0.0%	2.2%	15.3%	81.8%	0.7%	4.77	137
Having an educated and trained workforce on Alzheimer's disease and related dementias	0.0%	0.0%	4.4%	19.0%	76.6%	0.0%	4.72	137
Transportation	0.0%	6.1%	22.0%	25.0%	46.2%	0.8%	4.09	132
Employment	3.8%	10.7%	22.9%	31.3%	28.2%	3.1%	3.60	131
Tax credits for caregivers	1.5%	5.2%	12.7%	24.6%	53.0%	3.0%	4.13	134
Access to non-dementia-specific services	4.5%	7.5%	26.9%	25.4%	32.1%	3.0%	3.65	133
Specialized care facilities	0.7%	3.0%	17.0%	23.7%	54.8%	0.7%	4.27	135
Emergency Management/Disaster Preparedness	0.8%	6.0%	21.1%	28.6%	42.1%	1.5%	4.01	133
Medical care	0.7%	1.5%	11.9%	33.6%	52.2%	0.0%	4.35	134
Mental health/depression	0.0%	3.1%	10.7%	26.7%	58.8%	0.8%	4.39	131
Other (please specify below)	0.0%	0.0%	0.0%	9.1%	63.6%	27.3%	3.55	11

## Policy, Legal, Education and Other Professionals Survey

7. In your opinion, what are the most critical issues that the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	5.1%	2.6%	7.7%	17.9%	66.7%	0.0%	4.38	39
Clinical assessment, diagnosis, and testing	0.0%	2.6%	5.3%	36.8%	52.6%	2.6%	4.32	38
Assisting families in paying for care	0.0%	0.0%	12.2%	17.1%	70.7%	0.0%	4.59	41
Protecting people with Alzheimer's disease and related dementias	0.0%	7.5%	10.0%	27.5%	55.0%	0.0%	4.30	40
Ensuring quality of care	0.0%	0.0%	2.5%	20.0%	77.5%	0.0%	4.75	40
Education and training for caregivers	0.0%	2.6%	2.6%	30.8%	64.1%	0.0%	4.56	39
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	0.0%	7.3%	7.3%	22.0%	63.4%	0.0%	4.41	41
Access to affordable and appropriate dementia-specific care	0.0%	0.0%	2.5%	12.5%	85.0%	0.0%	4.83	40
Having an educated and trained workforce on Alzheimer's disease and related dementias	0.0%	2.5%	7.5%	20.0%	70.0%	0.0%	4.58	40
Transportation	0.0%	4.9%	17.1%	26.8%	51.2%	0.0%	4.24	41
Employment	7.7%	12.8%	17.9%	25.6%	33.3%	2.6%	3.56	39
Tax credits for caregivers	0.0%	7.5%	12.5%	17.5%	62.5%	0.0%	4.35	40
Access to non-dementia-specific services	0.0%	17.5%	20.0%	22.5%	37.5%	2.5%	3.73	40
Specialized care facilities	2.5%	0.0%	17.5%	20.0%	60.0%	0.0%	4.35	40
Emergency Management/ Disaster Preparedness	0.0%	15.0%	17.5%	17.5%	47.5%	2.5%	3.90	40
Medical care	0.0%	2.6%	20.5%	33.3%	43.6%	0.0%	4.18	39
Mental health/ Depression	0.0%	0.0%	15.4%	17.9%	66.7%	0.0%	4.51	39
Other (please specify below)	0.0%	0.0%	0.0%	0.0%	50.0%	50.0%	2.50	10

## APPENDIX B: Survey Instruments

## Survey for People with Alzheimer's Disease or Related Dementia

We need your help. Your personal experiences will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease and related dementias. Your ideas and insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

## Please tell us about yourself

### 1. Where do you live or work?

City:

County:

State:

### 2. Have you been diagnosed with a specific condition? (Check all that apply.)

- I have not been diagnosed
- Alzheimer's disease
- Mild Cognitive Impairment (MCI)
- Frontotemporal Dementia
- Lewy Body Dementia
- Vascular Dementia
- Memory Loss
- Dementia
- Stroke
- Parkinson's Disease
- Don't know
- Other (please specify below)

Other (please specify)

### 3. How long have you been dealing with this problem or condition?

- Less than a year
- 1-5 years
- 6-10 years
- Over 10 years

Please tell us about your experience with memory difficulties

4. How challenging are the following issues for you?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>					
Access to medical care for yourself	<input type="radio"/>					
Dealing with financial, legal and insurance issues	<input type="radio"/>					
Access to support groups	<input type="radio"/>					
Loss of ability to drive	<input type="radio"/>					
Paying for services	<input type="radio"/>					
Depression or anxiety	<input type="radio"/>					
Changing relationships in the family	<input type="radio"/>					
Communication with family and friends	<input type="radio"/>					
Worrying about being a burden on others	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Creating a State Plan - Public Awareness

5. What ways of getting information about Alzheimer's disease and related dementias would be most helpful to you? (Check all that apply.)

- Internet or web-based information and training
- In-person support groups
- Community education and training
- Toll-free 24-hr telephone helpline
- One-on-one counseling
- Other (please specify below)

Other (please specify)

## Creating a State Plan - Critical Issues

6. In your opinion, what are the most critical issues the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>					
Clinical assessment, diagnosis, and testing	<input type="radio"/>					
Assisting families in paying for care	<input type="radio"/>					
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>					
Ensuring quality of care	<input type="radio"/>					
Education and training for caregivers	<input type="radio"/>					
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>					
Access to affordable and appropriate dementia-specific care	<input type="radio"/>					
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>					
Transportation	<input type="radio"/>					
Employment	<input type="radio"/>					
Tax credits for caregivers	<input type="radio"/>					
Access to non-dementia-specific services	<input type="radio"/>					
Specialized care facilities	<input type="radio"/>					
Emergency management/ Disaster preparedness	<input type="radio"/>					
Medical care	<input type="radio"/>					
Mental health/ Depression	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

7. What is your gender?

- Female  
 Male

8. What is your age?

9. What is your marital status?

- Now married  
 Partnered  
 Widowed  
 Divorced  
 Separated  
 Never married  
 Don't know

10. Are you of Hispanic, Latino, or Spanish origin?

- No  
 Yes

11. What is your race? (Check all that apply.)

- White  
 Black or African American  
 American Indian or Alaska Native  
 Asian  
 Native Hawaiian or Other Pacific Islander  
 Other (please specify below)

Other (please specify)

12. Please estimate your household income.

- Under \$25,000
- \$25,000 - \$35,999
- \$36,000 - \$45,999
- \$46,000 - \$55,999
- \$56,000 - \$65,999
- \$66,000 - \$75,999
- \$76,000 - \$85,999
- \$86,000 and over

## THANK YOU!

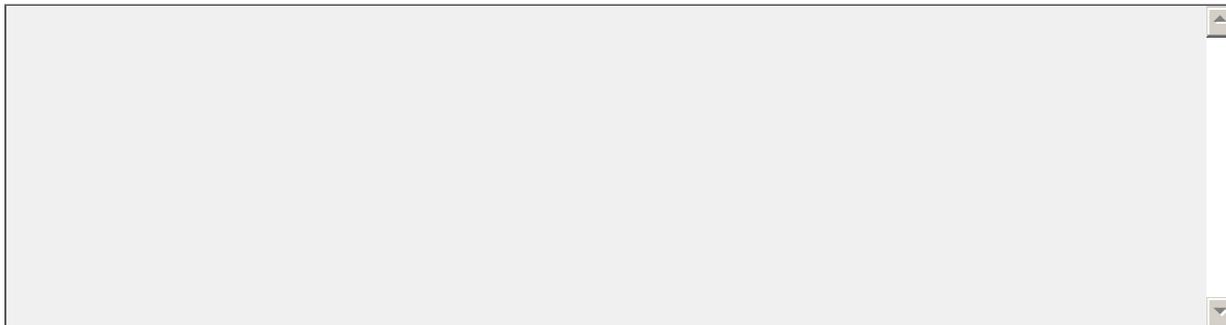
Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

[http://elderaffairs.state.fl.us/doea/purple\\_ribbon.php](http://elderaffairs.state.fl.us/doea/purple_ribbon.php)

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and related dementias.

### 13. Any other comments or suggestions?



This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.

## Survey for Family Caregivers

We need your help. Your ideas and experience as a current or former family caregiver will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease and related dementias. Your insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

## Please tell us about yourself and your caregiving situation

### 1. Where do you live or work?

City:

County:

State:

### 2. How many years have you been caregiving for the person with Alzheimer's disease or related dementia?

Newly diagnosed

1-3 years

4-7 years

8-11 years

Over 12 years

### 3. Are you the primary caregiver?

Yes

No

### 4. Do you consider yourself a long distance caregiver?

Yes

No

### 5. Are you part of the "sandwich generation," caring for younger loved ones such as children, and elder parents or other elder family members?

Yes

No

### 6. Have you taken care of more than one person with Alzheimer's disease or related dementia?

Yes

No

## Please tell us about the person you are caring for

7. What is your relationship to the person you are caring for?

- Spouse
- Adult child
- Significant partner
- Sibling
- Friend
- Grandchild
- Other (please specify below)

Other (please specify)

8. What is the gender of the person you are caring for?

- Female
- Male

9. What is the age of the person you are caring for?

- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85-94
- 95 or older

10. Where does the person you are caring for live?

- Alone in their own home
- In their own home, with others
- In your home
- Assisted living facility
- Nursing home
- Other (please specify below)

Other (please specify)

11. What is the diagnosis of the person you are caring for? (Check all that apply.)

- Not diagnosed
- Alzheimer's Disease
- Mild Cognitive Impairment
- Frontotemporal Dementia
- Lewy Body Dementia
- Vascular Dementia
- Memory loss
- Dementia
- Stroke
- Parkinson's Disease
- Don't know
- Other (please specify below)

Other (please specify)

12. Who diagnosed the person you are caring for?

- Family doctor/Primary care physician
- Neurologist
- Geriatrician
- (Florida) Memory Disorder Clinic
- Don't know
- Other (please specify below)

Other (please specify)

## What kind of help does the person you are caring for need?

### 13. How much help does the person you care for need in the following areas?

	No Help	A Little Help	Some Help	Quite a Bit of Help	A Lot of Help
Taking care of himself/herself, such as eating, dressing, or bathing	<input type="radio"/>				
Taking care of his/her residence or personal living spaces, such as cleaning, managing money, or preparing meals	<input type="radio"/>				
Communicating with others	<input type="radio"/>				
Seeing or hearing	<input type="radio"/>				
Moving around within the house	<input type="radio"/>				
Transportation outside of the home	<input type="radio"/>				
Getting along with people	<input type="radio"/>				
Relieving/decreasing anxiety or depression	<input type="radio"/>				
Other (please specify below)	<input type="radio"/>				

Other (please specify)

## Please describe your caregiving responsibilities

14. In an average week, how many hours do you provide care for this person?

Average hours per week

15. Do you have others helping you with the care of this person?

Yes

No

16. If yes, who helps you with your caregiving responsibilities? (Check all that apply.)

Spouse

Adult child

Sibling

In-laws

Friend

Relative (aunt/uncle/cousin)

Paid help

Other (please specify below)

Other (please specify)

17. Who provides routine assistance when the primary caregiver is absent?

## Issues affecting the person you are caring for

18. Please indicate how challenging the following issues affecting the person with Alzheimer's disease or related dementia have been for you and your family. Check N/A if the topic is not applicable to you.

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	N/A
Loss of ability to drive	<input type="radio"/>					
Depression or anxiety of the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Difficult behaviors	<input type="radio"/>					
Wandering or safety	<input type="radio"/>					
Becoming a financial burden	<input type="radio"/>					
Losing control over lifestyle	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Challenges for the Caregiver

19. Please indicate how challenging the following issues are (or have been) to you as a caregiver.

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	N/A
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>					
Getting information about community resources	<input type="radio"/>					
Access to medical care for yourself	<input type="radio"/>					
Access to medical care for your family member with Alzheimer's disease or related dementia	<input type="radio"/>					
Dealing with financial, legal, and insurance issues	<input type="radio"/>					
Access to support groups	<input type="radio"/>					
Access to respite care, adult day care, and other services	<input type="radio"/>					
Paying for services	<input type="radio"/>					
Changing relationships in the family	<input type="radio"/>					
Communication with the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Dying before the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Losing control of lifestyle	<input type="radio"/>					
Loss of employment	<input type="radio"/>					
Getting an appropriate diagnosis	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Difficulties for the Caregiver

20. Below is a list of difficulties you may have faced as a caregiver. Please indicate how much you agree or disagree with the following:

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree	N/A
Creates a financial burden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doesn't leave enough time for yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doesn't leave enough time for your family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interferes with your work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Creates anxiety or depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling resentful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Creates or aggravates health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Affects family relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interferes with employment/loss of employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficult behaviors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wandering or safety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

## Services needed to continue to live at home

21. What type of support do you need to keep the person you care for at home? (Check all that apply.)

- Financial assistance
- Transportation
- Education
- Legal advice
- Medical care
- Respite
- Meals
- Personal care
- Other (please specify below)

Other (please specify)

22. Have you made a plan or other preparations for what to do in case there is a disaster, like a hurricane? (Check all that apply.)

- No, I do not have a plan or other preparations
- Yes, I have a written plan
- Yes, I have a survival kit
- Yes, I have registered with my county for a Special Needs Shelter
- Other (please specify below)

Other (please specify)

23. What ways of getting information about Alzheimer's disease and related dementias and caregiving would be most helpful to you? (Check all that apply.)

- Internet or web-based information and training
- In-person support groups
- Community education and training
- Toll-free 24-hr telephone helpline
- Case management
- Seminars
- One-on-one counseling
- Employers
- Other (please specify below)

Other (please specify)

## Services Received

24. What services have you accessed to care for the person with Alzheimer's disease or related dementia? (Check all that apply.)

- Home health
- Personal care/ Bath assistance
- Homemaker/ Housekeeper
- Counseling
- Case management
- Adult day services
- Respite
- Hospice
- Aging and Disability Resource Center
- Area Agency on Aging
- Education
- Research/ Clinical trials
- Support Groups
- Telephone reassurance
- Personal emergency response systems
- Wanderguards/ Project Lifesaver
- Meals on Wheels
- On-line support through professional or informal groups (for example, Facebook)
- On-line research/ Support/ Blogging
- Legal services
- Memory Disorder Clinic
- Other (please specify below)

Other (please specify)

25. How were the services paid for? (Check all that apply.)

- Private pay/ Out of pocket of person
- Trust funds
- Family supported
- Long-term care insurance
- Medicaid
- Nursing Home Diversion Medicaid Waiver
- Employee Assistance Program
- Government funding
- County/ City funding
- Veterans Administration
- Other (please specify below)

Other (please specify)

26. What prevents you from receiving the services or resources you need but don't have?  
(Check all that apply.)

- I don't know where to find them
- I can't afford them
- I don't have transportation to use the service
- I don't have time
- They are not available
- Family dynamics - I'm a long distance caregiver
- Other (please specify below)

Other (please specify)

## Creating a State Plan - Public Awareness

27. The Purple Ribbon Task Force wants to increase general awareness and understanding of Alzheimer's disease across Florida. Which of the following would be the best ways to raise public awareness of Alzheimer's disease and related dementias in your community? (Check all that apply.)

- Employers and workplaces
- Hospitals
- Aging services and senior centers
- Churches and faith communities
- Veterans Administration
- Public service announcements on radio and TV
- Medical training schools
- Law enforcement
- Physicians
- Nursing schools
- Religious organization
- Website with updated information
- Other (please specify below)

Other (please specify)

## Creating a State Plan - Critical Issues

28. In your opinion, what are the most critical issues that the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>					
Clinical assessment, diagnosis, and testing	<input type="radio"/>					
Assisting families in paying for care	<input type="radio"/>					
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>					
Ensuring quality of care	<input type="radio"/>					
Education and training for caregivers	<input type="radio"/>					
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>					
Access to affordable and appropriate dementia-specific care	<input type="radio"/>					
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>					
Transportation	<input type="radio"/>					
Employment	<input type="radio"/>					
Tax credits for caregivers	<input type="radio"/>					
Access to non-dementia-specific services	<input type="radio"/>					
Specialized care facilities	<input type="radio"/>					
Emergency management/disaster preparedness	<input type="radio"/>					
Medical care	<input type="radio"/>					
Mental health/depression	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

29. What is your gender?

- Female  
 Male

30. What is your age?

31. What is your marital status?

- Now married  
 Partnered  
 Widowed  
 Divorced  
 Separated  
 Never married  
 Don't know

32. Are you of Hispanic, Latino, or Spanish origin?

- No  
 Yes

33. What is your race? (Check all that apply.)

- White  
 Black or African American  
 American Indian or Alaska Native  
 Asian  
 Native Hawaiian or Other Pacific Islander  
 Other (please specify below)

Other (please specify)

34. Do you speak a language other than English in your work or home life?

- Just English
- Spanish
- Russian
- Creole
- Other (please specify below)

Other (please specify)

35. What is your highest level of education attained?

- Grade School
- High School
- College
- Post College

36. Are you employed?

- Full-time
- Part-time
- Retired
- Military
- Unemployed
- Other (please specify below)

Other (please specify)

37. Do your caregiver responsibilities affect your employment?

- Yes
- No

38. If yes, did you have to cut back on your hours of work?

- Yes
- No
- Other (please specify below)

Other (please specify)

39. If yes, did you leave your job?

- Yes
- No
- Other (please specify below)

Other (please specify)

40. Please estimate your household income.

- Under \$25,000
- \$25,000 - \$35,999
- \$36,000 - \$45,999
- \$46,000 - \$55,999
- \$56,000 - \$65,999
- \$66,000 - \$75,999
- \$76,000 - \$85,999
- \$86,000 and over

## THANK YOU!

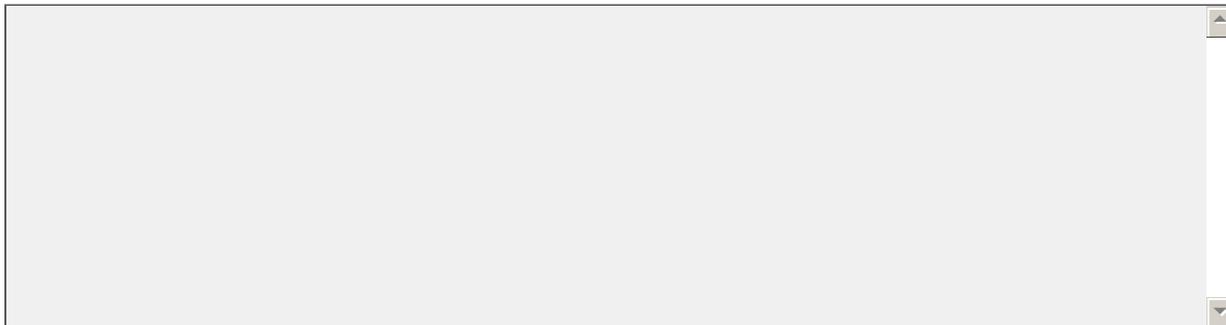
Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

[http://elderaffairs.state.fl.us/doea/purple\\_ribbon.php](http://elderaffairs.state.fl.us/doea/purple_ribbon.php)

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and related dementias.

### 41. Any other comments or suggestions?



This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.

## Survey for Concerned Family and Friends

We need your help. Your ideas and experiences with persons with Alzheimer's disease and related dementias will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease. Your ideas and insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

## Please tell us about yourself

### 1. Where do you live or work?

City:

County:

State:

### 2. What is your involvement or relationship to those with Alzheimer's disease and related dementias and their families? (Check all that apply.)

Family

Friend

Neighbor

Co-worker

Other (please specify below)

Other (please specify)

### 3. If you provide support to someone with Alzheimer's disease or related dementia or their family, please indicate approximately how many hours per week of help you provide.

Average hours per week

## Challenges for Families

4. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>					
Getting information about community resources	<input type="radio"/>					
Caregivers feeling depressed or anxious	<input type="radio"/>					
Caregivers feeling resentful	<input type="radio"/>					
Access to medical care for caregivers	<input type="radio"/>					
Access to medical care for people with Alzheimer's disease and related dementias	<input type="radio"/>					
Dealing with financial, legal, and insurance issues	<input type="radio"/>					
Access to support groups	<input type="radio"/>					
Access to respite care, adult day care, and other services	<input type="radio"/>					
Paying for services	<input type="radio"/>					
Changing relationships in the family	<input type="radio"/>					
Communication with the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Becoming a financial burden on children	<input type="radio"/>					
Dying before the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Losing control of lifestyle	<input type="radio"/>					
Loss of employment	<input type="radio"/>					
Getting an appropriate diagnosis	<input type="radio"/>					
Understanding the disease	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Challenges for Individuals

5. How challenging do you feel the following issues are for individuals with Alzheimer's disease and related dementias and their families?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Loss of ability to drive	<input type="radio"/>					
Depression or anxiety of the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Difficult behaviors	<input type="radio"/>					
Wandering or safety	<input type="radio"/>					
Becoming a financial burden	<input type="radio"/>					
Losing control over lifestyle	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Creating a State Plan - Public Awareness

6. The Alzheimer's Purple Ribbon Task Force wants to increase general awareness and understanding of Alzheimer's disease across Florida. Which of the following would be best ways to raise public awareness of Alzheimer's disease and related dementias in your community? (Check all that apply.)

- Employers and workplaces
- Hospitals
- Aging services and senior centers
- Churches and faith communities
- Veterans Administration
- Public service announcements on radio and TV
- Medical training schools
- Law enforcement
- Physicians
- Nursing schools
- Religious organization
- Website with updated information
- Other (please specify below)

Other (please specify)

## Creating a State Plan - Critical Issues

7. In your opinion, what are the most critical issues the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>					
Clinical assessment, diagnosis, and testing	<input type="radio"/>					
Assisting families in paying for care	<input type="radio"/>					
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>					
Ensuring quality of care	<input type="radio"/>					
Education and training for caregivers	<input type="radio"/>					
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>					
Access to affordable and appropriate dementia-specific care	<input type="radio"/>					
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>					
Transportation	<input type="radio"/>					
Employment	<input type="radio"/>					
Tax credits for caregivers	<input type="radio"/>					
Access to non-dementia-specific services	<input type="radio"/>					
Specialized care facilities	<input type="radio"/>					
Emergency Management/ Disaster Preparedness	<input type="radio"/>					
Medical care	<input type="radio"/>					
Mental health/ Depression	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

8. What is your gender?

Female

Male

9. What is your age?

10. Are you of Hispanic, Latino, or Spanish origin?

No

Yes

11. What is your race? (Check all that apply.)

White

Black or African American

American Indian or Alaska Native

Asian

Native Hawaiian or Other Pacific Islander

Other (please specify below)

Other (please specify)

## THANK YOU!

Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

[http://elderaffairs.state.fl.us/does/purple\\_ribbon.php](http://elderaffairs.state.fl.us/does/purple_ribbon.php)

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and related dementias.

### 12. Any other comments or suggestions?

This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.

## Survey for Healthcare Providers and Paid Caregivers

We need your help. Your ideas and experience in providing care for persons with Alzheimer's disease and related dementias will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease. Your ideas and insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

## Please tell us about yourself

### 1. Where do you live or work?

City:

County:

State:

### 2. How long have you been providing care for persons with Alzheimer's disease and related dementias?

- 0-5 years
- 6-10 years
- 11-15 years
- 16-20 years
- 21-25 years
- Over 25 years

### 3. What kind of training certification or license do you have? (Check all that apply.)

- No specific training or certification
- CNA
- LPN
- RN
- NP
- PA
- MD/DO
- MSW/LCSW
- Other (please specify below)

Other certification or license

## Please tell us about your work

4. In what kind of setting do you work? (Check all that apply.)

- Adult day care facility
- Adult family care home
- Assisted living facility
- Community health center
- Hospice
- Hospital
- Memory Disorder Clinic
- Nursing facility
- Physician's office
- Private residence
- Other (please specify below)

Other (please specify)

5. Do you, or does your facility/agency, provide cognitive assessment or screening?

- Yes
- No
- Unsure/Don't know
- Other (please specify below)

Other (please specify)

6. What type of services do you provide to people with Alzheimer's disease and related dementias? (Check all that apply.)

- Home health
- Personal care/ Bath assistance
- Homemaker/ Housekeeper
- Counseling
- Case management
- Adult day services
- Respite
- Hospice
- Education
- Research/ Clinical trials
- Support groups
- Telephone reassurance
- Personal emergency response systems
- Wanderguards/ Project Lifesaver
- Meals on Wheels
- On-line support through professional or informal groups (for example, Facebook)
- On-line research/ Support/ Blogging
- Legal services
- Other (please specify below)

Other (please specify)

7. How do you, or does your facility/ agency, advertise? (Check all that apply.)

- Newspaper
- On-line/website
- Facebook
- Newsletters
- Don't know
- Other (please specify below)

Other (please specify)

## Challenges for Families

8. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>					
Getting information on community resources	<input type="radio"/>					
Caregivers feeling depressed or anxious	<input type="radio"/>					
Caregivers feeling resentful	<input type="radio"/>					
Access to medical care for caregivers	<input type="radio"/>					
Access to medical care for people with Alzheimer's disease and related dementias	<input type="radio"/>					
Dealing with financial, legal, and insurance issues	<input type="radio"/>					
Access to support groups	<input type="radio"/>					
Access to respite care, adult day care, and other services	<input type="radio"/>					
Paying for services	<input type="radio"/>					
Changing relationships in the family	<input type="radio"/>					
Communication with the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Dying before the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Losing control of lifestyle	<input type="radio"/>					
Loss of employment	<input type="radio"/>					
Getting an appropriate diagnosis	<input type="radio"/>					
Understanding the disease	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Challenges for Individuals

9. How challenging do you feel the following issues are for individuals with Alzheimer's disease or related dementia and their families?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Loss of ability to drive	<input type="radio"/>					
Depression or anxiety of the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Difficult behaviors	<input type="radio"/>					
Wandering or safety	<input type="radio"/>					
Becoming a financial burden	<input type="radio"/>					
Losing control over lifestyle	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Creating a State Plan - Public Awareness

10. The Purple Ribbon Task Force wants to increase general awareness and understanding of Alzheimer's disease across Florida. Which of the following would be the best ways to raise public awareness of Alzheimer's disease and related dementias in your community? (Check all that apply.)

- Employers and workplaces
- Hospitals
- Aging services and senior centers
- Churches and faith communities
- Veterans Administration
- Public service announcements on radio and TV
- Medical training schools
- Law enforcement
- Physicians
- Nursing schools
- Religious organization
- Website with updated information
- Other (please specify below)

Other (please specify)

## Creating a State Plan - Issues of the Newly Diagnosed

11. How important is it for Florida to address the following issues relating to identifying and meeting the needs of newly diagnosed individuals with Alzheimer's disease and related dementias?

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Increase public awareness of Alzheimer's disease and related dementias	<input type="radio"/>					
Promote annual cognitive assessment/ screening for older adults	<input type="radio"/>					
Improve access to information and resources for newly diagnosed individuals	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					
Other (please specify)	<input type="text"/>					

## Creating a State Plan - Critical Issues

12. In your opinion, what are the most critical issues that the state government of Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>					
Clinical assessment, diagnosis, and testing	<input type="radio"/>					
Assisting families in paying for care	<input type="radio"/>					
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>					
Ensuring quality of care	<input type="radio"/>					
Education and training for caregivers	<input type="radio"/>					
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>					
Access to affordable and appropriate dementia-specific care	<input type="radio"/>					
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>					
Transportation	<input type="radio"/>					
Employment	<input type="radio"/>					
Tax credits for caregivers	<input type="radio"/>					
Access to non-dementia-specific services	<input type="radio"/>					
Specialized care facilities	<input type="radio"/>					
Emergency Management/Disaster Preparedness	<input type="radio"/>					
Medical care	<input type="radio"/>					
Mental health/depression	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

13. What is your gender?

Female

Male

14. What is your age?

15. Are you of Hispanic, Latino, or Spanish origin?

No

Yes

16. What is your race? (Check all that apply.)

White

Black or African American

American Indian or Alaska Native

Asian

Native Hawaiian or Other Pacific Islander

Other (please specify below)

Other (please specify)

17. Do you speak a language other than English in your work or home life?

Just English

Spanish

Russian

Creole

Other (please specify below)

Other (please specify)

## THANK YOU!

Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

[http://elderaffairs.state.fl.us/doea/purple\\_ribbon.php](http://elderaffairs.state.fl.us/doea/purple_ribbon.php)

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and related dementias.

### 18. Any other comments or suggestions?

This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.

## Survey for Policy, Legal, Educational, and Other Professionals

We need your help. Your ideas and experience will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease and related dementias. Your ideas and insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

## Please tell us about yourself

### 1. Where do you live or work?

City:

County:

State:

### 2. Please indicate the category that fits you best.

- Case manager
- Elected official
- Ombudsman
- Advocate
- Educator, trainer, or academic
- Legal or financial professional
- Public safety or law enforcement
- State or county government coordination/regulation of care and services
- Other (please specify below)

Other (please specify)

### 3. Do you have personal experience as a primary caregiver for someone with Alzheimer's disease and related dementias?

- Yes
- No

# Challenges for Families

4. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>					
Getting information about community resources	<input type="radio"/>					
Caregivers feeling depressed or anxious	<input type="radio"/>					
Caregivers feeling resentful	<input type="radio"/>					
Access to medical care for caregivers	<input type="radio"/>					
Access to medical care for people with Alzheimer's disease and related dementias	<input type="radio"/>					
Dealing with financial, legal, and insurance issues	<input type="radio"/>					
Access to support groups	<input type="radio"/>					
Access to respite care, adult day care, and other services	<input type="radio"/>					
Paying for services	<input type="radio"/>					
Changing relationships in the family	<input type="radio"/>					
Communication with the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Becoming a financial burden on children	<input type="radio"/>					
Dying before the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Losing control of lifestyle	<input type="radio"/>					
Loss of employment	<input type="radio"/>					
Getting an appropriate diagnosis	<input type="radio"/>					
Understanding the disease	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Challenges for Individuals

5. How challenging do you feel the following issues are for individuals with Alzheimer's disease or related dementia and their families?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Loss of ability to drive	<input type="radio"/>					
Depression or anxiety of the person with Alzheimer's disease or related dementia	<input type="radio"/>					
Difficult behaviors	<input type="radio"/>					
Wandering or safety	<input type="radio"/>					
Becoming a financial burden	<input type="radio"/>					
Losing control over lifestyle	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Creating a State Plan - Public Awareness

6. The Purple Ribbon Task Force wants to increase general awareness and understanding of Alzheimer's disease across Florida. Which of the following would be best ways of raising public awareness of Alzheimer's disease and related dementias in your community? (Check all that apply.)

- Employers and workplaces
- Hospitals
- Aging services and senior centers
- Churches and faith communities
- Veterans Administration
- Public service announcements on radio & TV
- Medical training schools
- Law enforcement
- Physicians
- Nursing schools
- Religious organizations
- Website with updated information
- Other (please specify below)

Other (please specify)

## Creating a State Plan - Critical Issues

7. In your opinion, what are the most critical issues that the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>					
Clinical assessment, diagnosis, and testing	<input type="radio"/>					
Assisting families in paying for care	<input type="radio"/>					
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>					
Ensuring quality of care	<input type="radio"/>					
Education and training for caregivers	<input type="radio"/>					
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>					
Access to affordable and appropriate dementia-specific care	<input type="radio"/>					
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>					
Transportation	<input type="radio"/>					
Employment	<input type="radio"/>					
Tax credits for caregivers	<input type="radio"/>					
Access to non-dementia-specific services	<input type="radio"/>					
Specialized care facilities	<input type="radio"/>					
Emergency Management/ Disaster Preparedness	<input type="radio"/>					
Medical care	<input type="radio"/>					
Mental health/ Depression	<input type="radio"/>					
Other (please specify below)	<input type="radio"/>					

Other (please specify)

## Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

8. What is your gender?

Female

Male

9. What is your age?

10. Are you of Hispanic, Latino or Spanish origin?

No

Yes

Don't know

11. What is your race? (Check all that apply.)

White

Black or African American

American Indian or Alaska Native

Asian

Native Hawaiian or Other Pacific Islander

Other (please specify below)

Other (please specify)

## THANK YOU!

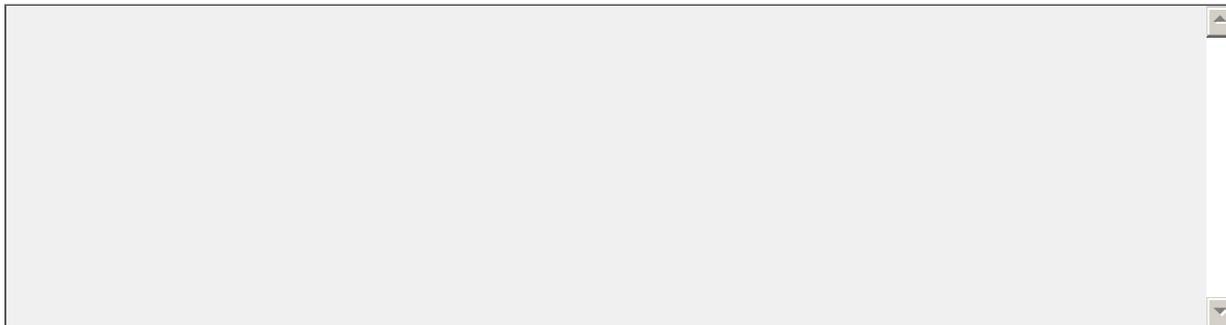
Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

[http://elderaffairs.state.fl.us/doea/purple\\_ribbon.php](http://elderaffairs.state.fl.us/doea/purple_ribbon.php)

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and other related dementias.

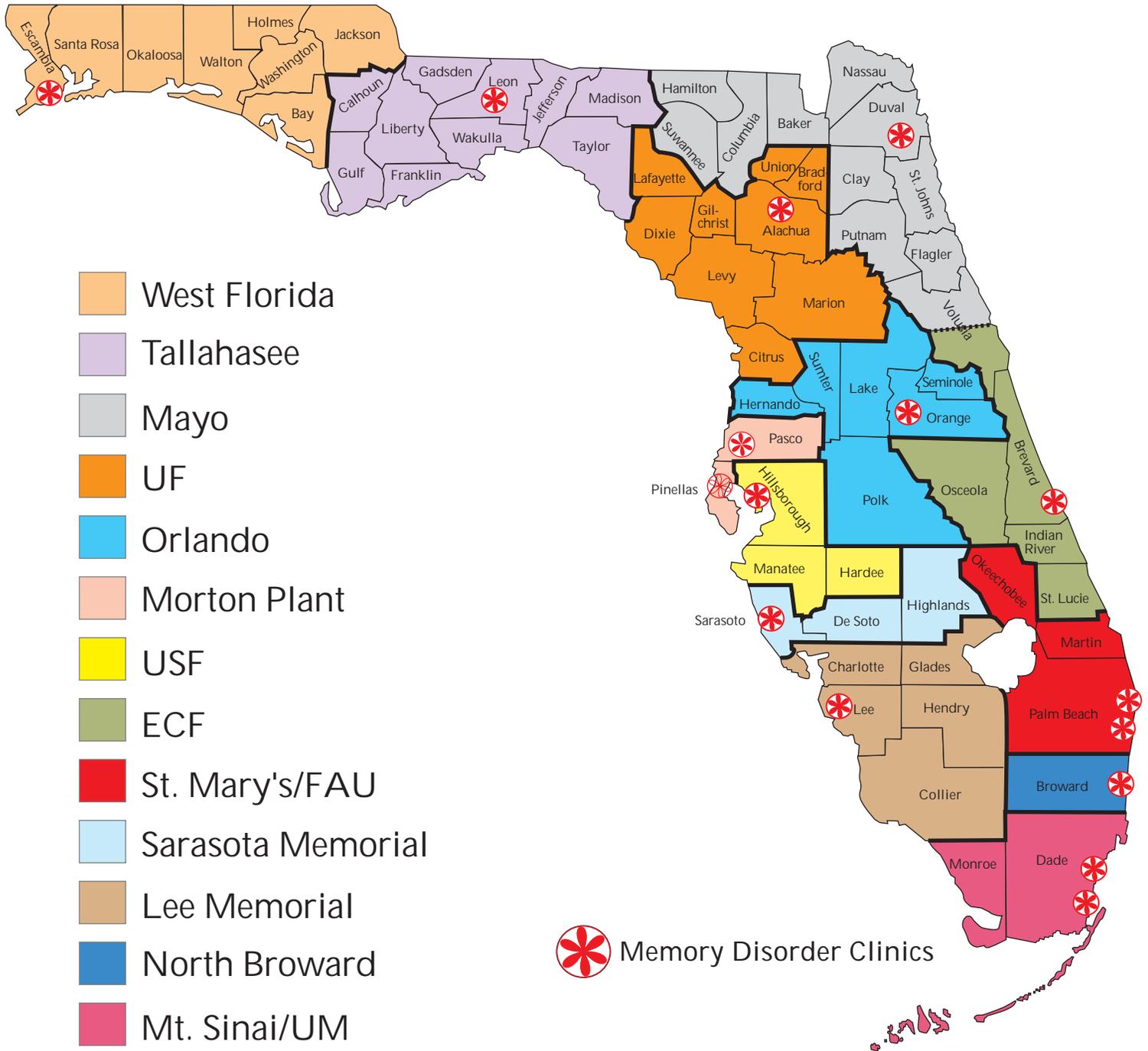
### 12. Any other comments or suggestions?



This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.

## **Appendix 3: Florida Memory Disorder Clinics Map 2013**

# Memory Disorder Clinics



## Appendix 4: Alzheimer's Analysis Report

### About This Report

This report provides statistical data related to Alzheimer's disease in Florida and its counties.

### Death Rate

It is customary to use rates per 100,000 population for deaths. To calculate:

$$\frac{\text{number of deaths from alzheimer's in year x}}{\text{estimated county population in year x}} * 100,000$$

There may or may not be 100,000 residents in the county under review, but multiplying the results by 100,000 makes that rate comparable with counties with more than 100,000 population or less than 100,000 population.

### AADR

An AADR (age-adjusted death rate) is an estimate of what the death rate would be if the selected population had the same age distribution as the standard population.

<http://www.floridacharts.com/charts/Calculate.aspx?RepID=6>

### Statistical Note from Florida CHARTS

Rates based on small numbers of events may be encountered while using this system.

These rates are considered unstable if they are based on fewer than 5 events or if the denominator (population at risk) is fewer than 20. An erratic trends line illustrates this instability. Use of this tool is for analytical and statistical purposes only.

Counties with 60% (8 or more years) between 1999-2011 with death counts less than 5 are indentified by a purple tab.

Those counties include: DeSoto, Dixie, Franklin, Gilchrist, Glades, Gulf, Hamilton, Hardee, Lafayette, Liberty, Taylor, Union Washington

## Contents

1. Summary
2. Geographical Distribution
3. Death Rates in Florida
4. Florida Profile
5. County Profiles

## Summary

### Death Rates in Florida

Death rates for Alzheimer's have increased every year from 1999-2011. From 1999-2010, death from Alzheimer's had the highest percentage increase when compared to ten years prior.

### County Profiles

There are 13 out of 67 counties with unstable statistics.

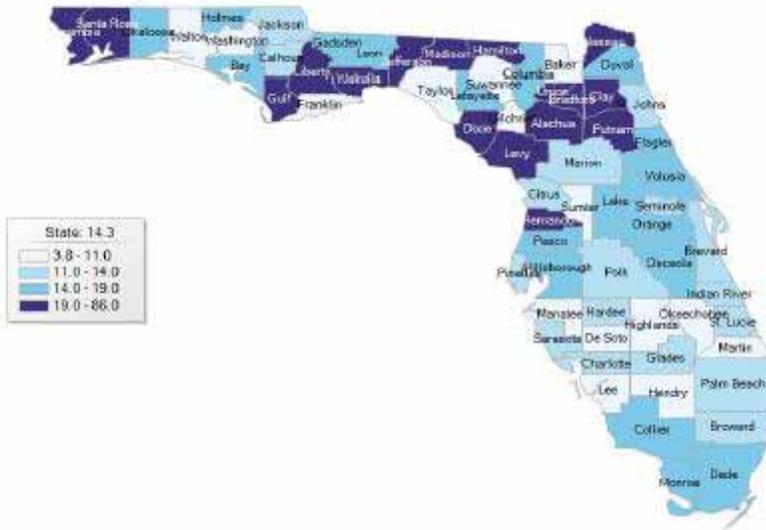
These counties are: DeSoto, Dixie, Franklin, Gilchrist, Glades, Gulf, Hamilton, Hardee, Lafayette, Liberty, Taylor, Union, Washington. (Highlighted in purple below)

Alzheimer's Disease Age-Adjusted Death Rate, Single Year All Race/Ethnicity/Gender, 2011			
County	Rate	Count	Special Needs Info Status
Jackson	41.4	25	Poor
Holmes	35.2	8	Poor
Jefferson	33.3	6	Poor
Clay	31.9	49	Average
Okaloosa	31.6	58	Poor
Wakulla	30.5	6	Poor
Walton	29.3	18	Poor
Putnam	27.7	28	Poor
Marion	27.6	177	Good
Gadsden	27.4	13	Average
Lake	26.9	150	Good
Indian River	26.6	93	Good
Escambia	26.3	92	Poor
Hillsborough	25.7	309	Good
Bay	25.3	48	Poor
Madison	25	6	Poor
Nassau	25	19	Average
Brevard	24.8	229	Good
Baker	24.6	5	Poor
Calhoun	24.6	4	Poor
Leon	24.4	52	Poor
Franklin	24	3	Good
Seminole	23	101	Good
Okeechobee	22.9	11	Poor
Sumter	22.1	44	Good
Liberty	21.8	1	Poor
Hamilton	21.6	3	Poor
Orange	21.3	192	Poor
St. Lucie	21.2	94	Average
Santa Rosa	20.9	25	Average
Collier	20.7	136	Average
Washington	19.8	5	Average

Alzheimer's Disease Age-Adjusted Death Rate, Single Year All Race/Ethnicity/Gender, 2011			
County	Rate	Count	Special Needs Info Status
Levy	18.4	9	Average
Bradford	18.3	6	Average
Duval	18.2	143	Good
Volusia	17.6	162	Good
Monroe	16.9	14	Good
Alachua	16.5	39	Good
Florida	16.1	4,470	Average
Dade	15.7	473	Good
Hardee	15.6	4	Average
Pinellas	14.8	275	Good
Osceola	14.6	31	Average
Pasco	14.5	116	Average
Lafayette	13.3	1	Poor
Suwannee	12.5	8	Poor
Martin	12.4	47	Average
Citrus	12.3	43	Average
Gulf	12.1	2	Poor
Taylor	12.1	3	Poor
Palm Beach	11.9	346	Average
Polk	11.9	97	Average
St. Johns	11.9	29	Average
Hernando	11.3	41	Good
Flagler	11	18	Average
Columbia	10.6	8	Poor
Union	10.4	1	Poor
Sarasota	10	110	Poor
Charlotte	9.7	43	Poor
Broward	9	220	Average
Lee	8.2	90	Good
Manatee	8.2	53	Good
Highlands	7.8	20	Poor
Glades	5	1	Poor
Dixie	4.7	1	Poor
Hendry	3	1	Average
De Soto	2.1	1	Unknown
Gilchrist	0		Poor

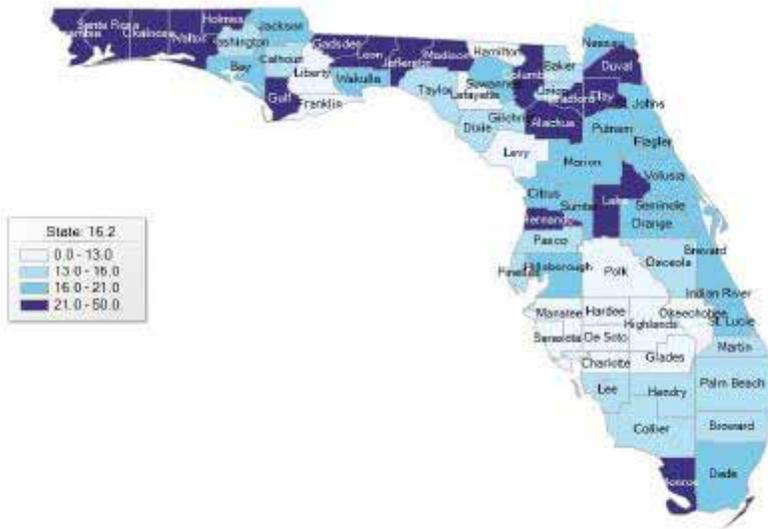
## Appendix 5: Geographical Distribution

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 1999**



Data source: Florida Department of Health, Bureau of Vital Statistics

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 2001**



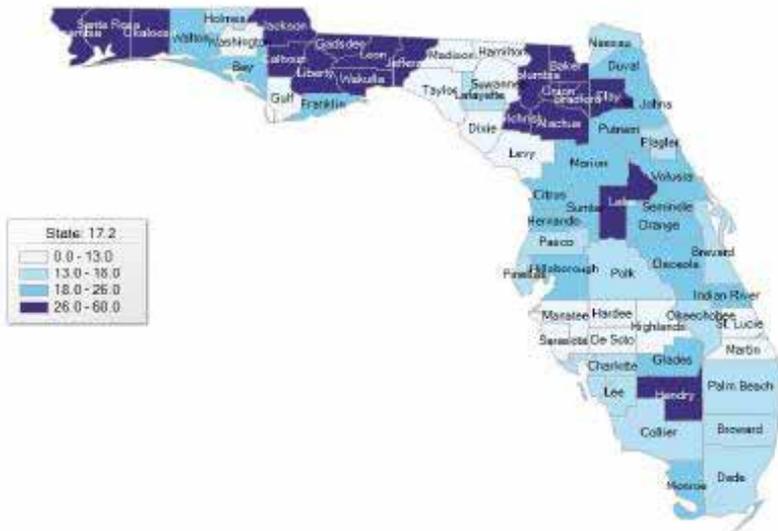
Data source: Florida Department of Health, Bureau of Vital Statistics

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 2000**



Data source: Florida Department of Health, Bureau of Vital Statistics

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 2002**



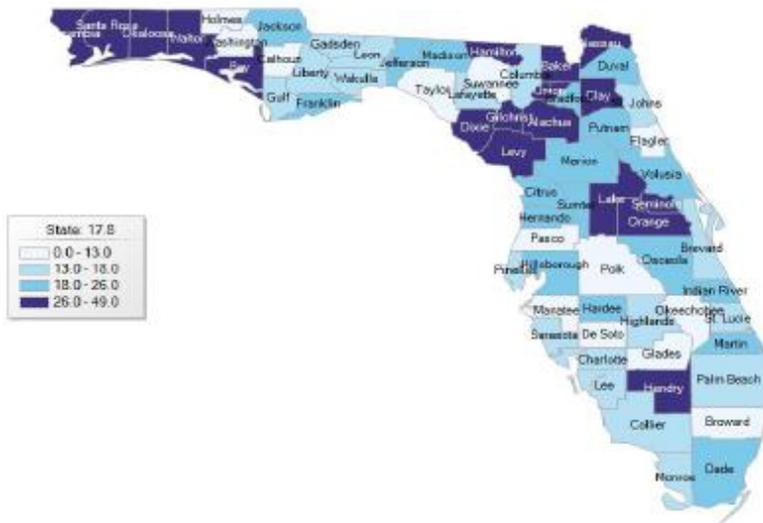
Data source: Florida Department of Health, Bureau of Vital Statistics

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 2003**



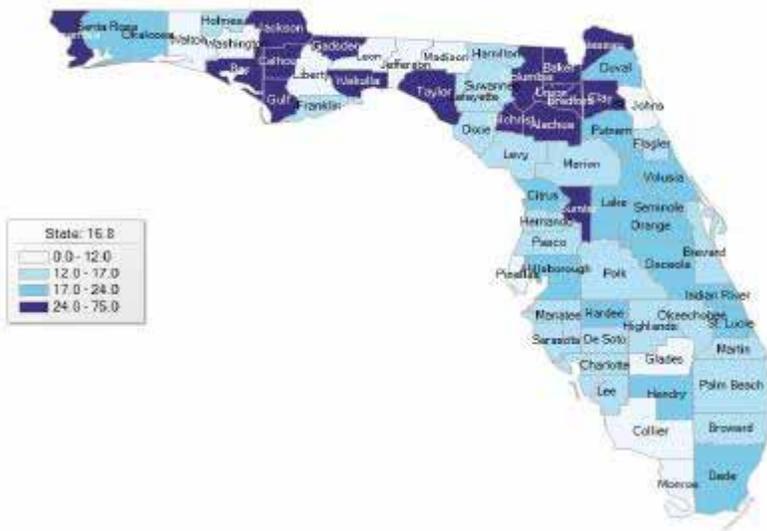
Data source: Florida Department of Health, Bureau of Vital Statistics

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 2005**



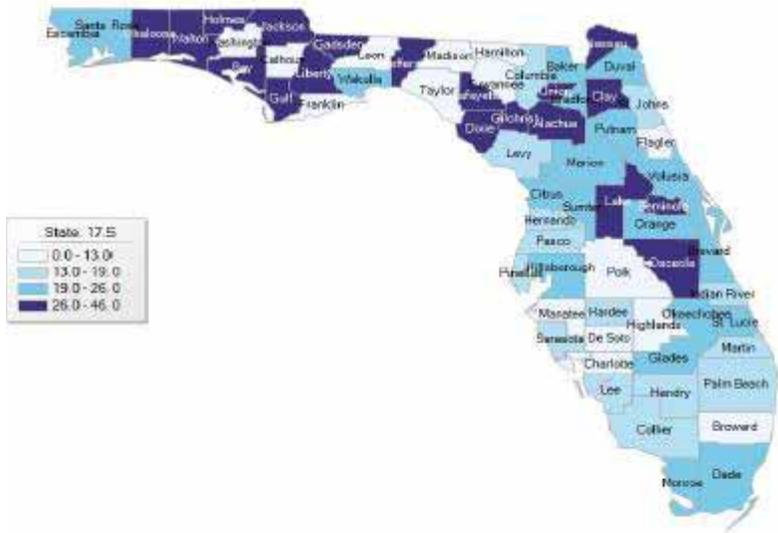
Data source: Florida Department of Health, Bureau of Vital Statistics

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 2004**



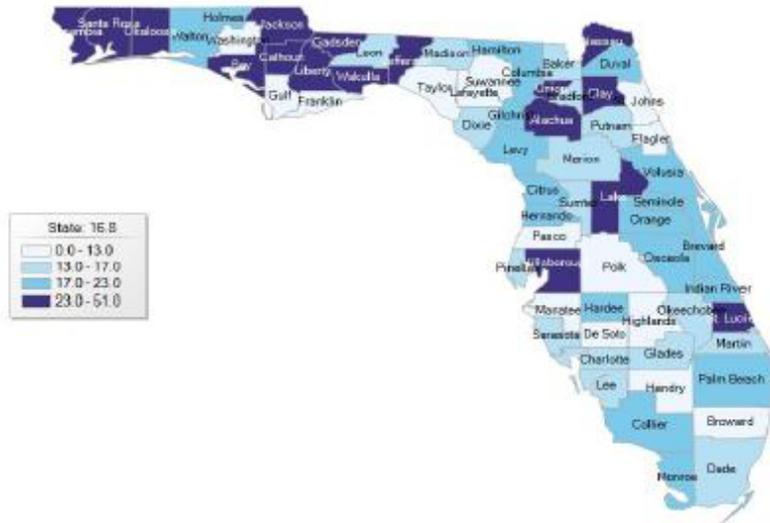
Data source: Florida Department of Health, Bureau of Vital Statistics

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 2006**



Data source: Florida Department of Health, Bureau of Vital Statistics

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 2007**



Data source: Florida Department of Health, Bureau of Vital Statistics

**Alzheimer's Disease Age-Adjusted Death Rate, All Races, 2009**



Data source: Florida Department of Health, Bureau of Vital Statistics





## Death Rates in Florida 1999-2006

Cause of Death	1999			2000			2001			2002		
	Rate		% Change									
Hearth Disease	332.1	358.6	-7.4%	319.4	343.4	-7.0%	306.7	343.6	-10.7%	293.7	346.5	-15.2%
Malignant Neoplasm (Cancer)	248.0	252.3	-1.7%	246.7	253.5	-2.7%	236.6	256.7	-7.8%	233.0	256.9	-9.3%
Cerebrovascular Disease (Stroke)	68.3	64.9	5.2%	66.3	63.6	4.2%	63.2	63.9	-1.1%	61.3	64.0	-4.2%
Chronic Lower Respiratory Disease (C.L.R.D.)	59.4	42.5	39.8%	55.0	42.8	28.5%	54.3	45.3	19.9%	54.1	48.0	12.7%
Unintentional Injury (Accident)	38.9	40.4	-3.7%	40.8	37.9	7.7%	41.9	34.9	20.1%	44.1	34.8	26.7%
Diabetes Mellitus	28.7	21.8	31.7%	28.5	22.3	27.8%	27.9	21.6	29.2%	27.4	22.6	21.2%
Alzheimer's Disease	19.9	6.3	215.9%	20.8	6.7	210.4%	22.1	6.9	220.3%	24.2	7.2	236.1%
Influenza and Pneumonia	21.6	25.0	-13.6%	21.3	26.3	-19.0%	20	24.9	-19.7%	19.6	24.8	-21.0%

Cause of Death	2003			2004			2005			2006		
	Rate		% Change									
Hearth Disease	280.4	350	-19.9%	265.9	272.8	-2.5%	255.2	342.4	-25.5%	238.4	336.6	-29.2%
Malignant Neoplasm (Cancer)	228.6	257.9	-11.4%	224.3	205.2	9.3%	223.8	255.9	-12.5%	217.4	254.9	-14.7%
Cerebrovascular Disease (Stroke)	57.5	67.6	-14.9%	54.9	53.9	1.9%	51.7	68	-24.0%	48.1	66.7	-27.9%
Chronic Lower Respiratory Disease (C.L.R.D.)	52.6	51.2	2.7%	50.7	40.3	25.8%	52.5	51.7	1.5%	48.1	52.2	-7.9%
Unintentional Injury (Accident)	46	35.9	28.1%	46.4	44.2	5.0%	48.5	45.1	7.5%	47.9	45.3	5.7%
Diabetes Mellitus	27.7	23.6	17.4%	27.2	18.9	43.9%	28.8	25.4	13.4%	27.9	25.8	8.1%
Alzheimer's Disease	25.1	8.5	195.3%	24.4	7.2	238.9%	25.5	9.6	165.6%	25.4	10	154.0%
Influenza and Pneumonia	17.4	26.5	-34.3%	17.2	21.3	-19.2%	15.5	26.4	-41.3%	13.1	25.7	-49.0%

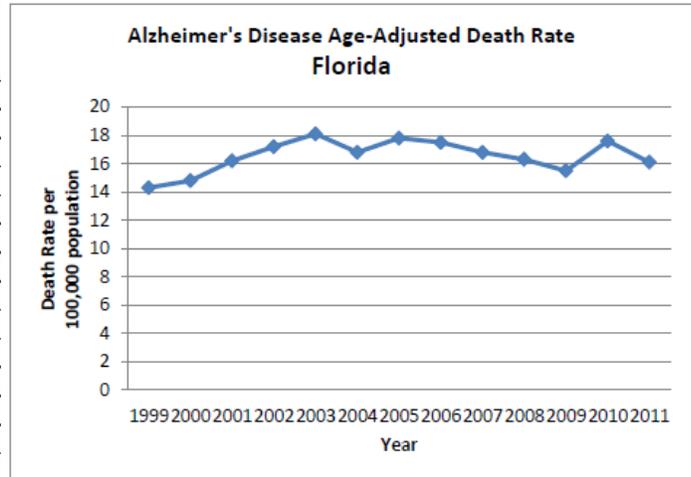
## Death Rates in Florida 2007-2011

Cause of Death	2007			2008			2009			2010		
	Rate		% Change									
Hearth Disease	224	330	-32.1%	222.9	331.4	-32.7%	218.9	326.1	-32.9%	219.5	311.1	-29.4%
Malignant Neoplasm (Cancer)	212.4	251.9	-15.7%	215.5	246.8	-12.7%	216.9	243.5	-10.9%	217.6	240.3	-9.4%
Cerebrovascular Disease (Stroke)	46.5	66.4	-30.0%	45	65.4	-31.2%	44.6	67	-33.4%	44.3	64.6	-31.4%
Chronic Lower Respiratory Disease (C.L.R.D.)	49.7	53.7	-7.4%	54	53.2	1.5%	54	58.3	-7.4%	54.6	53.5	2.1%
Unintentional Injury (Accident)	48.2	44.9	7.3%	47.4	37.5	26.4%	46.6	38.2	22.0%	46	39.7	15.9%
Diabetes Mellitus	27.2	25.5	6.7%	27.4	26.2	4.6%	26	28.2	-7.8%	26.6	27.8	-4.3%
Alzheimer's Disease	24.7	10.6	133.0%	25.1	10.4	141.3%	24.5	19.5	25.6%	25.4	20.3	25.1%
Influenza and Pneumonia	11.9	25.8	-53.9%	12.2	26.2	-53.4%	12.8	21.2	-39.6%	11.8	20.8	-43.3%

Cause of Death	2011		
	Rate	% Change	
Hearth Disease	214	307.2	-30.3%
Malignant Neoplasm (Cancer)	217.7	237	-8.1%
Cerebrovascular Disease (Stroke)	44	63.3	-30.5%
Chronic Lower Respiratory Disease (C.L.R.D.)	54.1	54.4	-0.6%
Unintentional Injury (Accident)	44.8	41.9	6.9%
Diabetes Mellitus	26.6	28	-5.0%
Alzheimer's Disease	23.6	22.2	6.3%
Influenza and Pneumonia	12.8	20.1	-36.3%

Data Source: Florida Department of Health, Bureau of Vital Statistics Annual Reports 1999-2011

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
State					
Years	65-85+	% of Pop	Population	Count	Rate
1999	2,774,918	17.7%	15,679,606	3,057	14.3
2000	2,818,453	17.5%	16,074,896	3,257	14.8
2001	2,851,111	17.4%	16,384,860	3,632	16.2
2002	2,938,349	17.6%	16,718,033	4,046	17.2
2003	2,985,062	17.5%	17,074,368	4,311	18.1
2004	2,926,039	16.7%	17,476,489	4,294	16.8
2005	3,013,199	16.9%	17,876,663	4,600	17.8
2006	3,095,723	17.0%	18,237,596	4,679	17.5
2007	3,147,874	17.0%	18,500,958	4,632	16.8
2008	3,203,878	17.2%	18,636,837	4,724	16.3
2009	3,236,934	17.3%	18,711,844	4,613	15.5
2010	3,314,373	17.6%	18,820,278	4,776	17.6
2011	3,375,283	17.8%	18,934,175	4,470	16.1



1999-2011      21.6%      0.7%      20.8%      **12.6%**

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

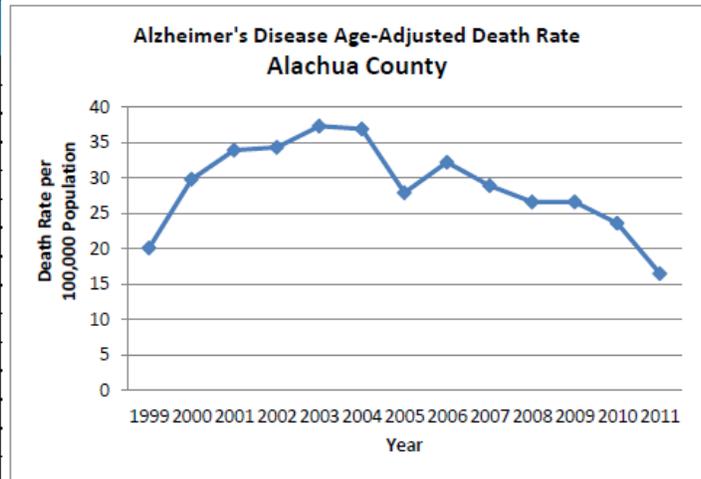
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 21.6%

The rate of alzheimer's disease age-adjusted deaths increased 12.6%

State Website	<a href="http://www.dos.state.fl.us">www.dos.state.fl.us</a>
Emergency Management Page	<a href="http://www.floridadisaster.org/index.asp">www.floridadisaster.org/index.asp</a>
Special Needs Page	<a href="http://www.floridadisaster.org/disability/index.html">www.floridadisaster.org/disability/index.html</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	No
Status	Average
Recommendations	Link to each county's Special Needs Page

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Alachua					
Years	65-85+	% of Pop	Population	Count	Rate
1999	20,543	9.6%	213,346	32	20.1
2000	21,006	9.6%	219,239	49	29.8
2001	21,052	9.5%	221,643	56	33.9
2002	21,526	9.6%	224,556	60	34.3
2003	21,625	9.5%	226,976	65	37.3
2004	21,882	9.5%	229,846	69	36.9
2005	21,773	9.3%	233,859	51	27.9
2006	22,747	9.5%	238,704	63	32.2
2007	23,453	9.7%	242,215	58	28.9
2008	24,477	10.0%	244,664	58	26.6
2009	25,127	10.2%	246,489	58	26.6
2010	26,993	10.9%	247,669	52	23.6
2011	28,104	11.4%	247,403	39	16.5



1999-2011      36.8%      18.0%      16.0%      -17.9%

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

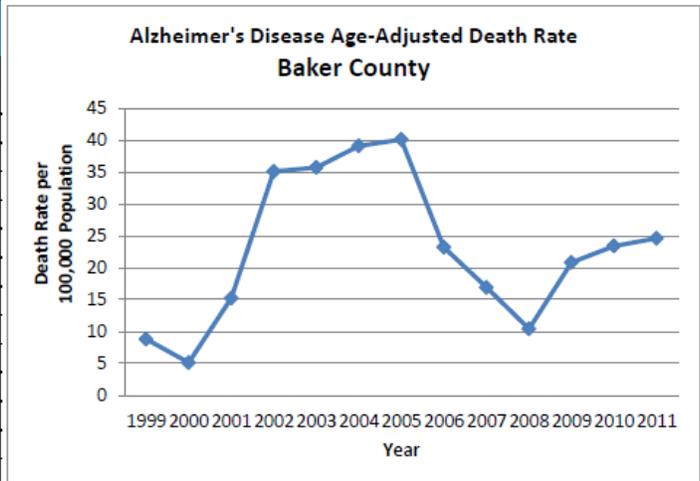
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 36.8%

The rate of alzheimer's disease age-adjusted deaths decreased 17.9%

County Website	<a href="http://www.alachuacounty.us">www.alachuacounty.us</a>
Emergency Management Page	<a href="http://www.alachuacounty.us/EmSvcs/Pages/EmergencyServices.aspx">www.alachuacounty.us/EmSvcs/Pages/EmergencyServices.aspx</a>
Special Needs Page	<a href="http://www.alachuacounty.us/Depts/PublicSafety/em/firstSteps/beinformed/specialneeds/Pages/SpecialNeeds.aspx">www.alachuacounty.us/Depts/PublicSafety/em/firstSteps/beinformed/specialneeds/Pages/SpecialNeeds.aspx</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Contact information needs to be more prevalent on page

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Baker					
Years	65-85+	% of Pop	Population	Count	Rate
1999	1,984	9.2%	21,498	1	8.8
2000	2,064	9.2%	22,388	1	5.1
2001	2,135	9.4%	22,706	2	15.2
2002	2,227	9.6%	23,231	5	35.1
2003	2,269	9.6%	23,625	5	35.7
2004	2,374	9.8%	24,170	6	39.1
2005	2,457	9.9%	24,826	7	40.1
2006	2,633	10.3%	25,521	4	23.2
2007	2,783	10.6%	26,189	3	16.9
2008	2,938	11.0%	26,720	2	10.4
2009	3,049	11.3%	27,077	5	20.8
2010	3,003	11.1%	27,070	5	23.4
2011	3,056	11.4%	26,924	5	24.6



1999-2011      54.0%      23.0%      25.2%      **179.5%**

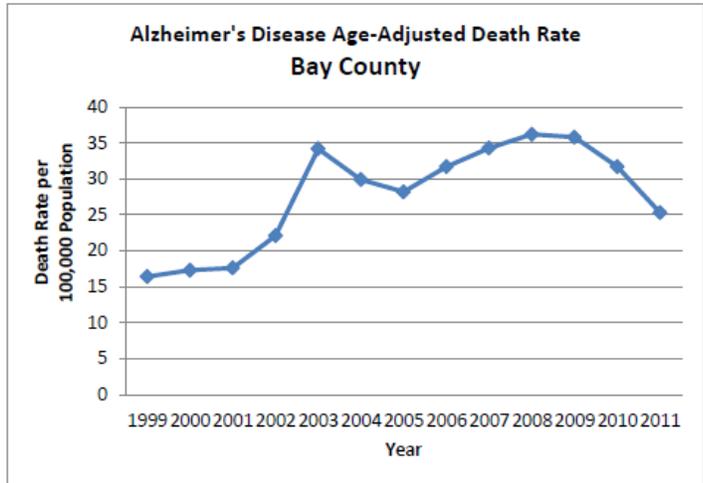
Data Source: [www.floridacharts.com](http://www.floridacharts.com)

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 54.0%  
The rate of alzheimer's disease age-adjusted deaths increased 179.5%

County Website	<a href="http://www.bakercountyfl.org">www.bakercountyfl.org</a>
Emergency Management Page	<a href="http://www.bakerso.com/My-Baker_County_Sheriffs_Office/EOC.html">www.bakerso.com/My-Baker_County_Sheriffs_Office/EOC.html</a>
Special Needs Page	DOC file
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	No; Memory Impaired
Registration Form	Yes
Status	Poor
Recommendations	Add Alzheimer's to Special Needs Reg.doc; Provide information on webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Bay					
Years	65-85+	% of Pop	Population	Count	Rate
1999	19,494	13.3%	147,075	20	16.4
2000	19,909	13.4%	148,692	22	17.3
2001	20,056	13.4%	150,121	22	17.6
2002	20,528	13.5%	151,632	30	22.1
2003	20,714	13.5%	153,710	47	34.2
2004	21,319	13.6%	156,846	46	29.9
2005	22,306	13.9%	160,437	45	28.2
2006	23,481	14.3%	163,946	54	31.7
2007	24,355	14.6%	166,648	61	34.3
2008	25,259	15.0%	168,495	69	36.2
2009	25,794	15.3%	168,464	71	35.8
2010	24,793	14.7%	168,957	59	31.7
2011	25,311	14.9%	169,443	48	25.3



1999-2011      29.8%      12.7%      15.2%      **54.3%**

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

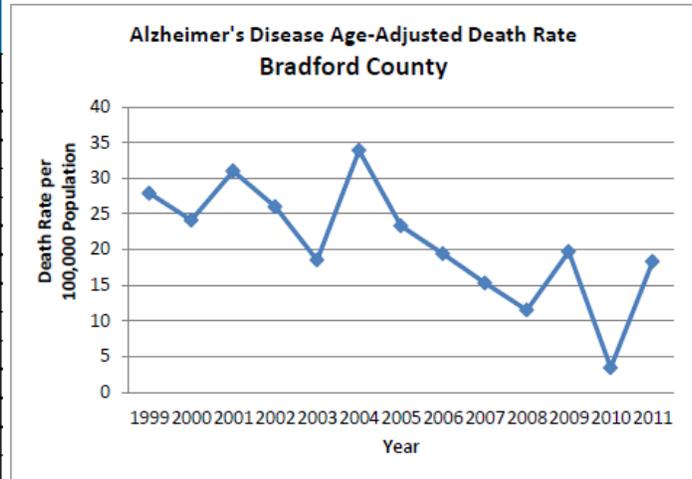
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 29.8%

The rate of alzheimer's disease age-adjusted deaths increased 54.3%

County Website	<a href="http://www.co.bay.fl.us">www.co.bay.fl.us</a>
Emergency Management Page	<a href="http://www.co.bay.fl.us/emergency/management.php">www.co.bay.fl.us/emergency/management.php</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Add Special Needs information and registration form if applicable

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Bradford					
Years	65-85+	% of Pop	Population	Count	Rate
1999	3,316	12.9%	25,767	7	27.9
2000	3,387	13.0%	26,110	6	24.1
2001	3,442	13.2%	26,159	8	31
2002	3,548	13.4%	26,511	7	26
2003	3,586	13.3%	27,062	5	18.5
2004	3,596	13.0%	27,670	10	33.9
2005	3,710	13.2%	28,002	7	23.3
2006	3,792	13.3%	28,461	6	19.4
2007	3,893	13.5%	28,837	5	15.3
2008	4,008	13.8%	28,964	4	11.5
2009	4,040	14.0%	28,919	7	19.7
2010	4,141	14.5%	28,479	1	3.4
2011	4,258	14.8%	28,753	6	18.3



1999-2011      28.4%      15.1%      11.6%      -34.4%

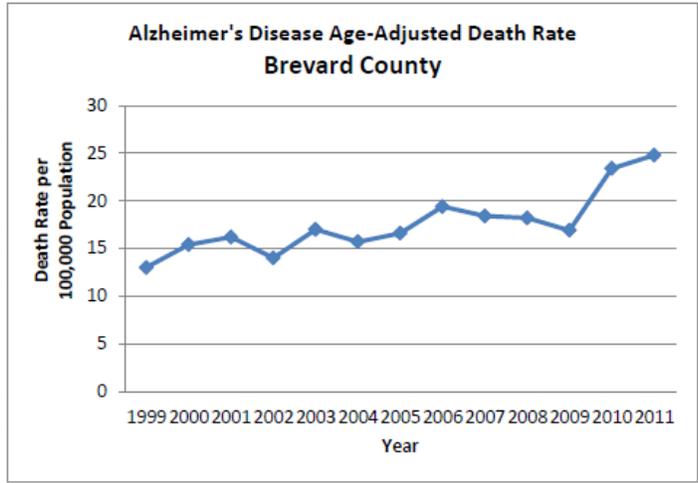
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 28.4%  
The rate of alzheimer's disease age-adjusted deaths decreased 34.4%

County Website	<a href="http://www.bradford-co-fla.org">www.bradford-co-fla.org</a>
Emergency Management Page	<a href="http://www.bradford-co-fla.org/Emergency%20Man/EMindex.html">www.bradford-co-fla.org/Emergency%20Man/EMindex.html</a>
Special Needs Page	<a href="http://www.bradford-co-fla.org/Emergency%20Man/emSpecialNeeds.html">www.bradford-co-fla.org/Emergency%20Man/emSpecialNeeds.html</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No; Memory Impaired
Registration Form	Yes
Status	Average
Recommendations	Move Special Needs registration form to the top of the webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Brevard					
Years	65-85+	% of Pop	Population	Count	Rate
1999	93,231	19.9%	469,515	83	13
2000	95,014	19.9%	478,541	102	15.4
2001	95,462	19.6%	486,791	107	16.2
2002	97,764	19.7%	495,800	98	14
2003	99,267	19.6%	505,975	119	17
2004	103,107	19.9%	518,389	130	15.7
2005	105,873	20.0%	528,565	137	16.6
2006	108,126	20.2%	534,637	167	19.4
2007	109,757	20.4%	539,207	164	18.4
2008	111,847	20.6%	541,732	173	18.2
2009	113,201	20.9%	542,438	164	16.9
2010	111,901	20.6%	543,627	211	23.4
2011	113,544	20.8%	545,750	229	24.8



1999-2011      21.8%      4.8%      16.2%      90.8%

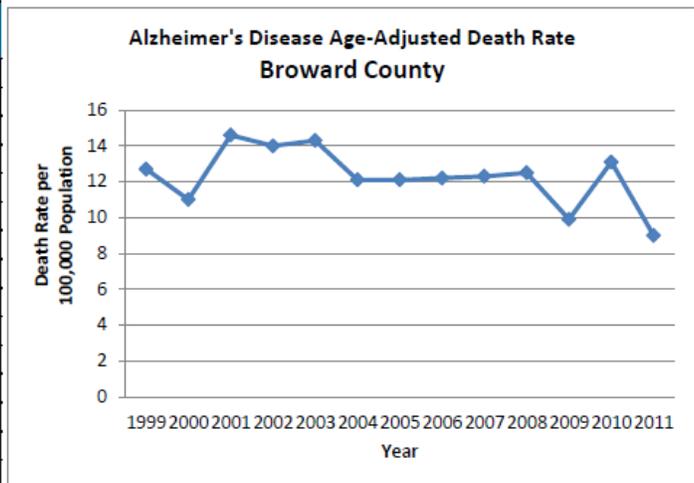
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 21.8%  
The rate of alzheimer's disease age-adjusted deaths increased 90.8%

County Website	<a href="http://www.brevardcounty.us">www.brevardcounty.us</a>
Emergency Management Page	<a href="http://www.brevardcounty.us/EmergencyManagement/">www.brevardcounty.us/EmergencyManagement/</a>
Special Needs Page	<a href="http://web.brevardcounty.us/SpecialNeeds/Registration.aspx">http://web.brevardcounty.us/SpecialNeeds/Registration.aspx</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Contact information needs to be more prevalent on page

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Broward					
Years	65-85+	% of Pop	Population	Count	Rate
1999	260,202	16.4%	1,590,361	309	12.7
2000	261,376	16.0%	1,631,445	274	11
2001	261,428	15.7%	1,659,975	362	14.6
2002	266,489	15.8%	1,684,473	360	14
2003	266,391	15.6%	1,706,559	362	14.3
2004	248,743	14.4%	1,727,910	324	12.1
2005	246,257	14.1%	1,745,138	305	12.1
2006	245,959	14.1%	1,746,544	299	12.2
2007	244,115	14.0%	1,740,832	302	12.3
2008	244,679	14.1%	1,739,002	316	12.5
2009	244,703	14.1%	1,739,812	251	9.9
2010	254,710	14.6%	1,748,502	309	13.1
2011	260,508	14.9%	1,753,678	220	9



1999-2011      0.1%      -9.2%      10.3%      -29.1%

Data Source: www.floridacharts.com

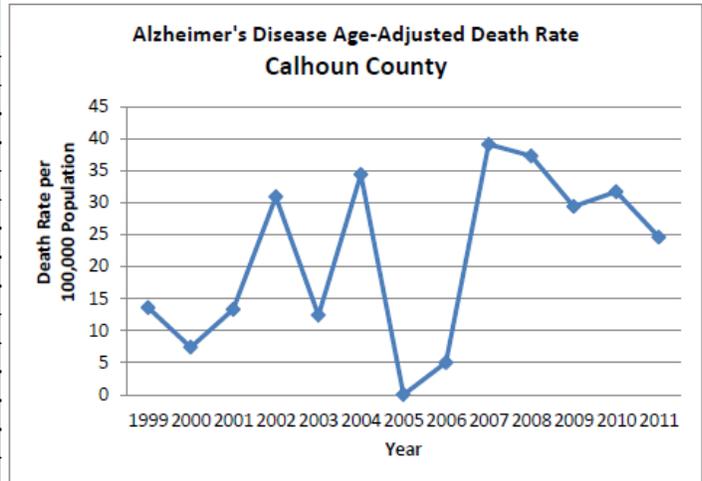
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 0.1%

The rate of alzheimer's disease age-adjusted deaths decreased 29.1%

County Website	<a href="http://www.broward.org">www.broward.org</a>
Emergency Management Page	<a href="http://www.broward.org/Emergency/Pages/Default.aspx">www.broward.org/Emergency/Pages/Default.aspx</a>
Special Needs Page	<a href="http://www.broward.org/AtRisk/Pages/Default.aspx">www.broward.org/AtRisk/Pages/Default.aspx</a>
Number of Clicks	3
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	Yes
Status	Average
Recommendations	At Risk page needs to be easier to navigate to from the main county website

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Calhoun					
Years	65-85+	% of Pop	Population	Count	Rate
1999	1,797	14.0%	12,863	2	13.6
2000	1,821	14.0%	13,038	1	7.4
2001	1,829	14.1%	12,929	2	13.3
2002	1,892	14.4%	13,122	5	30.9
2003	1,922	14.4%	13,372	2	12.4
2004	1,973	14.5%	13,617	6	34.4
2005	2,015	14.6%	13,841	0	0
2006	2,114	15.0%	14,077	1	5
2007	2,159	15.1%	14,297	7	39.1
2008	2,248	15.6%	14,410	7	37.3
2009	2,300	15.7%	14,677	6	29.4
2010	2,290	15.6%	14,640	5	31.7
2011	2,335	15.9%	14,676	4	24.6



1999-2011    29.9%    13.9%    14.1%    **80.9%**

Data Source: www.floridacharts.com

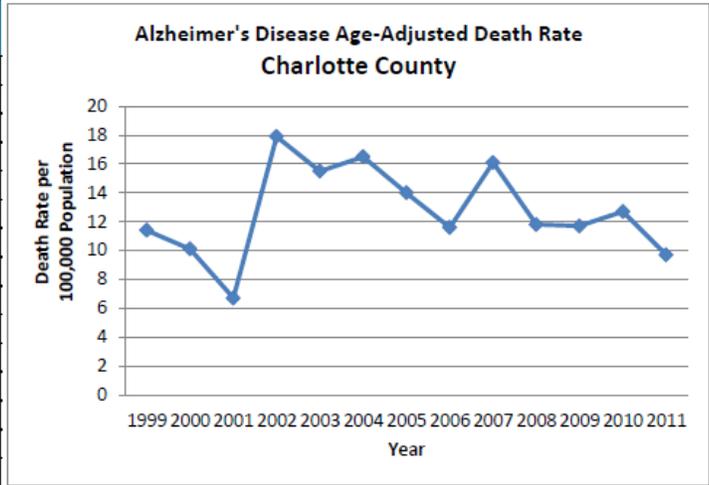
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 29.9%

The rate of alzheimer's disease age-adjusted deaths increased 80.9%

County Website	None
Emergency Management Page	<a href="http://www.calhounflorida.org">www.calhounflorida.org</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Provide Special Needs information

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Charlotte					
Years	65-85+	% of Pop	Population	Count	Rate
1999	48,430	34.8%	139,032	40	11.4
2000	49,271	34.6%	142,357	36	10.1
2001	49,512	34.0%	145,749	24	6.7
2002	50,265	33.7%	148,999	68	17.9
2003	51,234	33.6%	152,337	59	15.5
2004	50,482	32.7%	154,553	71	16.5
2005	52,133	33.9%	153,569	63	14
2006	53,206	33.8%	157,610	55	11.6
2007	53,872	33.6%	160,434	78	16.1
2008	53,973	33.7%	160,269	61	11.8
2009	53,851	33.7%	159,821	62	11.7
2010	54,865	34.3%	160,012	55	12.7
2011	55,290	34.4%	160,632	43	9.7



1999-2011      14.2%      -1.2%      15.5%      -14.9%

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

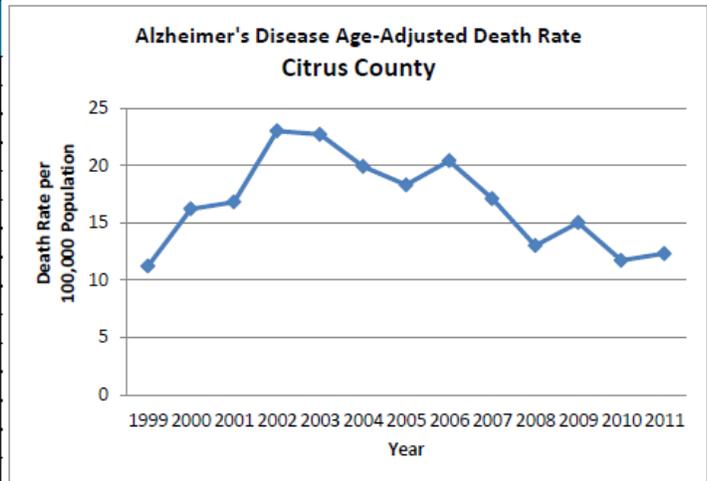
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 14.2%

The rate of alzheimer's disease age-adjusted deaths decreased 14.9%

County Website	<a href="http://www.charlottecountyfl.gov">www.charlottecountyfl.gov</a>
Emergency Management Page	<a href="http://www.charlottecountyfl.com/Emergency/">www.charlottecountyfl.com/Emergency/</a>
Special Needs Page	PDF file
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create a Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Citrus					
Years	65-85+	% of Pop	Population	Count	Rate
1999	37,503	32.3%	116,208	29	11.2
2000	38,186	32.2%	118,689	43	16.2
2001	38,741	32.0%	120,974	45	16.8
2002	39,843	32.3%	123,347	67	23
2003	40,570	32.2%	126,068	66	22.7
2004	39,339	30.4%	129,371	65	19.9
2005	42,777	32.1%	133,169	64	18.3
2006	44,154	32.1%	137,530	76	20.4
2007	45,222	32.1%	140,902	66	17.1
2008	45,872	32.3%	141,926	53	13
2009	45,864	32.4%	141,581	63	15
2010	45,245	32.1%	141,136	40	11.7
2011	45,431	32.2%	141,018	43	12.3



1999-2011      21.1%      -0.2%      21.3%      9.8%

Data Source: www.floridacharts.com

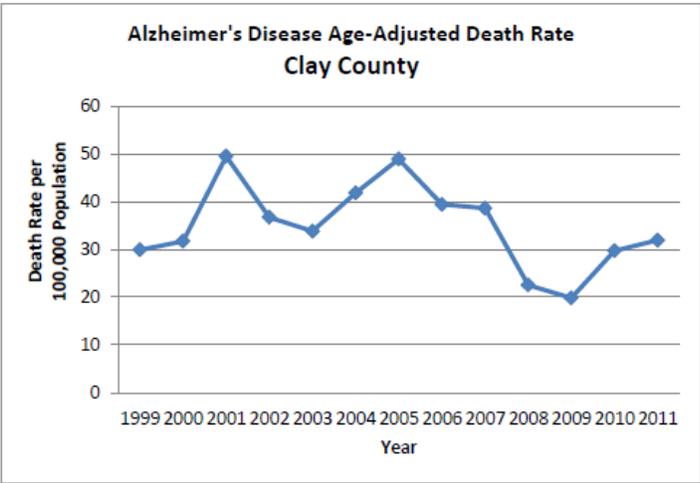
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 21.1%

The rate of alzheimer's disease age-adjusted deaths increased 9.8%

County Website	<a href="http://www.citruscountyfl.org">www.citruscountyfl.org</a>
Emergency Management Page	<a href="http://www.sheriffcitrus.org/EM/EOC.html">www.sheriffcitrus.org/EM/EOC.html</a>
Special Needs Page	PDF file
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No; Memory Impairment
Registration Form	Yes
Status	Average
Recommendations	Add Special Needs information directly to webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Clay					
Years	65-85+	% of Pop	Population	Count	Rate
1999	13,373	9.7%	137,357	28	29.9
2000	13,867	9.8%	141,331	30	31.7
2001	14,488	10.0%	145,559	50	49.5
2002	15,551	10.3%	151,493	42	36.7
2003	16,049	10.2%	157,584	39	33.8
2004	17,013	10.3%	164,604	52	41.8
2005	17,987	10.5%	171,525	65	48.9
2006	19,429	10.8%	180,199	57	39.4
2007	20,542	11.0%	186,410	60	38.6
2008	21,252	11.3%	187,883	37	22.5
2009	21,904	11.6%	189,350	34	19.8
2010	22,622	11.8%	190,982	44	29.7
2011	23,355	12.2%	191,397	49	31.9



1999-2011      74.6%      25.3%      39.3%      6.7%

Data Source: www.floridacharts.com

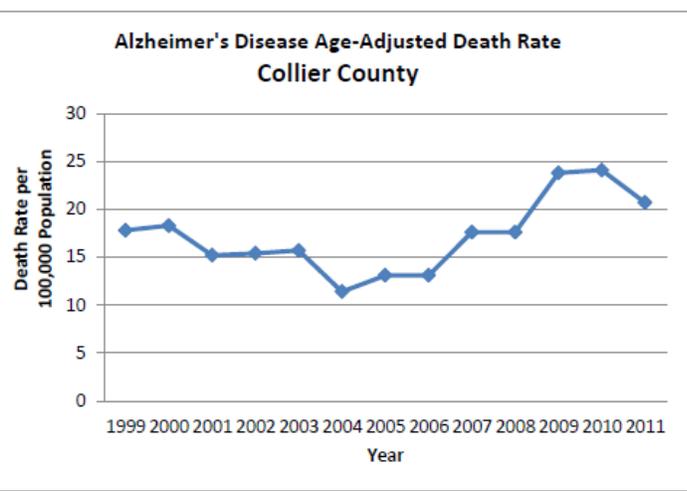
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 74.6%

The rate of alzheimer's disease age-adjusted deaths increased 6.7%

County Website	<a href="http://www.claycountygov.com">www.claycountygov.com</a>
Emergency Management Page	<a href="http://www.claycountygov.com/public-safety/emergency-management">www.claycountygov.com/public-safety/emergency-management</a>
Special Needs Page	PDF file
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Average
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Collier					
Years	65-85+	% of Pop	Population	Count	Rate
1999	59,920	24.7%	242,408	65	17.8
2000	62,257	24.5%	254,571	71	18.3
2001	64,714	24.5%	264,478	63	15.2
2002	68,120	24.7%	275,271	70	15.4
2003	70,205	24.6%	285,412	73	15.7
2004	69,080	23.3%	296,073	56	11.4
2005	71,042	23.2%	306,011	66	13.1
2006	72,623	23.3%	311,578	70	13.1
2007	73,332	23.3%	314,255	97	17.6
2008	74,652	23.6%	316,437	105	17.6
2009	75,680	23.7%	318,929	149	23.8
2010	86,130	26.7%	322,052	153	24.1
2011	87,144	26.9%	324,422	136	20.7



1999-2011      45.4%      8.7%      33.8%      **16.3%**

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

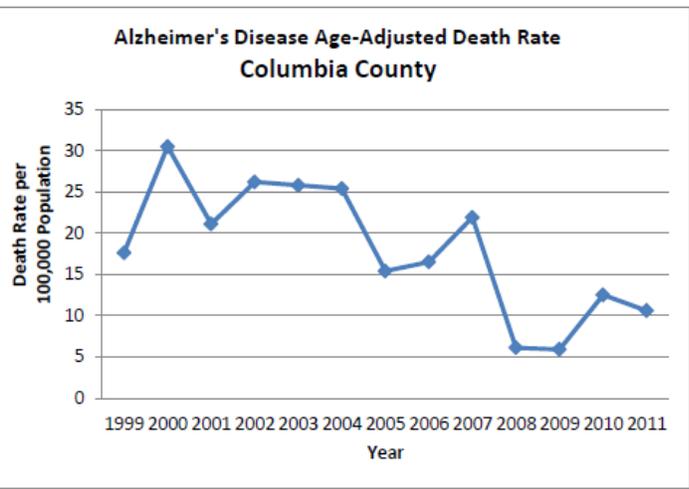
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 45.4%

The rate of alzheimer's disease age-adjusted deaths increased 16.3%

County Website	<a href="http://www.colliergov.net">www.colliergov.net</a>
Emergency Management Page	<a href="http://www.colliergov.net/Index.aspx?page=101">www.colliergov.net/Index.aspx?page=101</a>
Special Needs Page	<a href="http://www.colliergov.net/index.aspx?page=1844">www.colliergov.net/index.aspx?page=1844</a>
Number of Clicks	1
Special Needs Info	Yes; PDF file
Lists Alzheimer's	Yes
Registration Form	Yes; 2011-2012 form
Status	Average
Recommendations	Add Special Needs information directly to webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Columbia					
Years	65-85+	% of Pop	Population	Count	Rate
1999	7,795	14.1%	55,446	9	17.6
2000	7,933	14.0%	56,683	17	30.5
2001	8,016	14.0%	57,372	12	21.1
2002	8,158	14.0%	58,401	15	26.2
2003	8,287	13.9%	59,526	15	25.8
2004	8,448	13.8%	61,044	16	25.4
2005	9,208	14.6%	62,885	11	15.4
2006	9,758	15.0%	65,234	12	16.5
2007	10,104	15.2%	66,446	17	21.9
2008	10,392	15.5%	67,100	5	6.1
2009	10,663	15.8%	67,330	5	5.9
2010	10,519	15.6%	67,549	9	12.5
2011	10,703	15.8%	67,567	8	10.6



1999-2011    37.3%    12.7%    21.9%    -39.8%

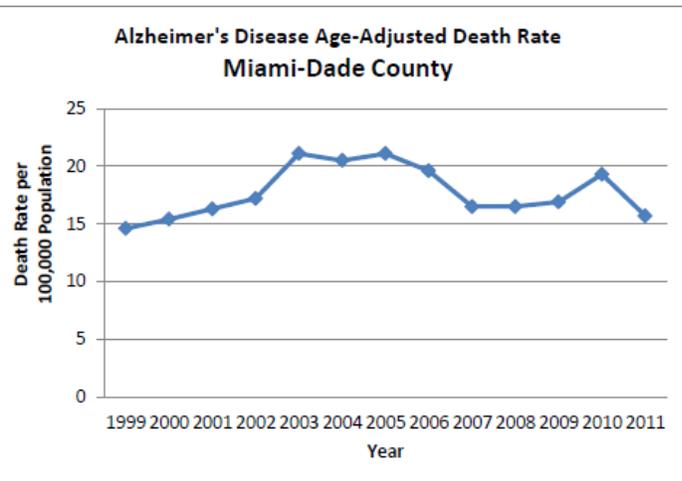
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 37.3%  
The rate of alzheimer's disease age-adjusted deaths decreased 39.8%

County Website	<a href="http://www.columbiacountyfla.com">www.columbiacountyfla.com</a>
Emergency Management Page	<a href="http://www.columbiacountyem.com">www.columbiacountyem.com</a>
Special Needs Page	DOC file
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	Yes
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Miami-Dade					
Years	65-85+	% of Pop	Population	Count	Rate
1999	295,806	13.3%	2,219,329	343	14.6
2000	301,582	13.3%	2,262,902	371	15.4
2001	304,465	13.3%	2,287,935	395	16.3
2002	313,355	13.5%	2,315,799	438	17.2
2003	315,733	13.5%	2,343,909	537	21.1
2004	319,665	13.5%	2,371,859	558	20.5
2005	324,025	13.5%	2,401,755	567	21.1
2006	331,274	13.6%	2,427,037	543	19.6
2007	337,944	13.8%	2,455,829	469	16.5
2008	346,117	14.0%	2,475,413	500	16.5
2009	350,860	14.1%	2,483,366	522	16.9
2010	360,391	14.4%	2,498,855	560	19.3
2011	369,027	14.6%	2,521,194	473	15.7



1999-2011      24.8%      9.8%      13.6%      7.5%

Data Source: www.floridacharts.com

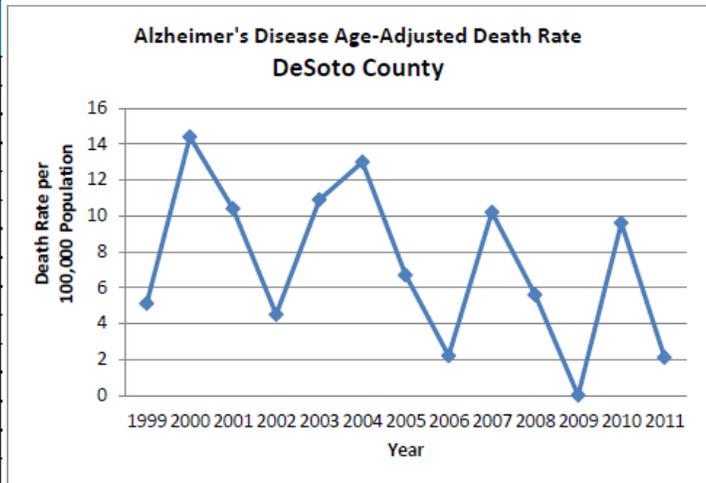
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 24.8%

The rate of alzheimer's disease age-adjusted deaths increased 7.5%

County Website	<a href="http://miamidade.gov">http://miamidade.gov</a>
Emergency Management Page	<a href="http://www.miamidade.gov/fire/emergency-management.asp">www.miamidade.gov/fire/emergency-management.asp</a>
Special Needs Page	<a href="http://www.miamidade.gov/fire/eeap-program-page.asp">www.miamidade.gov/fire/eeap-program-page.asp</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Add Contact information to webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
DeSoto					
Years	65-85+	% of Pop	Population	Count	Rate
1999	6,083	19.4%	31,436	2	5.1
2000	6,134	18.9%	32,404	5	14.4
2001	6,181	19.0%	32,613	4	10.4
2002	6,384	19.4%	32,823	2	4.5
2003	6,496	19.3%	33,651	5	10.9
2004	6,352	18.8%	33,803	6	13
2005	6,364	19.1%	33,345	3	6.7
2006	6,494	19.2%	33,808	1	2.2
2007	6,578	19.2%	34,259	5	10.2
2008	6,697	19.4%	34,524	3	5.6
2009	6,795	19.5%	34,769	0	0
2010	6,373	18.3%	34,837	4	9.6
2011	6,354	18.3%	34,672	1	2.1



1999-2011      4.5%      -5.3%      10.3%      -58.8%

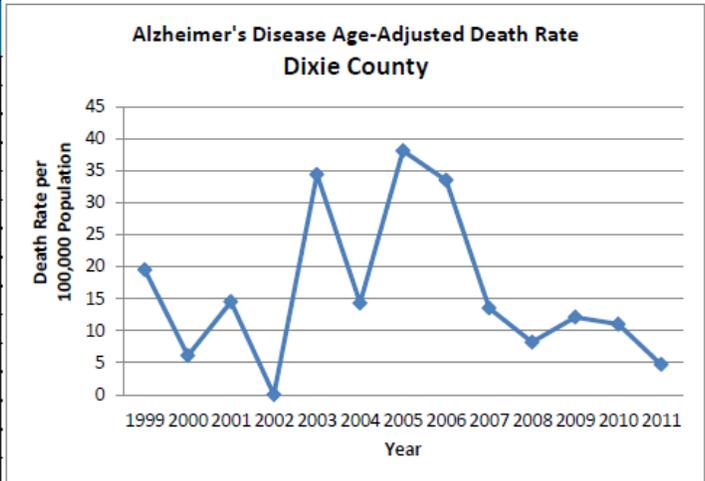
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 4.5%  
The rate of alzheimer's disease age-adjusted deaths decreased 58.8%

County Website	<a href="http://www.co.desoto.fl.us">www.co.desoto.fl.us</a> Website Unavailable
Emergency Management Page	
Special Needs Page	
Number of Clicks	
Special Needs Info	
Lists Alzheimer's	
Registration Form	
Status	
Recommendations	

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Dixie					
Years	65-85+	% of Pop	Population	Count	Rate
1999	2,295	16.9%	13,559	2	19.5
2000	2,392	17.2%	13,883	1	6.1
2001	2,481	17.7%	14,039	2	14.5
2002	2,614	18.2%	14,325	0	0
2003	2,638	18.2%	14,526	6	34.4
2004	2,597	17.5%	14,836	2	14.3
2005	2,800	18.2%	15,420	7	38.1
2006	2,952	18.7%	15,762	7	33.5
2007	3,048	19.1%	15,968	3	13.5
2008	3,163	19.6%	16,152	2	8.2
2009	3,250	19.9%	16,326	3	12.1
2010	3,202	19.5%	16,412	2	11
2011	3,240	19.7%	16,431	1	4.7



1999-2011      41.2%      16.5%      21.2%      -75.9%

Data Source: www.floridacharts.com

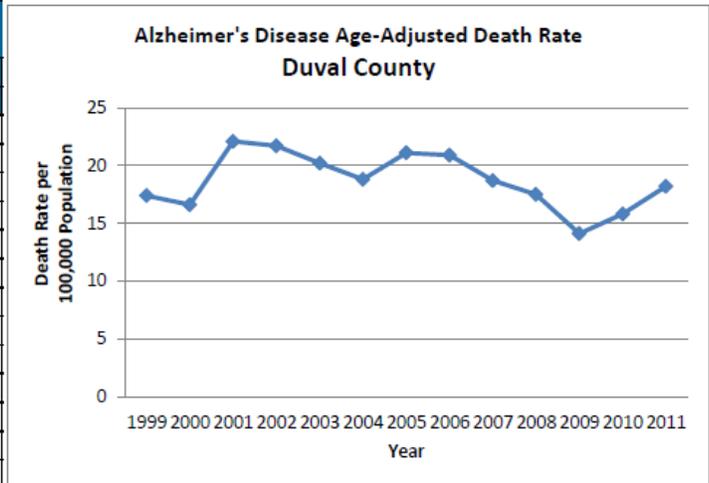
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 41.2%

The rate of alzheimer's disease age-adjusted deaths decreased 75.9%

County Website	<a href="http://dixie.fl.gov">http://dixie.fl.gov</a>
Emergency Management Page	<a href="http://www.dixieemergency.com/">www.dixieemergency.com/</a>
Special Needs Page	<a href="http://www.dixieemergency.com/Special_Needs.cfm">www.dixieemergency.com/Special_Needs.cfm</a>
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	Yes
Status	Poor
Recommendations	Add Special Needs information to webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Years	Duval				
	65-85+	% of Pop	Population	Count	Rate
1999	80,660	10.5%	767,860	105	17.4
2000	82,077	10.5%	782,691	104	16.6
2001	82,550	10.4%	791,495	140	22.1
2002	84,370	10.5%	802,061	143	21.7
2003	84,825	10.5%	811,032	133	20.2
2004	84,226	10.3%	820,761	133	18.8
2005	85,280	10.3%	830,844	147	21.1
2006	88,671	10.5%	841,485	152	20.9
2007	90,943	10.7%	848,993	140	18.7
2008	93,861	11.0%	854,347	137	17.5
2009	96,216	11.2%	859,960	114	14.1
2010	97,871	11.3%	864,680	123	15.8
2011	101,104	11.7%	864,726	143	18.2



1999-2011      25.3%      11.3%      12.6%      **4.6%**

Data Source: www.floridacharts.com

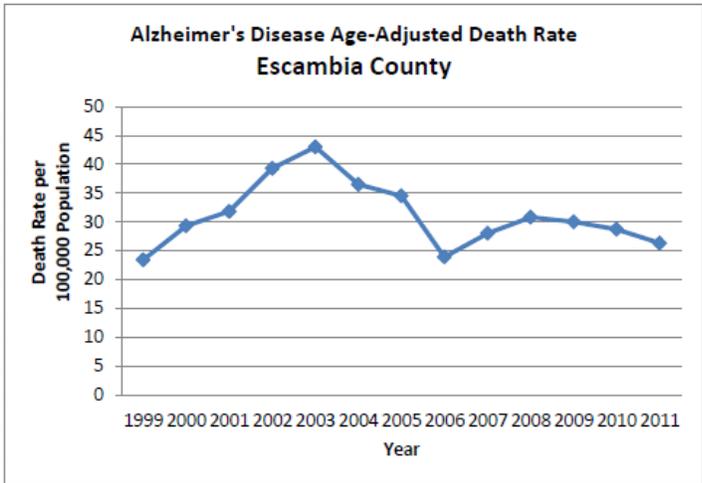
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 25.3%

The rate of alzheimer's disease age-adjusted deaths increased 4.6%

County Website	<a href="http://www.coj.net">www.coj.net</a> no central county website - City of Jacksonville site
Emergency Management Page	<a href="http://www.coj.net/departments/fire-and-rescue/emergency-preparedness.aspx">www.coj.net/departments/fire-and-rescue/emergency-preparedness.aspx</a>
Special Needs Page	<a href="http://www.coj.net/departments/fire-and-rescue/emergency-preparedness/news/special-needs-registration.aspx">www.coj.net/departments/fire-and-rescue/emergency-preparedness/news/special-needs-registration.aspx</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Make contact phone number bold

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Escambia					
Years	65-85+	% of Pop	Population	Count	Rate
1999	38,797	13.2%	292,937	66	23.4
2000	39,215	13.3%	294,911	84	29.3
2001	39,093	13.2%	296,729	92	31.8
2002	39,689	13.3%	297,568	119	39.3
2003	39,647	13.3%	298,738	129	43
2004	40,482	13.6%	298,659	121	36.5
2005	41,289	13.9%	297,043	117	34.5
2006	42,170	14.1%	299,877	85	23.9
2007	42,711	14.2%	300,176	103	28
2008	43,457	14.5%	299,838	119	30.8
2009	43,832	14.7%	298,391	119	30
2010	43,403	14.6%	297,830	97	28.7
2011	44,736	14.9%	299,603	92	26.3



1999-2011    15.3%    12.7%    2.3%    12.4%

Data Source: www.floridacharts.com

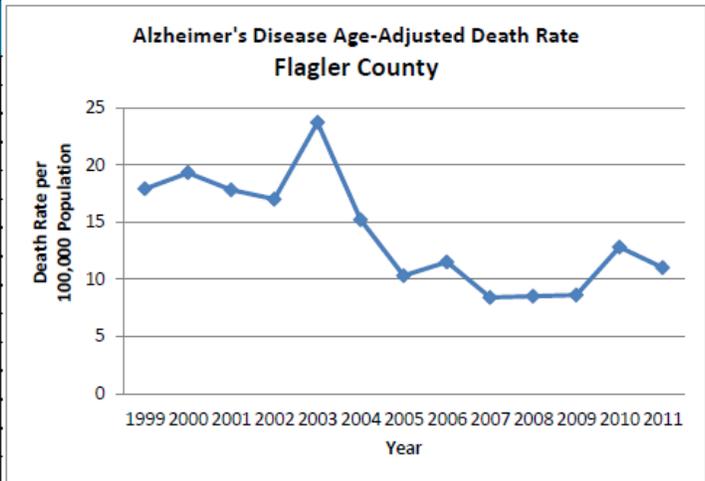
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 15.3%

The rate of alzheimer's disease age-adjusted deaths increased 12.4%

County Website	<a href="http://www.co.escambia.fl.us">www.co.escambia.fl.us</a>
Emergency Management Page	<a href="http://www.myescambia.com/government/departments/ps/emmgmt">www.myescambia.com/government/departments/ps/emmgmt</a>
Special Needs Page	<a href="http://www.bereadyescambia.com/">www.bereadyescambia.com/</a>
Number of Clicks	1
Special Needs Info	No; links to floridadisaster.org
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Flagler					
Years	65-85+	% of Pop	Population	Count	Rate
1999	13,756	28.9%	47,559	14	17.9
2000	14,499	28.6%	50,620	14	19.3
2001	15,679	28.9%	54,199	16	17.8
2002	17,174	29.4%	58,478	19	17
2003	18,694	29.3%	63,862	28	23.7
2004	19,144	26.9%	71,092	21	15.2
2005	20,998	26.6%	78,946	14	10.3
2006	23,374	27.0%	86,419	19	11.5
2007	24,914	27.2%	91,578	15	8.4
2008	25,799	27.5%	93,797	17	8.5
2009	26,267	27.7%	94,897	18	8.6
2010	23,639	24.7%	95,812	21	12.8
2011	23,922	24.8%	96,640	18	11



1999-2011      73.9%    -14.4%      103.2%      -38.5%

Data Source: www.floridacharts.com

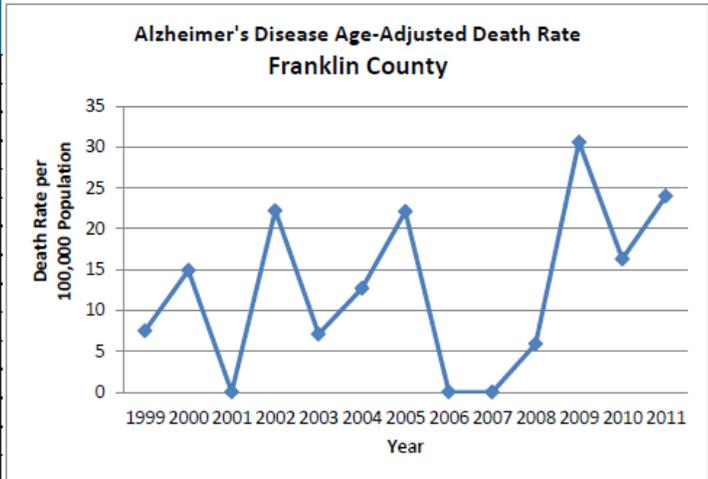
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 73.9%

The rate of alzheimer's disease age-adjusted deaths decreased 38.5%

County Website	<a href="http://www.flaglercounty.org">www.flaglercounty.org</a>
Emergency Management Page	<a href="http://www.flagleremergency.com">www.flagleremergency.com</a>
Special Needs Page	<a href="http://www.flagleremergency.com/pages.php?pid=7">www.flagleremergency.com/pages.php?pid=7</a>
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Average
Recommendations	Add Special Needs information to webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Franklin					
Years	65-85+	% of Pop	Population	Count	Rate
1999	1,736	17.9%	9,710	1	7.5
2000	1,735	17.6%	9,871	2	14.9
2001	1,804	18.1%	9,953	0	0
2002	1,894	18.9%	10,038	3	22.2
2003	1,907	18.7%	10,215	1	7.1
2004	1,900	18.6%	10,210	2	12.7
2005	1,955	18.7%	10,478	3	22.1
2006	2,142	18.8%	11,419	0	0
2007	2,189	18.9%	11,605	0	0
2008	2,217	19.1%	11,611	1	5.9
2009	2,240	19.3%	11,606	6	30.6
2010	2,033	17.6%	11,530	2	16.3
2011	2,063	17.9%	11,527	3	24



1999-2011    18.8%    0.1%    18.7%    **220.0%**

Data Source: www.floridacharts.com

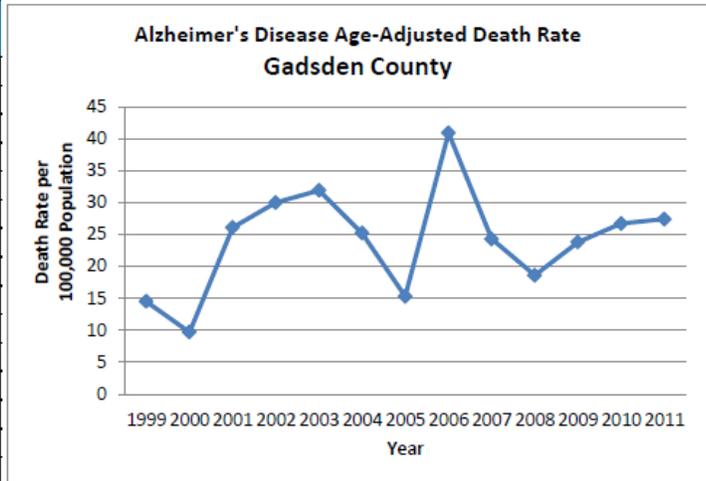
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 18.8%

The rate of alzheimer's disease age-adjusted deaths increased 220.0%

County Website	<a href="http://www.franklincountyflorida.com">www.franklincountyflorida.com</a>
Emergency Management Page	<a href="http://www.franklinemergencymanagement.com">www.franklinemergencymanagement.com</a>
Special Needs Page	<a href="http://www.franklinemergencymanagement.com/Shelter%20needs%20info.aspx">www.franklinemergencymanagement.com/Shelter%20needs%20info.aspx</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Create one main special needs page with links

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Gadsden					
Years	65-85+	% of Pop	Population	Count	Rate
1999	5,469	12.1%	45,312	6	14.5
2000	5,492	12.2%	45,070	4	9.7
2001	5,512	12.2%	45,311	11	26.1
2002	5,559	12.2%	45,425	13	30
2003	5,523	12.2%	45,298	14	31.9
2004	5,353	11.8%	45,322	11	25.2
2005	5,706	12.5%	45,687	7	15.3
2006	5,878	12.8%	45,903	19	40.9
2007	6,067	13.1%	46,338	12	24.3
2008	6,313	13.5%	46,823	10	18.6
2009	6,336	13.7%	46,202	12	23.8
2010	6,485	13.9%	46,788	12	26.7
2011	6,873	14.3%	48,143	13	27.4



1999-2011    25.7%    18.3%    6.2%    **89.0%**

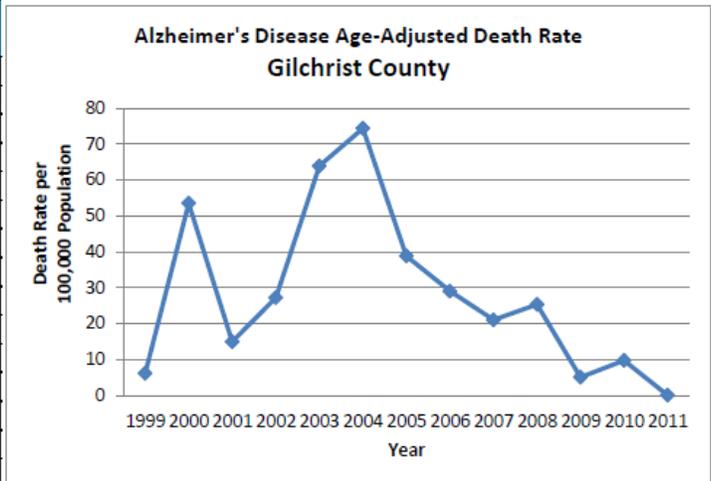
Data Source: [www.floridacharts.com](http://www.floridacharts.com)

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 25.7%  
The rate of alzheimer's disease age-adjusted deaths increased 89.0%

County Website	<a href="http://www.gadsgov.net">www.gadsgov.net</a>
Emergency Management Page	<a href="http://gadsgov.net/emergency_mgmt.html">http://gadsgov.net/emergency_mgmt.html</a>
Special Needs Page	PDF file
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Average
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Gilchrist					
Years	65-85+	% of Pop	Population	Count	Rate
1999	1,943	13.9%	13,980	1	6.1
2000	1,974	13.6%	14,533	7	53.5
2001	1,999	13.7%	14,608	2	14.9
2002	2,094	14.0%	14,921	4	27.2
2003	2,133	13.9%	15,316	9	63.9
2004	2,147	13.7%	15,704	12	74.4
2005	2,373	14.8%	15,998	6	38.8
2006	2,522	15.5%	16,257	5	29
2007	2,621	15.8%	16,601	4	21
2008	2,696	16.1%	16,721	5	25.3
2009	2,793	16.6%	16,842	1	5
2010	2,900	17.1%	16,955	2	9.7
2011	2,958	17.4%	16,971	0	0



1999-2010      49.3%      25.4%      21.3%      59.0%

Data Source: www.floridacharts.com

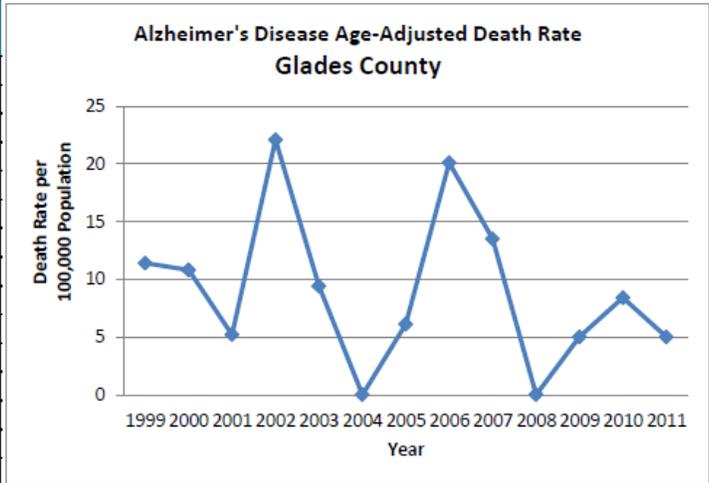
**Summary from 1999 to 2010**

The population of persons age 65-85+ increased 49.3%

The rate of alzheimer's disease age-adjusted deaths increased 59.0%

County Website	<a href="http://gilchrist.fl.us">http://gilchrist.fl.us</a>
Emergency Management Page	<a href="http://gilchrist.fl.us/publicsafety.php">http://gilchrist.fl.us/publicsafety.php</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Add Special Needs information

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Glades					
Years	65-85+	% of Pop	Population	Count	Rate
1999	1,984	19.1%	10,407	1	11.4
2000	1,992	18.8%	10,595	1	10.8
2001	2,060	18.9%	10,926	1	5.2
2002	2,172	19.3%	11,270	3	22.1
2003	2,205	19.2%	11,502	1	9.4
2004	2,177	18.3%	11,908	0	0
2005	2,289	18.7%	12,260	1	6.1
2006	2,269	18.3%	12,389	3	20.1
2007	2,301	18.5%	12,436	2	13.5
2008	2,299	18.1%	12,699	0	0
2009	2,339	18.2%	12,822	1	5
2010	2,821	21.9%	12,866	1	8.4
2011	2,783	21.8%	12,774	1	5



1999-2011      40.3%      14.3%      22.7%      -56.1%

Data Source: www.floridacharts.com

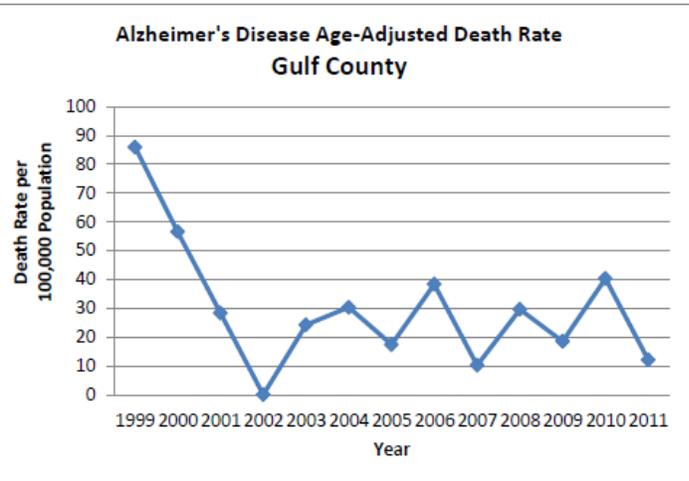
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 40.3%

The rate of alzheimer's disease age-adjusted deaths decreased 56.1%

County Website	<a href="http://www.myglades.com">www.myglades.com</a>
Emergency Management Page	<a href="http://www.myglades.com/BOCC/EM/">www.myglades.com/BOCC/EM/</a>
Special Needs Page	<a href="http://www.myglades.com/BOCC/EM/shelters.php">www.myglades.com/BOCC/EM/shelters.php</a>
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	No; Memory Impaired
Registration Form	Yes
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Gulf					
Years	65-85+	% of Pop	Population	Count	Rate
1999	2,048	15.1%	13,559	11	85.9
2000	2,196	14.9%	14,785	8	56.5
2001	2,187	14.7%	14,905	4	28.3
2002	2,248	15.0%	15,013	0	0
2003	2,279	14.8%	15,368	4	24.2
2004	2,358	15.0%	15,696	5	30.3
2005	2,369	14.9%	15,952	3	17.4
2006	2,479	15.6%	15,930	7	38.3
2007	2,543	15.8%	16,075	2	10.2
2008	2,621	16.4%	15,995	6	29.6
2009	2,674	16.7%	15,989	4	18.5
2010	2,623	16.6%	15,813	7	40.3
2011	2,672	16.9%	15,797	2	12.1



1999-2011    30.5%    12.0%    16.5%    -85.9%

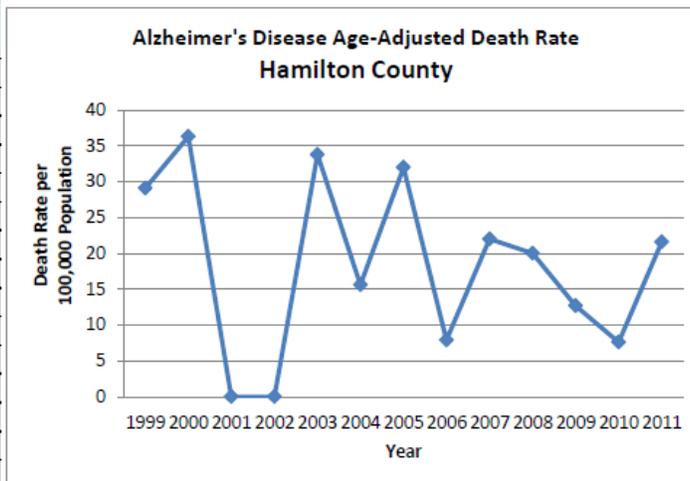
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 30.5%  
The rate of alzheimer's disease age-adjusted deaths decreased 85.9%

County Website	<a href="http://www.gulfcounty-fl.gov">www.gulfcounty-fl.gov</a>
Emergency Management Page	<a href="http://www.gulfcounty-fl.gov/EmergencyManagement.cfm">www.gulfcounty-fl.gov/EmergencyManagement.cfm</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No; contact for information
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Hamilton					
Years	65-85+	% of Pop	Population	Count	Rate
1999	1,450	11.3%	12,831	3	29.1
2000	1,500	11.1%	13,457	4	36.3
2001	1,522	11.1%	13,758	0	0
2002	1,542	11.1%	13,847	0	0
2003	1,581	11.3%	14,052	4	33.8
2004	1,579	11.2%	14,154	2	15.6
2005	1,608	11.3%	14,216	4	32
2006	1,727	11.9%	14,528	1	7.9
2007	1,774	12.1%	14,685	3	22
2008	1,847	12.5%	14,805	3	20
2009	1,897	12.8%	14,850	2	12.7
2010	1,971	13.3%	14,782	1	7.6
2011	2,028	13.8%	14,733	3	21.6



1999-2011    39.9%    21.8%    14.8%    -25.8%

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

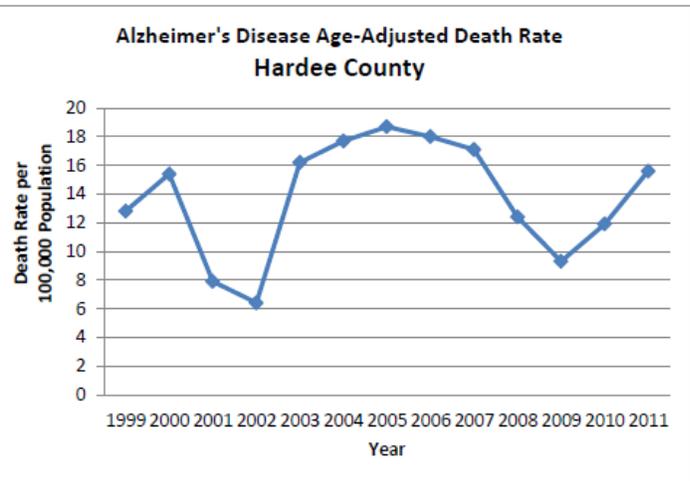
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 39.9%

The rate of alzheimer's disease age-adjusted deaths decreased 25.8%

County Website	<a href="http://www.hamiltoncountyflorida.com">www.hamiltoncountyflorida.com</a>
Emergency Management Page	<a href="http://www.hamcoem.com">www.hamcoem.com</a>
Special Needs Page	PDF file
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	Yes
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Hardee					
Years	65-85+	% of Pop	Population	Count	Rate
1999	3,723	14.0%	26,543	3	12.8
2000	3,748	13.9%	26,952	4	15.4
2001	3,752	14.0%	26,715	2	7.9
2002	3,852	14.2%	27,088	2	6.4
2003	3,828	14.2%	27,050	4	16.2
2004	3,661	13.5%	27,170	5	17.7
2005	3,620	13.4%	26,973	5	18.7
2006	3,629	13.5%	26,979	5	18
2007	3,691	13.4%	27,476	5	17.1
2008	3,738	13.5%	27,645	4	12.4
2009	3,715	13.4%	27,706	3	9.3
2010	3,636	13.2%	27,524	3	11.9
2011	3,669	13.3%	27,621	4	15.6



1999-2011      -1.5%      -5.3%      4.1%      **21.9%**

Data Source: www.floridacharts.com

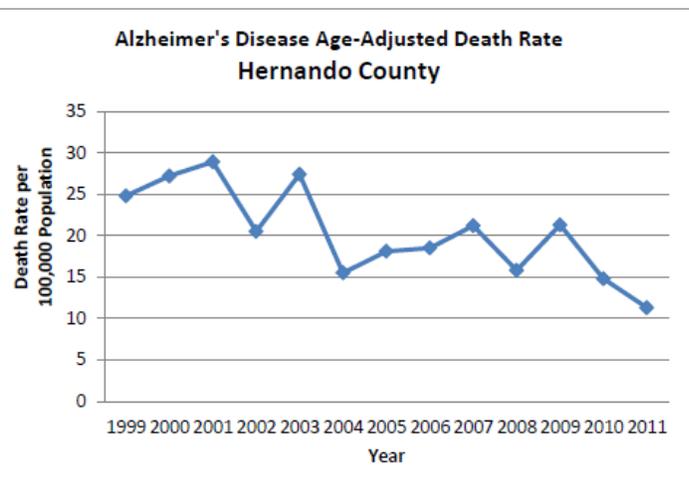
**Summary from 1999 to 2011**

The population of persons age 65-85+ decreased 1.5%

The rate of alzheimer's disease age-adjusted deaths increased 21.9%

County Website	<a href="http://www.hardeecounty.net">www.hardeecounty.net</a>
Emergency Management Page	<a href="http://www.hardeecounty.net/eoc.cfm">www.hardeecounty.net/eoc.cfm</a>
Special Needs Page	<a href="http://www.hardeecounty.net/Site/content/eoc/specialneeds.cfm">www.hardeecounty.net/Site/content/eoc/specialneeds.cfm</a>
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Average
Recommendations	Add Special Needs information to webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Hernando					
Years	65-85+	% of Pop	Population	Count	Rate
1999	39,971	31.0%	128,733	59	24.8
2000	40,392	30.8%	131,298	70	27.2
2001	40,788	30.3%	134,519	79	28.9
2002	42,000	30.3%	138,620	61	20.5
2003	43,306	30.2%	143,587	82	27.4
2004	41,596	27.8%	149,716	53	15.5
2005	44,863	28.6%	156,730	64	18.1
2006	46,848	28.6%	163,791	71	18.5
2007	48,182	28.5%	169,282	85	21.2
2008	49,108	28.6%	171,587	67	15.8
2009	49,334	28.7%	172,075	94	21.3
2010	44,856	26.0%	172,799	52	14.8
2011	44,958	25.9%	173,329	41	11.3



1999-2011    12.5%    -16.5%    34.6%    -54.4%

Data Source: www.floridacharts.com

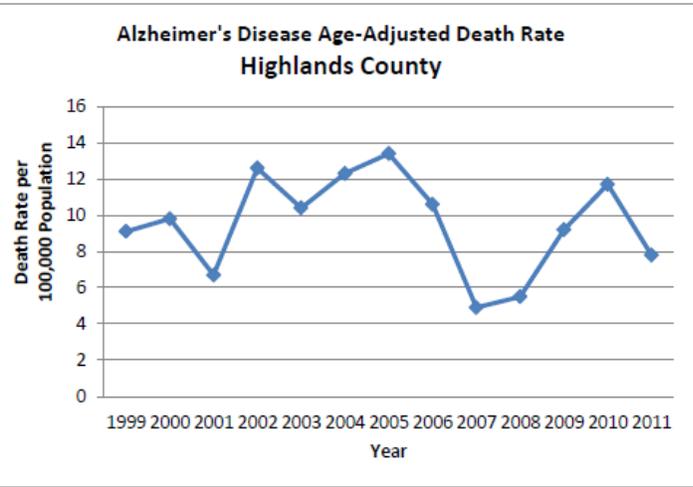
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 12.5%

The rate of alzheimer's disease age-adjusted deaths decreased 54.4%

County Website	<a href="http://www.co.hernando.fl.us">www.co.hernando.fl.us</a>
Emergency Management Page	<a href="http://www.hernandosheriff.org/em/">www.hernandosheriff.org/em/</a>
Special Needs Page	<a href="http://www.hernandosheriff.org/em/event/before/SpecialNeeds.htm">www.hernandosheriff.org/em/event/before/SpecialNeeds.htm</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	Yes
Status	Good
Recommendations	Add Alzheimer's to registration form

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Highlands					
Years	65-85+	% of Pop	Population	Count	Rate
1999	28,570	33.3%	85,892	17	9.1
2000	28,908	33.0%	87,676	21	9.8
2001	29,030	32.8%	88,396	15	6.7
2002	29,818	33.3%	89,582	28	12.6
2003	30,201	33.1%	91,128	23	10.4
2004	28,961	31.2%	92,847	31	12.3
2005	30,576	32.3%	94,789	35	13.4
2006	31,334	32.2%	97,429	29	10.6
2007	31,720	32.0%	99,243	14	4.9
2008	31,903	32.0%	99,663	17	5.5
2009	31,721	32.0%	99,125	28	9.2
2010	32,252	32.7%	98,713	31	11.7
2011	32,112	32.5%	98,782	20	7.8



1999-2011      12.4%      -2.3%      15.0%      -14.3%

Data Source: www.floridacharts.com

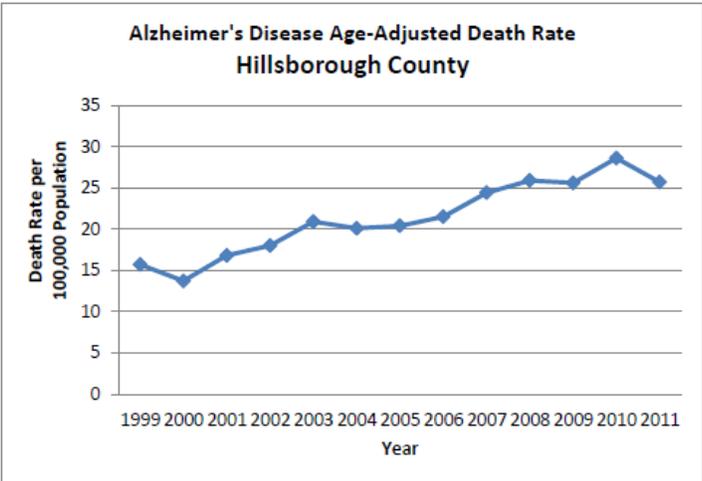
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 12.4%

The rate of alzheimer's disease age-adjusted deaths decreased 14.3%

County Website	<a href="http://www.hbcc.net">www.hbcc.net</a>
Emergency Management Page	<a href="http://www.hbcc.net/departments/emergency_operations/emergency_management.php">www.hbcc.net/departments/emergency_operations/emergency_management.php</a>
Special Needs Page	PDF file
Number of Clicks	2
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Provide Special Needs information

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Hillsborough					
Years	65-85+	% of Pop	Population	Count	Rate
1999	117,864	12.1%	978,079	138	15.7
2000	120,389	12.0%	1,005,808	125	13.7
2001	123,450	12.0%	1,032,781	158	16.8
2002	129,249	12.2%	1,060,100	183	18
2003	131,376	12.1%	1,086,425	213	20.9
2004	128,685	11.5%	1,115,817	214	20.1
2005	132,950	11.6%	1,146,900	226	20.4
2006	138,827	11.8%	1,177,896	251	21.5
2007	142,599	11.9%	1,198,257	295	24.4
2008	146,224	12.1%	1,208,197	325	25.9
2009	149,170	12.2%	1,218,521	339	25.6
2010	149,987	12.2%	1,231,553	339	28.6
2011	153,613	12.4%	1,241,496	309	25.7



1999-2011      30.3%      2.7%      26.9%      **63.7%**

Data Source: www.floridacharts.com

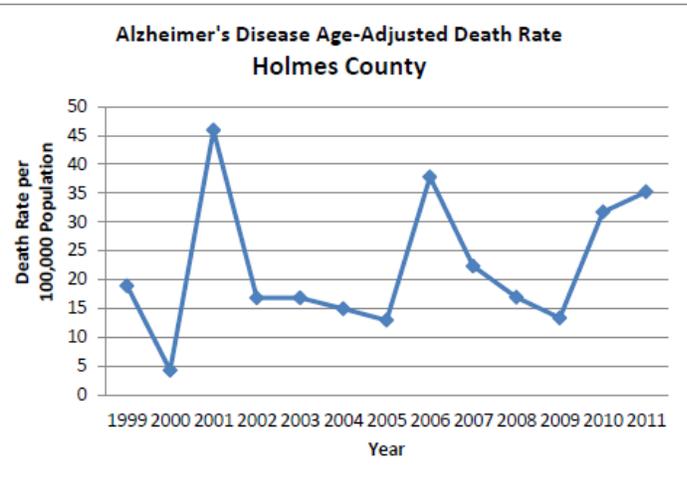
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 30.3%

The rate of alzheimer's disease age-adjusted deaths increased 63.7%

County Website	<a href="http://www.hillsboroughcounty.org">www.hillsboroughcounty.org</a>
Emergency Management Page	<a href="http://www.hillsboroughcounty.org/index.aspx?NID=115">www.hillsboroughcounty.org/index.aspx?NID=115</a>
Special Needs Page	<a href="http://www.hillsboroughcounty.org/index.aspx?nid=664">www.hillsboroughcounty.org/index.aspx?nid=664</a>
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Add link for Special Needs to main Emergency Management Page

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Holmes					
Years	65-85+	% of Pop	Population	Count	Rate
1999	2,715	14.8%	18,371	4	18.9
2000	2,763	14.8%	18,620	1	4.2
2001	2,792	14.9%	18,724	10	45.9
2002	2,898	15.3%	18,913	4	16.8
2003	2,930	15.3%	19,186	4	16.8
2004	2,916	15.1%	19,302	4	14.9
2005	3,004	15.4%	19,463	3	12.9
2006	3,142	16.0%	19,654	10	37.8
2007	3,247	16.3%	19,936	6	22.3
2008	3,322	16.5%	20,096	5	16.9
2009	3,402	16.9%	20,088	4	13.3
2010	3,465	17.4%	19,894	8	31.7
2011	3,511	17.7%	19,878	8	35.2



1999-2011    29.3%    19.5%    8.2%    **86.2%**

Data Source: www.floridacharts.com

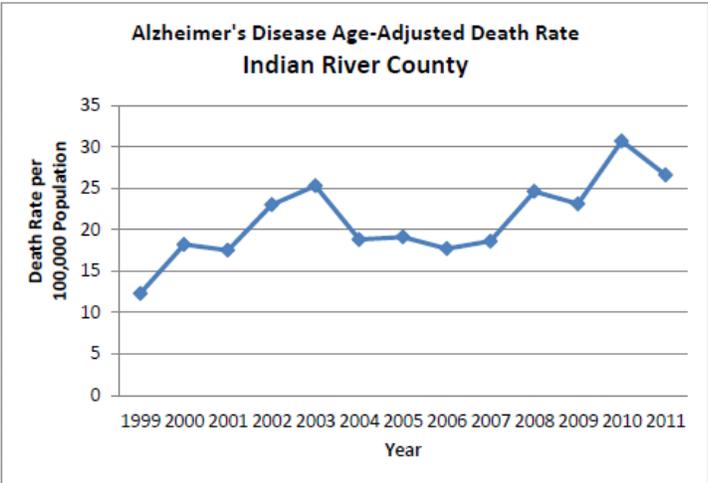
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 29.3%

The rate of alzheimer's disease age-adjusted deaths increased 86.2%

County Website	<a href="http://www.holmescountyfl.org">www.holmescountyfl.org</a>
Emergency Management Page	<a href="http://www.holmescountyfl.org/EmergencyManagement.htm">www.holmescountyfl.org/EmergencyManagement.htm</a>
Special Needs Page	PDF file
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	No; Memory
Registration Form	Yes
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Indian River					
Years	65-85+	% of Pop	Population	Count	Rate
1999	32,331	29.4%	110,142	30	12.3
2000	33,119	29.1%	113,755	45	18.2
2001	33,139	28.6%	115,711	44	17.5
2002	33,802	28.6%	117,993	60	23
2003	34,523	28.5%	121,034	69	25.3
2004	34,200	27.4%	124,974	59	18.8
2005	34,769	27.1%	128,369	60	19.1
2006	35,987	27.1%	132,752	60	17.7
2007	36,784	27.0%	136,184	64	18.6
2008	37,240	27.1%	137,553	92	24.6
2009	37,312	27.1%	137,617	89	23.1
2010	37,863	27.4%	138,110	106	30.7
2011	38,164	27.5%	138,925	93	26.6



1999-2011    18.0%    -6.4%    26.1%    **116.3%**

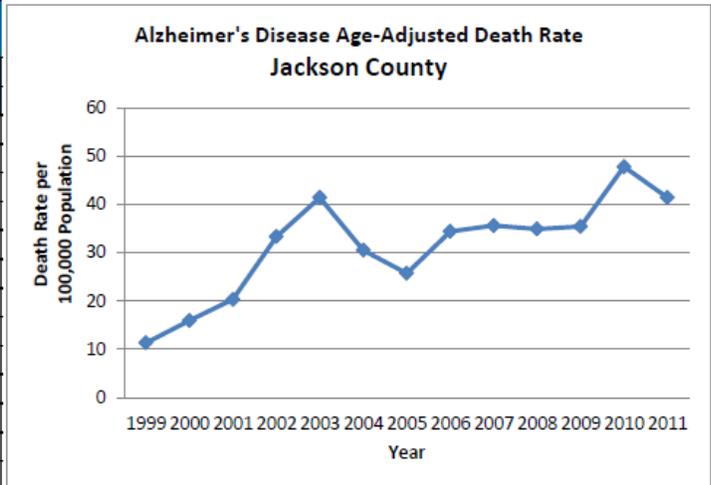
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 18.0%  
The rate of alzheimer's disease age-adjusted deaths increased 116.3%

County Website	<a href="http://www.irgov.com">www.irgov.com</a>
Emergency Management Page	<a href="http://www.irces.com/EM/index.htm">www.irces.com/EM/index.htm</a>
Special Needs Page	<a href="http://www.irces.com/EM/Special_Needs.htm">www.irces.com/EM/Special_Needs.htm</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No; Memory Impairment
Registration Form	Yes
Status	Good
Recommendations	Make contact information more prevalent on page

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Jackson					
Years	65-85+	% of Pop	Population	Count	Rate
1999	6,725	14.6%	46,050	6	11.3
2000	6,819	14.5%	46,998	9	15.9
2001	6,643	14.3%	46,436	11	20.3
2002	6,641	14.3%	46,497	19	33.3
2003	6,693	14.2%	47,015	23	41.4
2004	6,798	14.3%	47,627	17	30.5
2005	7,114	14.7%	48,239	16	25.7
2006	7,345	15.2%	48,439	23	34.4
2007	7,587	15.5%	48,860	24	35.6
2008	7,931	15.7%	50,395	24	34.9
2009	8,029	16.1%	49,992	26	35.4
2010	7,879	15.8%	49,759	29	47.8
2011	8,076	16.2%	49,942	25	41.4



1999-2011      20.1%      10.7%      8.5%      **266.4%**

Data Source: www.floridacharts.com

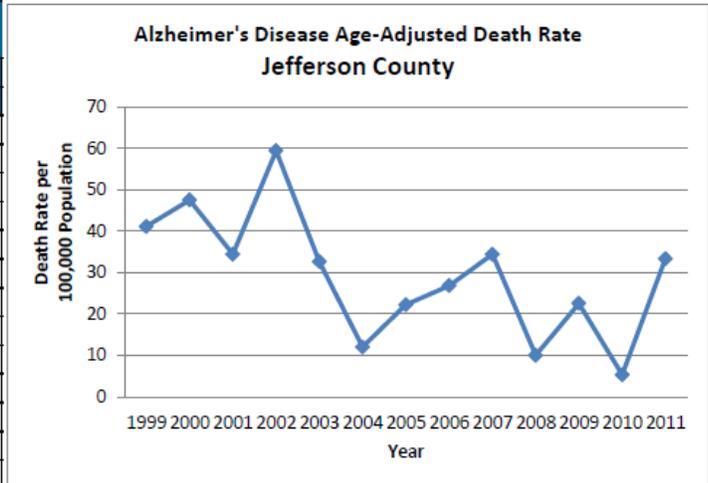
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 20.1%

The rate of alzheimer's disease age-adjusted deaths increased 266.4%

County Website	<a href="http://www.jacksoncountyfl.net">www.jacksoncountyfl.net</a>
Emergency Management Page	<a href="http://www.jacksoncountyfl.net/emergency-management">www.jacksoncountyfl.net/emergency-management</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Jefferson					
Years	65-85+	% of Pop	Population	Count	Rate
1999	1,879	14.1%	13,307	6	41.1
2000	1,862	14.5%	12,874	7	47.5
2001	1,877	14.4%	13,075	5	34.4
2002	1,926	14.5%	13,307	9	59.4
2003	1,972	14.4%	13,697	5	32.6
2004	1,983	14.1%	14,084	2	12
2005	2,055	14.5%	14,205	4	22.2
2006	2,158	14.9%	14,459	5	26.8
2007	2,201	15.1%	14,576	7	34.4
2008	2,276	15.5%	14,684	2	10
2009	2,339	15.8%	14,784	5	22.5
2010	2,473	16.8%	14,724	1	5.3
2011	2,524	17.3%	14,612	6	33.3



1999-2011      34.3%      22.3%      9.8%      -19.0%

Data Source: www.floridacharts.com

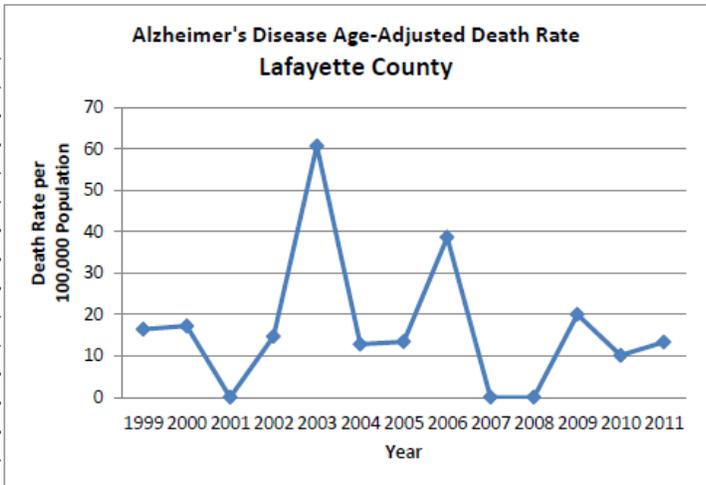
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 34.3%

The rate of alzheimer's disease age-adjusted deaths decreased 19.0%

County Website	<a href="http://www.jeffersoncountyfl.gov">www.jeffersoncountyfl.gov</a>
Emergency Management Page	<a href="http://www.jeffersoncountyfl.gov/p/county-departments/emergency-management">www.jeffersoncountyfl.gov/p/county-departments/emergency-management</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Lafayette					
Years	65-85+	% of Pop	Population	Count	Rate
1999	854	12.7%	6,703	1	16.4
2000	871	12.3%	7,061	1	17.2
2001	895	12.5%	7,162	0	0
2002	925	12.7%	7,276	1	14.7
2003	929	12.5%	7,404	4	60.7
2004	971	12.7%	7,665	1	12.8
2005	1,020	12.7%	8,059	1	13.4
2006	1,043	12.8%	8,127	3	38.6
2007	1,095	13.1%	8,388	0	0
2008	1,111	13.1%	8,478	0	0
2009	1,130	13.3%	8,510	2	20
2010	1,115	12.6%	8,864	1	10.1
2011	1,084	12.4%	8,715	1	13.3



1999-2011      26.9%      -2.4%      30.0%      -18.9%

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

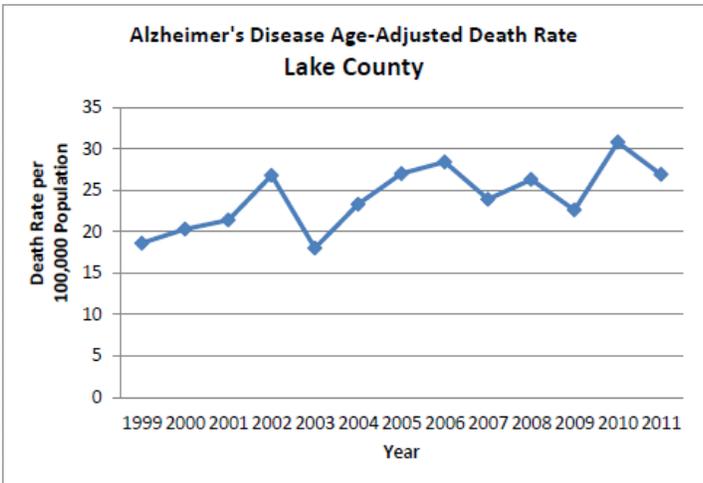
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 26.9%

The rate of alzheimer's disease age-adjusted deaths decreased 18.9%

County Website	<a href="http://www.lafayettecountyflorida.org">www.lafayettecountyflorida.org</a>
Emergency Management Page	<a href="http://www.lafayettecountyflorida.org/index.cfm/referer/content.contentList/ID/565/">www.lafayettecountyflorida.org/index.cfm/referer/content.contentList/ID/565/</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Lake					
Years	65-85+	% of Pop	Population	Count	Rate
1999	54,575	26.7%	204,152	72	18.6
2000	56,169	26.4%	212,823	79	20.3
2001	58,928	26.4%	223,005	92	21.4
2002	62,126	26.7%	232,394	120	26.8
2003	64,517	26.6%	242,714	85	18
2004	60,558	23.8%	254,476	113	23.3
2005	66,636	24.9%	267,334	136	27
2006	69,892	24.9%	280,941	154	28.4
2007	71,790	24.8%	289,885	135	23.9
2008	72,798	24.9%	292,703	156	26.3
2009	73,588	24.9%	295,165	139	22.6
2010	72,597	24.4%	297,367	169	30.8
2011	72,689	24.3%	298,887	150	26.9



1999-2011      33.2%      -9.0%      46.4%      **44.6%**

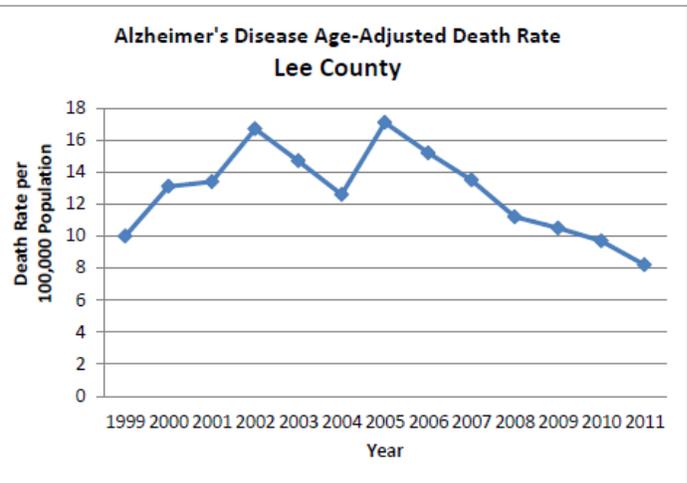
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 33.2%  
The rate of alzheimer's disease age-adjusted deaths increased 44.6%

County Website	<a href="http://www.lakecountyfl.gov">www.lakecountyfl.gov</a>
Emergency Management Page	<a href="http://www.lakecountyfl.gov/departments/public_safety/emergency_management/">www.lakecountyfl.gov/departments/public_safety/emergency_management/</a>
Special Needs Page	<a href="http://www.lakecountyfl.gov/departments/public_safety/emergency_management/special_needs_program.aspx">www.lakecountyfl.gov/departments/public_safety/emergency_management/special_needs_program.aspx</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No; Memory Impairment
Registration Form	Yes
Status	Good
Recommendations	Move Special Needs Program under Preparedness on Emergency Management Page

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Lee					
Years	65-85+	% of Pop	Population	Count	Rate
1999	110,679	25.7%	430,644	76	10
2000	112,609	25.4%	444,151	104	13.1
2001	115,390	25.0%	461,222	109	13.4
2002	120,248	25.1%	478,837	145	16.7
2003	124,395	25.0%	498,353	130	14.7
2004	123,504	23.6%	523,477	124	12.6
2005	129,509	23.4%	553,337	175	17.1
2006	135,412	23.3%	580,801	167	15.2
2007	138,822	23.1%	601,056	153	13.5
2008	141,785	23.3%	609,454	137	11.2
2009	143,914	23.5%	613,549	132	10.5
2010	147,024	23.7%	620,039	105	9.7
2011	149,341	23.8%	627,454	90	8.2



1999-2011      34.9%      -7.4%      45.7%      -18.0%

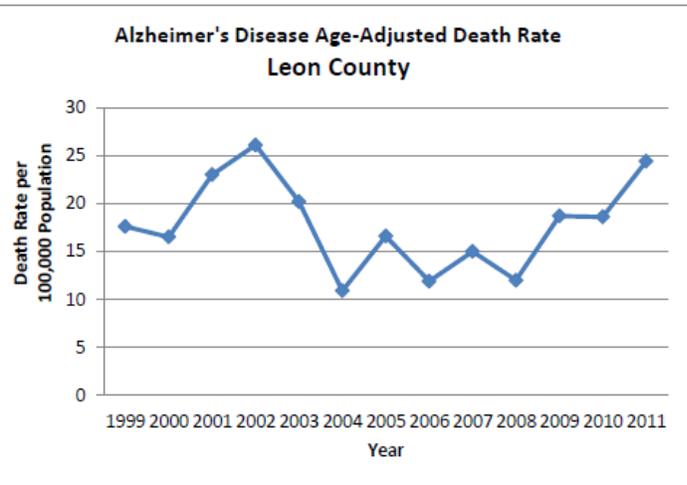
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 34.9%  
The rate of alzheimer's disease age-adjusted deaths decreased 18.0%

County Website	<a href="http://www.leegov.com">www.leegov.com</a>
Emergency Management Page	<a href="http://www.leeecoc.com/Pages/default.aspx">www.leeecoc.com/Pages/default.aspx</a>
Special Needs Page	<a href="http://www.leeecoc.com/shelterevacuation/Pages/SpecialNeeds.aspx">www.leeecoc.com/shelterevacuation/Pages/SpecialNeeds.aspx</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Make contact information and form location more prevalent

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Leon					
Years	65-85+	% of Pop	Population	Count	Rate
1999	19,766	8.4%	236,658	27	17.6
2000	19,931	8.3%	240,631	26	16.5
2001	19,926	8.2%	243,776	36	23
2002	20,348	8.2%	247,804	42	26.1
2003	20,748	8.2%	254,126	33	20.2
2004	21,665	8.3%	259,944	21	10.9
2005	21,859	8.2%	264,979	31	16.6
2006	22,681	8.5%	268,284	23	11.9
2007	23,283	8.6%	271,291	30	15
2008	24,277	8.9%	273,544	26	12
2009	24,842	9.0%	274,526	40	18.7
2010	26,334	9.6%	275,734	39	18.6
2011	27,608	10.0%	276,461	52	24.4



1999-2011      39.7%      19.6%      16.8%      **38.6%**

Data Source: www.floridacharts.com

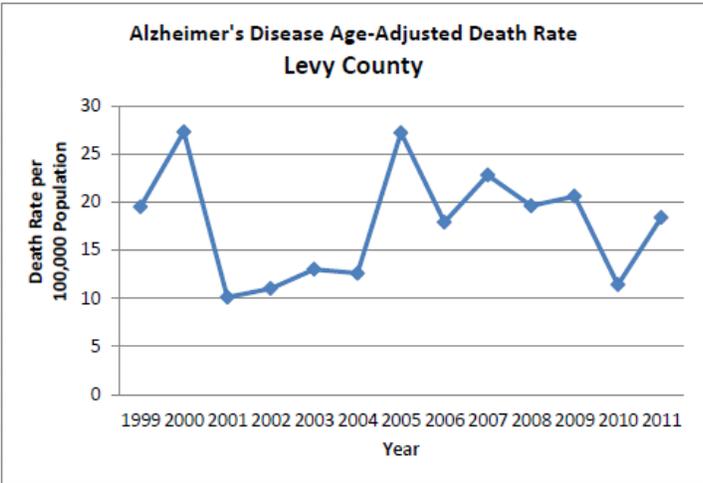
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 39.7%

The rate of alzheimer's disease age-adjusted deaths increased 38.6%

County Website	<a href="http://cms.leoncountyfl.gov">http://cms.leoncountyfl.gov</a>
Emergency Management Page	<a href="http://www.leoncountyso.com/emergency-management">www.leoncountyso.com/emergency-management</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Levy					
Years	65-85+	% of Pop	Population	Count	Rate
1999	6,091	18.0%	33,759	7	19.5
2000	6,230	18.0%	34,626	11	27.3
2001	6,542	18.5%	35,310	4	10.1
2002	6,888	19.1%	36,116	5	11
2003	6,985	19.0%	36,691	7	13
2004	6,522	17.4%	37,433	6	12.6
2005	7,144	18.7%	38,202	14	27.2
2006	7,410	18.9%	39,128	10	17.9
2007	7,659	19.1%	40,069	13	22.8
2008	7,856	19.4%	40,575	12	19.6
2009	7,992	19.6%	40,717	13	20.6
2010	7,993	19.6%	40,789	6	11.4
2011	8,090	19.8%	40,768	9	18.4



1999-2011      32.8%      10.0%      20.8%      -5.6%

Data Source: www.floridacharts.com

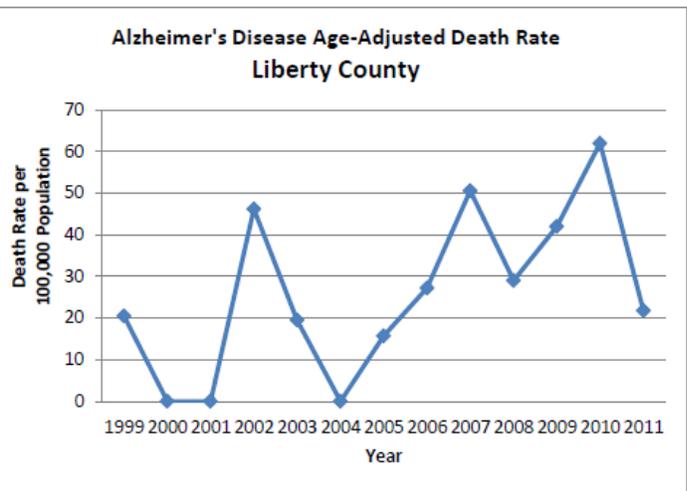
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 32.8%

The rate of alzheimer's disease age-adjusted deaths decreased 5.6%

County Website	<a href="http://www.levycounty.org">www.levycounty.org</a>
Emergency Management Page	<a href="http://www.levycounty.org/cd_emergencymanagement.aspx">www.levycounty.org/cd_emergencymanagement.aspx</a>
Special Needs Page	<a href="http://levydisaster.com/specialhelp.aspx">http://levydisaster.com/specialhelp.aspx</a>
Number of Clicks	3
Special Needs Info	No
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Average
Recommendations	Link to levymisaster.com on Emergency Management Page; Streamline navigation to site

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Liberty					
Years	65-85+	% of Pop	Population	Count	Rate
1999	688	9.9%	6,967	1	20.5
2000	720	10.2%	7,045	0	0
2001	741	10.4%	7,095	0	0
2002	729	10.1%	7,223	2	46.2
2003	741	10.2%	7,300	1	19.5
2004	792	10.5%	7,535	0	0
2005	822	10.5%	7,818	1	15.7
2006	866	10.8%	7,982	2	27.2
2007	907	11.2%	8,087	3	50.6
2008	937	11.3%	8,295	2	29
2009	956	11.5%	8,343	3	42
2010	916	11.0%	8,326	3	62
2011	923	11.0%	8,356	1	21.8



1999-2011      34.2%      11.9%      19.9%      6.3%

Data Source: www.floridacharts.com

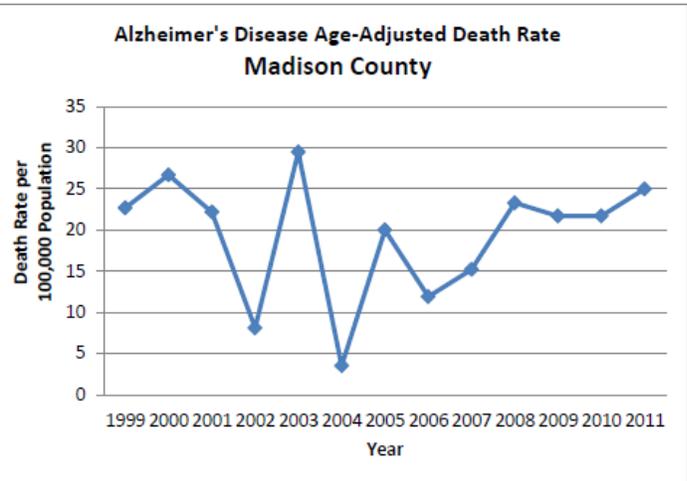
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 34.2%

The rate of alzheimer's disease age-adjusted deaths increased 6.3%

County Website	<a href="http://libertybocc.com">http://libertybocc.com</a>
Emergency Management Page	<a href="http://libertycountym.com">http://libertycountym.com</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Emergency Management site under construction; Creat Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Madison					
Years	65-85+	% of Pop	Population	Count	Rate
1999	2,715	14.6%	18,596	5	22.7
2000	2,729	14.5%	18,775	6	26.7
2001	2,747	14.6%	18,800	5	22.2
2002	2,723	14.5%	18,752	2	8.1
2003	2,750	14.5%	18,925	7	29.5
2004	2,903	15.2%	19,103	1	3.5
2005	2,794	14.7%	19,065	5	20
2006	2,877	15.0%	19,156	3	11.9
2007	2,904	15.1%	19,231	4	15.2
2008	3,001	15.5%	19,340	6	23.3
2009	3,043	15.7%	19,371	6	21.7
2010	3,095	16.1%	19,206	5	21.7
2011	3,187	16.5%	19,320	6	25



1999-2011    17.4%    13.0%    3.9%    10.1%

Data Source: www.floridacharts.com

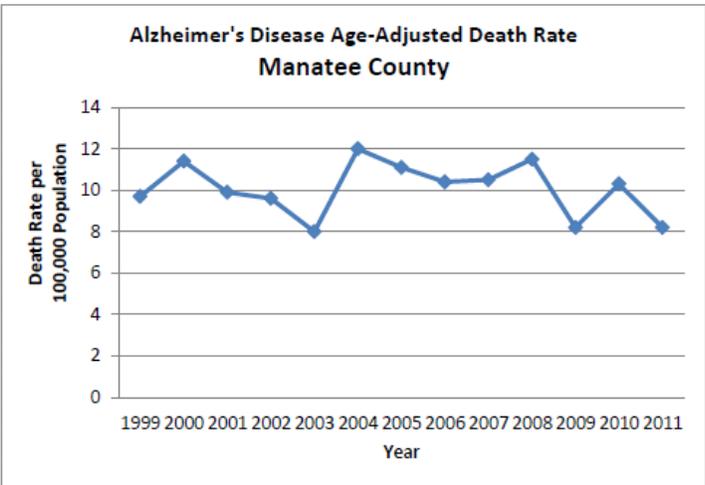
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 17.4%

The rate of alzheimer's disease age-adjusted deaths increased 10.1%

County Website	<a href="http://www.madisoncountyfl.com">www.madisoncountyfl.com</a>
Emergency Management Page	<a href="http://www.madisoncountyfl.com/emergencymanagement/">www.madisoncountyfl.com/emergencymanagement/</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Manatee					
Years	65-85+	% of Pop	Population	Count	Rate
1999	65,660	25.3%	259,039	49	9.7
2000	65,844	24.8%	265,701	59	11.4
2001	66,898	24.5%	272,645	53	9.9
2002	69,204	24.7%	279,854	54	9.6
2003	70,676	24.6%	287,609	46	8
2004	66,763	22.5%	296,380	69	12
2005	70,741	23.1%	306,107	72	11.1
2006	71,964	22.9%	314,096	68	10.4
2007	72,363	22.7%	318,669	72	10.5
2008	72,759	22.7%	320,265	79	11.5
2009	72,802	22.7%	321,367	57	8.2
2010	76,131	23.5%	323,440	64	10.3
2011	77,420	23.7%	326,774	53	8.2



1999-2011      17.9%      -6.5%      26.1%      -15.5%

Data Source: www.floridacharts.com

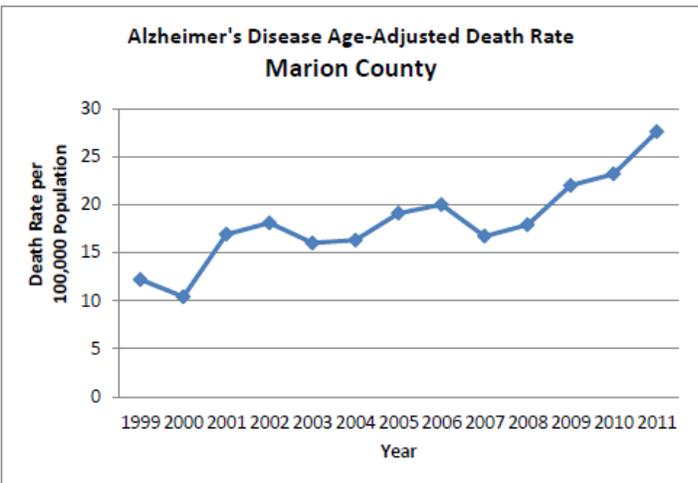
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 17.9%

The rate of alzheimer's disease age-adjusted deaths decreased 15.5%

County Website	<a href="http://www.mymanatee.org">www.mymanatee.org</a>
Emergency Management Page	<a href="http://www.mymanatee.org/home/government/departments/public-safety/emergency-management.html">www.mymanatee.org/home/government/departments/public-safety/emergency-management.html</a>
Special Needs Page	<a href="http://www.mymanatee.org/home/government/departments/public-safety/emergency-management/special-needs.html">www.mymanatee.org/home/government/departments/public-safety/emergency-management/special-needs.html</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Add video transcript

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Marion					
Years	65-85+	% of Pop	Population	Count	Rate
1999	62,336	24.6%	253,235	49	12.2
2000	63,849	24.5%	260,407	44	10.4
2001	64,957	24.5%	265,067	73	16.9
2002	67,516	24.8%	271,979	85	18.1
2003	69,373	24.7%	280,650	76	16
2004	68,487	23.5%	291,288	85	16.3
2005	72,188	23.8%	303,403	109	19.1
2006	75,078	23.8%	315,364	121	20
2007	76,972	23.7%	324,470	106	16.7
2008	78,572	23.9%	329,165	121	17.9
2009	79,127	23.9%	330,790	155	22
2010	86,301	26.0%	331,314	148	23.2
2011	87,011	26.2%	332,256	177	27.6



1999-2011    39.6%    6.4%    31.2%    **126.2%**

Data Source: www.floridacharts.com

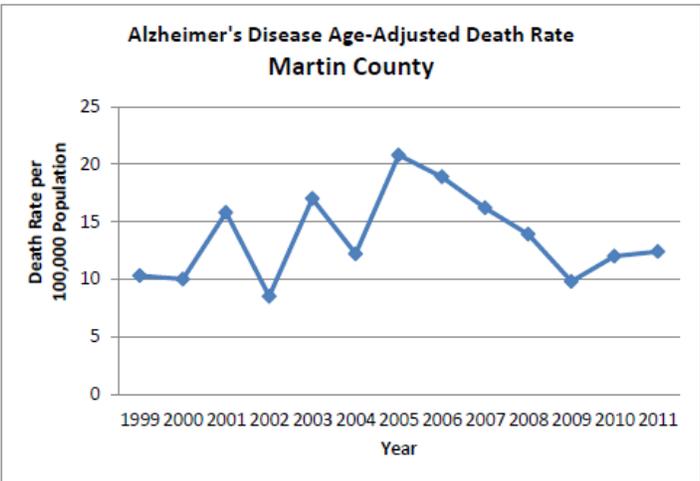
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 39.6%

The rate of alzheimer's disease age-adjusted deaths increased 126.2%

County Website	<a href="http://www.marioncountyfl.org">www.marioncountyfl.org</a>
Emergency Management Page	<a href="http://www.marionso.com/em-new-faq.php">www.marionso.com/em-new-faq.php</a>
Special Needs Page	<a href="http://www.marionso.com/em-new-special.php">www.marionso.com/em-new-special.php</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Make registration form more prevalent

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Martin					
Years	65-85+	% of Pop	Population	Count	Rate
1999	35,390	28.3%	124,952	27	10.3
2000	35,869	28.1%	127,430	27	10
2001	36,026	27.8%	129,820	44	15.8
2002	36,896	27.8%	132,585	25	8.5
2003	37,644	27.7%	135,873	50	17
2004	36,764	26.5%	138,883	41	12.2
2005	38,382	27.2%	141,081	71	20.8
2006	38,987	27.3%	142,779	65	18.9
2007	39,464	27.3%	144,320	58	16.2
2008	40,011	27.6%	145,101	53	13.9
2009	40,431	27.7%	145,843	40	9.8
2010	40,333	27.5%	146,434	42	12
2011	40,665	27.7%	146,840	47	12.4



1999-2011      14.9%      -2.2%      17.5%      20.4%

Data Source: www.floridacharts.com

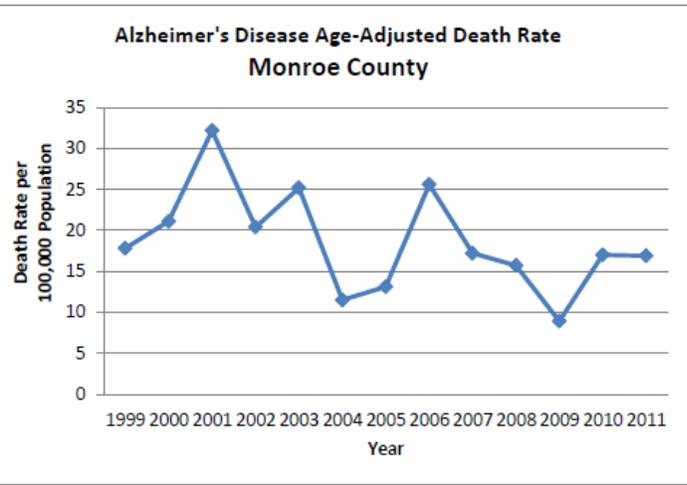
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 14.9%

The rate of alzheimer's disease age-adjusted deaths increased 20.4%

County Website	<a href="http://www.martin.fl.us">www.martin.fl.us</a>
Emergency Management Page	<a href="http://www.martin.fl.us/portal/page?_pageid=350,522034&amp;_dad=portal&amp;_schema=PORTAL">www.martin.fl.us/portal/page?_pageid=350,522034&amp;_dad=portal&amp;_schema=PORTAL</a>
Special Needs Page	PDF file
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	Yes
Status	Average
Recommendations	Create Special Needs webpage; add Alzheimer's to registration form

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Monroe					
Years	65-85+	% of Pop	Population	Count	Rate
1999	11,749	14.7%	79,875	13	17.8
2000	11,641	14.6%	79,721	16	21.1
2001	11,456	14.4%	79,528	24	32.2
2002	11,490	14.5%	79,465	16	20.4
2003	11,405	14.4%	79,156	18	25.2
2004	11,383	14.5%	78,363	10	11.5
2005	11,908	15.4%	77,232	11	13.1
2006	12,245	16.2%	75,770	23	25.6
2007	12,463	16.6%	74,857	16	17.2
2008	12,736	17.2%	73,976	15	15.7
2009	13,131	17.8%	73,634	9	8.9
2010	12,635	17.3%	72,946	14	17
2011	13,043	18.0%	72,605	14	16.9



1999-2011      11.0%      22.1%      -9.1%      -5.1%

Data Source: www.floridacharts.com

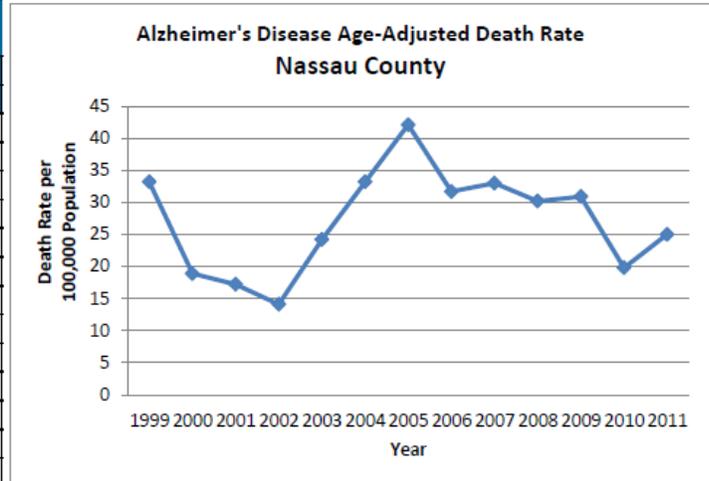
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 11.0%

The rate of alzheimer's disease age-adjusted deaths decreased 5.1%

County Website	<a href="http://www.monroecounty-fl.gov">www.monroecounty-fl.gov</a>
Emergency Management Page	<a href="http://www.monroecountyem.com">www.monroecountyem.com</a>
Special Needs Page	<a href="http://www.monroecounty-fl.gov/index.aspx?nid=148">www.monroecounty-fl.gov/index.aspx?nid=148</a>
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Update registration form to 2013

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Nassau					
Years	65-85+	% of Pop	Population	Count	Rate
1999	7,018	12.5%	56,022	12	33.2
2000	7,328	12.6%	58,037	7	18.9
2001	7,555	12.7%	59,340	9	17.2
2002	7,864	12.9%	60,788	7	14.1
2003	8,034	12.9%	62,146	11	24.2
2004	8,553	13.4%	63,726	18	33.2
2005	9,159	14.0%	65,597	24	42.1
2006	9,847	14.5%	67,747	21	31.7
2007	10,446	15.0%	69,820	22	33
2008	11,098	15.5%	71,438	22	30.2
2009	11,618	16.0%	72,633	24	30.9
2010	12,064	16.4%	73,455	14	19.8
2011	12,477	16.9%	73,838	19	25



1999-2011      77.8%      34.9%      31.8%      -24.7%

Data Source: www.floridacharts.com

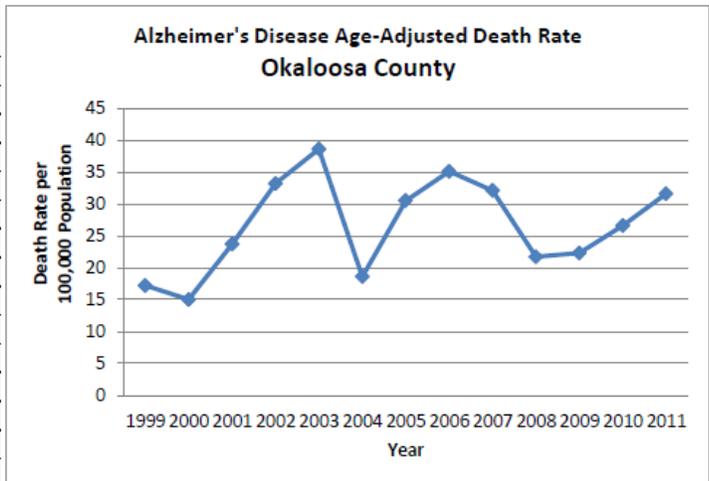
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 77.8%

The rate of alzheimer's disease age-adjusted deaths decreased 24.7%

County Website	<a href="http://www.nassaucountyfl.com">www.nassaucountyfl.com</a>
Emergency Management Page	<a href="http://www.nassaucountyfl.com/index.aspx?nid=370">www.nassaucountyfl.com/index.aspx?nid=370</a>
Special Needs Page	<a href="http://www.nassaucountyfl.com/index.aspx?NID=84">www.nassaucountyfl.com/index.aspx?NID=84</a>
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	No; Memory Impaired
Registration Form	Yes
Status	Average
Recommendations	Add Special Needs information to webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Okaloosa					
Years	65-85+	% of Pop	Population	Count	Rate
1999	20,068	12.0%	167,880	20	17.2
2000	20,768	12.1%	171,264	18	15
2001	20,737	12.0%	173,004	30	23.7
2002	21,418	12.2%	175,723	46	33.2
2003	21,625	12.1%	178,196	51	38.6
2004	22,969	12.6%	181,762	29	18.6
2005	22,988	12.5%	183,439	47	30.5
2006	23,641	12.9%	183,454	58	35.1
2007	24,032	13.2%	182,512	55	32.1
2008	24,513	13.5%	181,736	39	21.7
2009	24,947	13.8%	181,101	42	22.3
2010	25,538	14.1%	180,881	48	26.6
2011	26,177	14.4%	181,902	58	31.6



1999-2011    30.4%    20.4%    8.4%    **83.7%**

Data Source: www.floridacharts.com

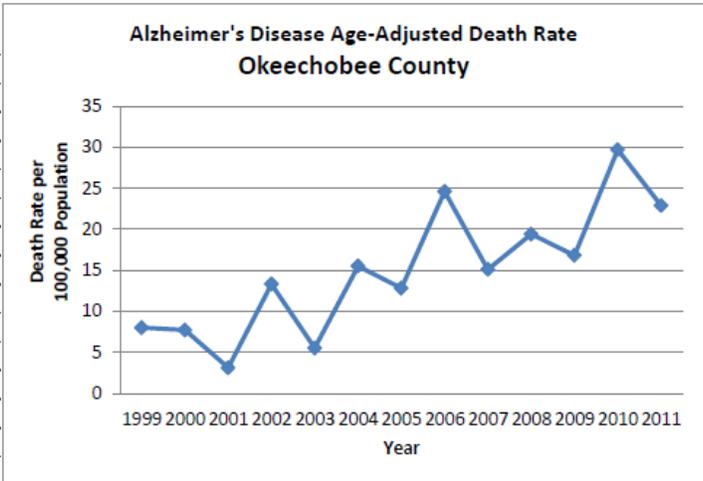
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 30.4%

The rate of alzheimer's disease age-adjusted deaths increased 83.7%

County Website	<a href="http://www.co.okaloosa.fl.us">www.co.okaloosa.fl.us</a>
Emergency Management Page	<a href="http://www.co.okaloosa.fl.us/dept_ps_em_mgmt.html">www.co.okaloosa.fl.us/dept_ps_em_mgmt.html</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Okeechobee					
Years	65-85+	% of Pop	Population	Count	Rate
1999	5,782	16.3%	35,452	3	8
2000	5,885	16.3%	35,998	3	7.7
2001	5,993	16.5%	36,346	1	3.1
2002	6,324	17.2%	36,853	6	13.3
2003	6,381	17.0%	37,576	2	5.5
2004	6,171	16.1%	38,399	7	15.5
2005	6,495	16.8%	38,722	6	12.8
2006	6,613	16.8%	39,263	12	24.6
2007	6,747	17.0%	39,799	8	15.1
2008	6,803	17.0%	40,025	11	19.4
2009	6,857	17.2%	39,975	10	16.8
2010	6,872	17.2%	39,976	14	29.7
2011	6,860	17.2%	39,900	11	22.9



1999-2011      18.6%      5.4%      12.5%      **186.3%**

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

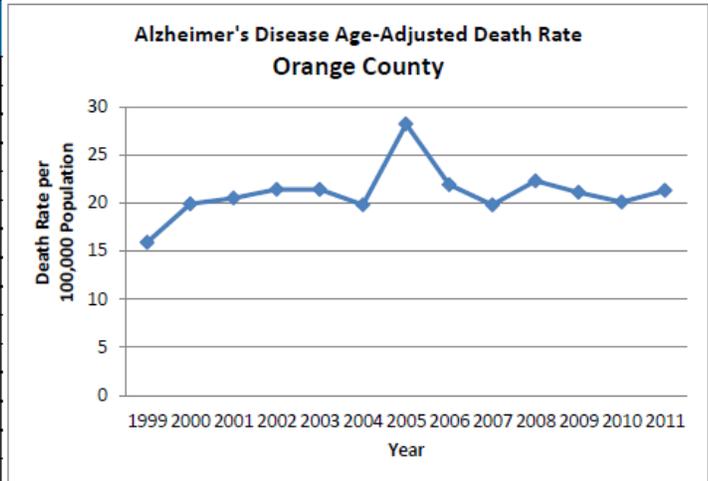
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 18.6%

The rate of alzheimer's disease age-adjusted deaths increased 186.3%

County Website	<a href="http://www.co.okeechobee.fl.us">www.co.okeechobee.fl.us</a>
Emergency Management Page	<a href="http://www.okeechobeeec.com">www.okeechobeeec.com</a>
Special Needs Page	<a href="http://www.okeechobeeec.com/shelterlist.htm">www.okeechobeeec.com/shelterlist.htm</a>
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs Page either within Emergency Management or Health Department

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Orange					
Years	65-85+	% of Pop	Population	Count	Rate
1999	87,476	10.1%	864,197	102	15.9
2000	90,705	10.0%	906,000	133	19.9
2001	93,001	9.9%	936,211	138	20.5
2002	97,061	10.1%	962,498	155	21.4
2003	98,873	10.0%	989,936	157	21.4
2004	97,746	9.6%	1,023,041	155	19.8
2005	96,203	9.1%	1,059,339	209	28.2
2006	100,532	9.2%	1,092,316	169	21.9
2007	103,254	9.3%	1,116,069	159	19.8
2008	105,709	9.4%	1,127,909	188	22.3
2009	107,437	9.5%	1,136,172	182	21.1
2010	115,075	10.0%	1,148,556	176	20.1
2011	118,416	10.2%	1,160,468	192	21.3



1999-2011    35.4%    0.8%    34.3%    **34.0%**

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

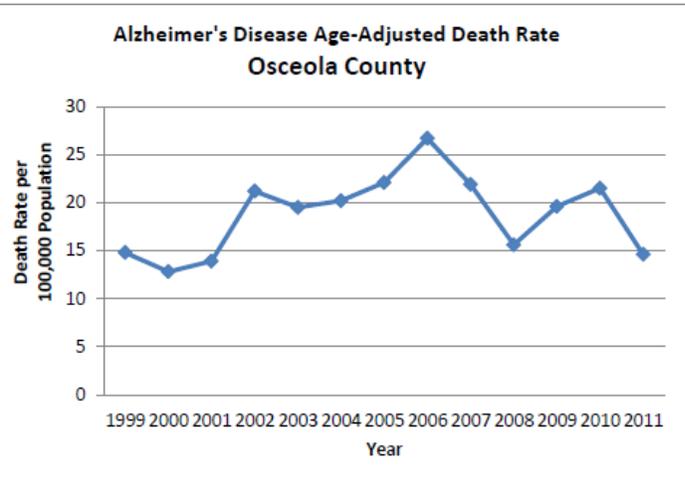
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 35.4%

The rate of alzheimer's disease age-adjusted deaths increased 34.0%

County Website	<a href="http://www.ocfl.net">www.ocfl.net</a>
Emergency Management Page	<a href="http://www.ocfl.net/?tabid=105">www.ocfl.net/?tabid=105</a>
Special Needs Page	PDF file
Number of Clicks	2
Special Needs Info	No
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Poor
Recommendations	Create Special Needs Page

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Osceola					
Years	65-85+	% of Pop	Population	Count	Rate
1999	19,261	11.6%	166,024	19	14.8
2000	19,877	11.4%	174,107	18	12.8
2001	21,053	11.5%	183,260	21	13.9
2002	22,760	11.8%	193,519	35	21.2
2003	23,935	11.7%	205,328	34	19.5
2004	22,398	10.3%	218,043	33	20.2
2005	23,437	10.2%	230,209	38	22.1
2006	24,913	10.3%	243,033	49	26.7
2007	26,051	10.3%	254,082	42	21.9
2008	27,091	10.4%	261,539	32	15.6
2009	27,731	10.4%	265,701	42	19.6
2010	31,057	11.5%	269,062	46	21.5
2011	32,051	11.6%	275,389	31	14.6



1999-2011      66.4%      0.3%      65.9%      -1.4%

Data Source: www.floridacharts.com

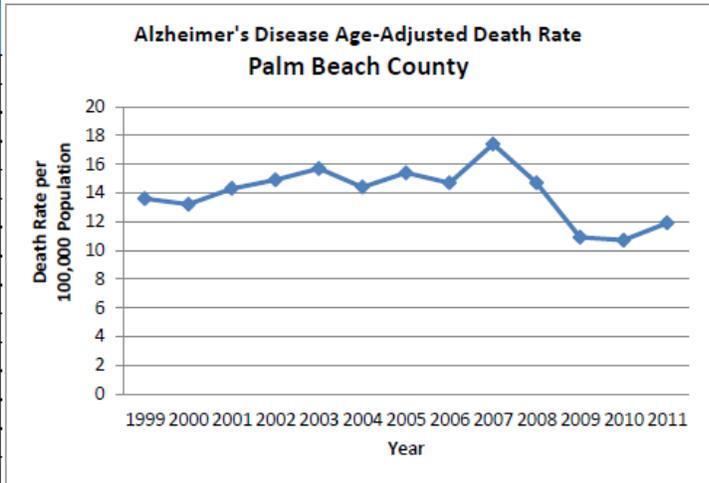
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 66.4%

The rate of alzheimer's disease age-adjusted deaths decreased 1.4%

County Website	<a href="http://www.osceola.org">www.osceola.org</a>
Emergency Management Page	<a href="http://www.osceola.org/emergencymanagement/home.cfm">www.osceola.org/emergencymanagement/home.cfm</a>
Special Needs Page	<a href="http://www.osceola.org/emergencymanagement/120-3779-3781/special_needs_program.cfm">www.osceola.org/emergencymanagement/120-3779-3781/special_needs_program.cfm</a>
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Average
Recommendations	Update to 2013 Packet; Include link to Special Needs Page on main Emergency Management webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Palm Beach					
Years	65-85+	% of Pop	Population	Count	Rate
1999	259,235	23.4%	1,107,053	298	13.6
2000	262,536	23.1%	1,137,532	295	13.2
2001	263,108	22.6%	1,163,115	323	14.3
2002	269,429	22.6%	1,191,948	354	14.9
2003	274,161	22.4%	1,223,687	382	15.7
2004	267,215	21.3%	1,255,696	372	14.4
2005	271,060	21.2%	1,278,804	414	15.4
2006	273,537	21.1%	1,294,795	405	14.7
2007	274,074	21.0%	1,304,214	485	17.4
2008	275,899	21.1%	1,308,741	429	14.7
2009	276,502	21.0%	1,313,848	329	10.9
2010	289,371	21.9%	1,320,309	312	10.7
2011	292,384	22.0%	1,327,313	346	11.9



1999-2011    12.8%    -5.9%    19.9%    -12.5%

Data Source: www.floridacharts.com

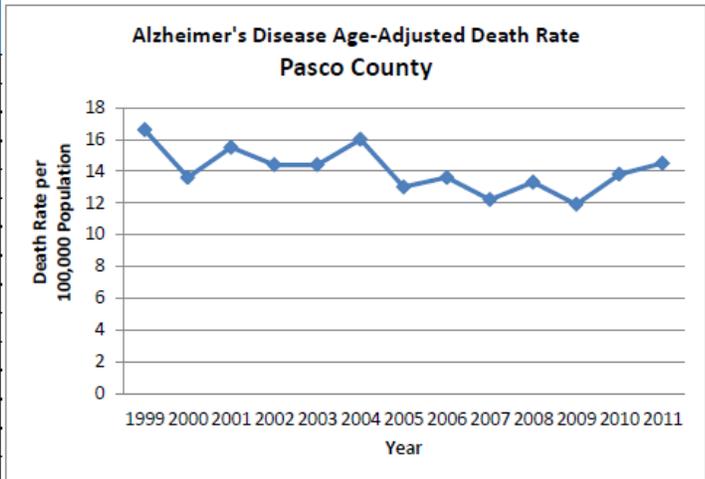
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 12.8%

The rate of alzheimer's disease age-adjusted deaths decreased 12.5%

County Website	<a href="http://www.pbcgov.com">www.pbcgov.com</a>
Emergency Management Page	<a href="http://www.pbcgov.com/publicsafety/emergencymanagement/">www.pbcgov.com/publicsafety/emergencymanagement/</a>
Special Needs Page	<a href="http://www.pbcgov.com/dem/sections/logistics/scu.htm">www.pbcgov.com/dem/sections/logistics/scu.htm</a>
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	Yes
Status	Average
Recommendations	Add Special Needs link on main Emergency Management Page

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Pasco					
Years	65-85+	% of Pop	Population	Count	Rate
1999	91,955	27.3%	337,348	119	16.6
2000	92,752	26.7%	346,882	101	13.6
2001	95,141	26.6%	357,966	118	15.5
2002	99,437	26.8%	370,525	117	14.4
2003	102,814	26.6%	385,893	120	14.4
2004	93,076	23.1%	403,512	138	16
2005	100,388	23.7%	423,139	116	13
2006	103,766	23.5%	441,890	128	13.6
2007	105,399	23.2%	454,541	117	12.2
2008	106,313	23.1%	459,946	134	13.3
2009	106,426	23.0%	462,510	122	11.9
2010	97,158	20.9%	465,118	109	13.8
2011	97,909	20.9%	467,515	116	14.5



1999-2011      6.5%    -23.2%      38.6%      -12.7%

Data Source: www.floridacharts.com

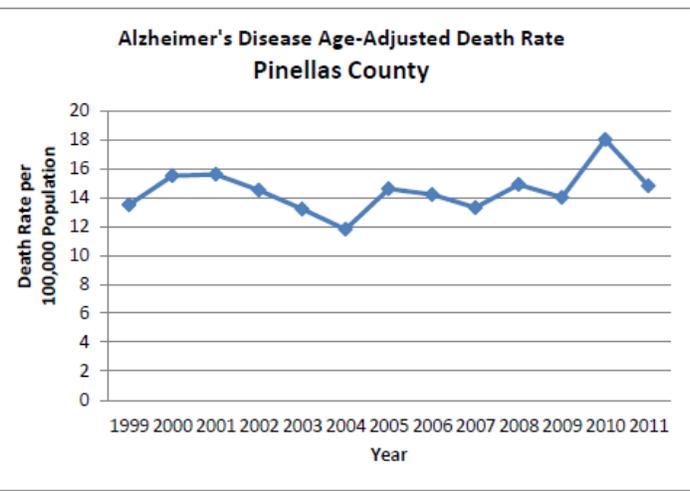
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 6.5%

The rate of alzheimer's disease age-adjusted deaths decreased 12.7%

County Website	<a href="http://www.pascocountyfl.net">www.pascocountyfl.net</a>
Emergency Management Page	<a href="http://www.pascocountyfl.net/Index.aspx?NID=365">www.pascocountyfl.net/Index.aspx?NID=365</a>
Special Needs Page	<a href="http://www.pascocountyfl.net/index.aspx?nid=713">www.pascocountyfl.net/index.aspx?nid=713</a>
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	Yes
Status	Average
Recommendations	Make link to Special Needs Information Packet more prevalent on main Special Needs webpage; link to registration form

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Pinellas					
Years	65-85+	% of Pop	Population	Count	Rate
1999	209,035	22.8%	917,331	252	13.5
2000	207,294	22.5%	923,308	291	15.5
2001	204,915	22.1%	926,342	290	15.6
2002	206,089	22.2%	928,384	281	14.5
2003	205,309	22.1%	931,063	252	13.2
2004	198,492	21.3%	932,419	248	11.8
2005	195,173	20.9%	932,904	286	14.6
2006	196,033	21.1%	930,912	276	14.2
2007	195,315	21.1%	926,761	260	13.3
2008	196,183	21.3%	922,144	297	14.9
2009	196,093	21.4%	917,786	287	14
2010	196,330	21.4%	916,501	331	18
2011	199,813	21.8%	918,624	275	14.8



1999-2011      -4.4%      -4.5%      0.1%      **9.6%**

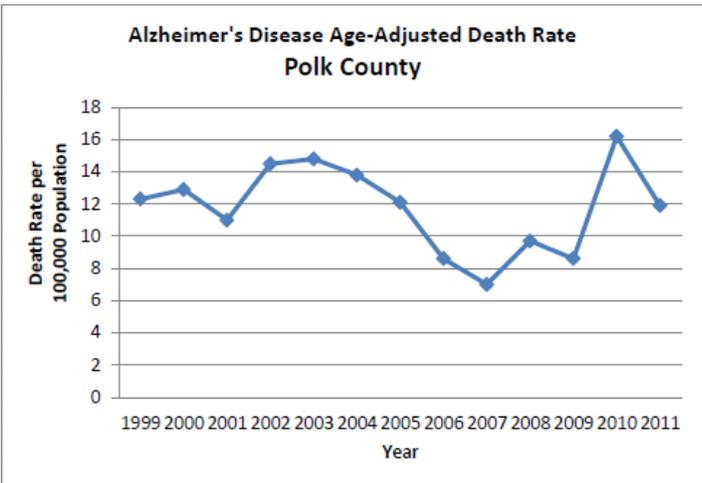
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ decreased 4.4%  
The rate of alzheimer's disease age-adjusted deaths increased 9.6%

County Website	<a href="http://www.pinellascounty.org">www.pinellascounty.org</a>
Emergency Management Page	<a href="http://www.pinellascounty.org/resident/disasters.htm">www.pinellascounty.org/resident/disasters.htm</a>
Special Needs Page	<a href="http://www.pinellascounty.org/emergency/specialneeds.htm">www.pinellascounty.org/emergency/specialneeds.htm</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Very comprehensive; Make contact information more prevalent

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Years	Polk				
	65-85+	% of Pop	Population	Count	Rate
1999	88,000	18.5%	475,268	75	12.3
2000	89,325	18.3%	487,183	82	12.9
2001	90,821	18.4%	493,172	74	11
2002	94,165	18.8%	502,208	103	14.5
2003	95,724	18.6%	513,634	106	14.8
2004	91,863	17.4%	528,527	103	13.8
2005	97,602	17.8%	547,191	94	12.1
2006	101,068	17.8%	567,216	70	8.6
2007	103,571	17.7%	583,869	60	7
2008	105,980	17.9%	593,498	89	9.7
2009	107,660	18.0%	598,817	80	8.6
2010	110,179	18.3%	602,442	130	16.2
2011	111,816	18.5%	605,832	97	11.9



1999-2011      27.1%      -0.3%      27.5%      -3.3%

Data Source: www.floridacharts.com

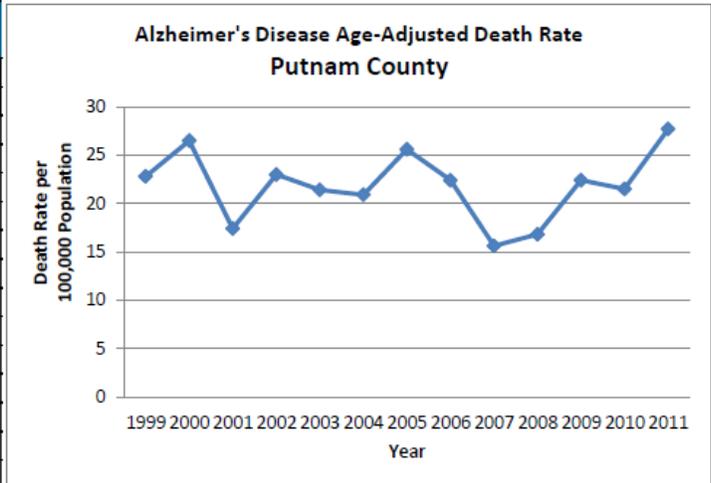
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 27.1%

The rate of alzheimer's disease age-adjusted deaths decreased 3.3%

County Website	<a href="http://www.polk-county.net">www.polk-county.net</a>
Emergency Management Page	<a href="http://www.polk-county.net/subpage.aspx?menu_id=20&amp;nav=res&amp;id=846">www.polk-county.net/subpage.aspx?menu_id=20&amp;nav=res&amp;id=846</a>
Special Needs Page	<a href="http://www.polk-county.net/subpage.aspx?menu_id=20&amp;nav=res&amp;id=852">www.polk-county.net/subpage.aspx?menu_id=20&amp;nav=res&amp;id=852</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	Yes
Status	Average
Recommendations	Make registration form link more prevalent

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Putnam					
Years	65-85+	% of Pop	Population	Count	Rate
1999	12,971	18.5%	70,029	18	22.8
2000	13,024	18.5%	70,532	21	26.5
2001	13,087	18.5%	70,818	15	17.4
2002	13,400	18.8%	71,370	20	23
2003	13,455	18.7%	72,017	19	21.4
2004	13,062	17.9%	72,923	20	20.9
2005	13,765	18.7%	73,630	24	25.6
2006	14,061	18.9%	74,388	23	22.4
2007	14,254	19.0%	74,960	16	15.6
2008	14,410	19.2%	74,984	18	16.8
2009	14,465	19.4%	74,621	25	22.4
2010	14,206	19.1%	74,276	22	21.5
2011	14,292	19.3%	73,973	28	27.7



1999-2011      10.2%      4.3%      5.6%      **21.5%**

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

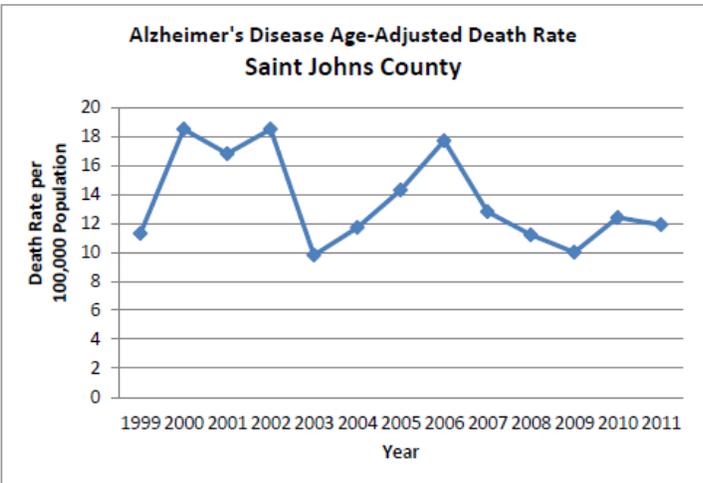
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 10.2%

The rate of alzheimer's disease age-adjusted deaths increased 21.5%

County Website	<a href="http://www.putnam-fl.com">www.putnam-fl.com</a>
Emergency Management Page	<a href="http://www.putnam-fl.com/bocc/index.php?option=com_content&amp;view=section&amp;id=46&amp;Itemid=173">www.putnam-fl.com/bocc/index.php?option=com_content&amp;view=section&amp;id=46&amp;Itemid=173</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs Page

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Saint Johns					
Years	65-85+	% of Pop	Population	Count	Rate
1999	19,093	16.1%	118,249	14	11.3
2000	19,809	15.9%	124,613	26	18.5
2001	20,898	16.1%	130,183	25	16.8
2002	22,210	16.3%	135,893	30	18.5
2003	23,252	16.3%	142,868	17	9.8
2004	22,427	14.8%	151,935	21	11.7
2005	24,025	15.0%	160,619	27	14.3
2006	25,840	15.2%	169,620	36	17.7
2007	27,364	15.4%	177,922	28	12.8
2008	28,747	15.7%	183,640	26	11.2
2009	29,622	15.8%	187,317	25	10
2010	30,191	15.8%	190,646	29	12.4
2011	31,296	16.2%	193,708	29	11.9



1999-2011      63.9%      0.1%      63.8%      5.3%

Data Source: www.floridacharts.com

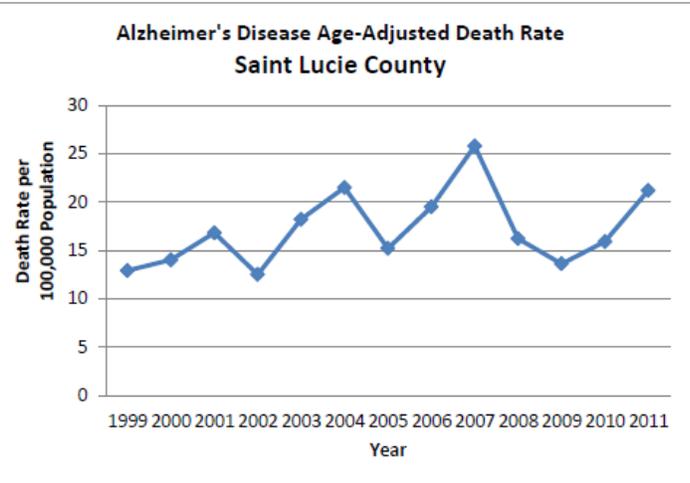
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 63.9%

The rate of alzheimer's disease age-adjusted deaths increased 5.3%

County Website	<a href="http://www.co.st-johns.fl.us">www.co.st-johns.fl.us</a>
Emergency Management Page	<a href="http://www.sjcemergencymanagement.org">www.sjcemergencymanagement.org</a>
Special Needs Page	<a href="http://www.sjcemergencymanagement.org/shetsns.html">www.sjcemergencymanagement.org/shetsns.html</a>
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Average
Recommendations	Move Assistance Program link to the top of the Special Needs Page; Current site navigation confusing

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Saint Lucie					
Years	65-85+	% of Pop	Population	Count	Rate
1999	43,153	22.8%	189,330	37	12.9
2000	43,954	22.6%	194,062	42	14
2001	44,323	22.3%	198,943	50	16.8
2002	46,022	22.3%	206,130	41	12.5
2003	47,865	22.2%	215,756	61	18.2
2004	48,552	21.3%	228,399	84	21.5
2005	51,119	21.2%	241,684	59	15.2
2006	53,426	21.0%	254,683	83	19.5
2007	54,980	20.7%	265,661	117	25.8
2008	56,477	20.8%	271,941	79	16.2
2009	57,287	20.8%	275,013	69	13.6
2010	56,353	20.3%	278,267	69	15.9
2011	56,942	20.3%	280,470	94	21.2



1999-2011      32.0%    -10.9%      48.1%      **64.3%**

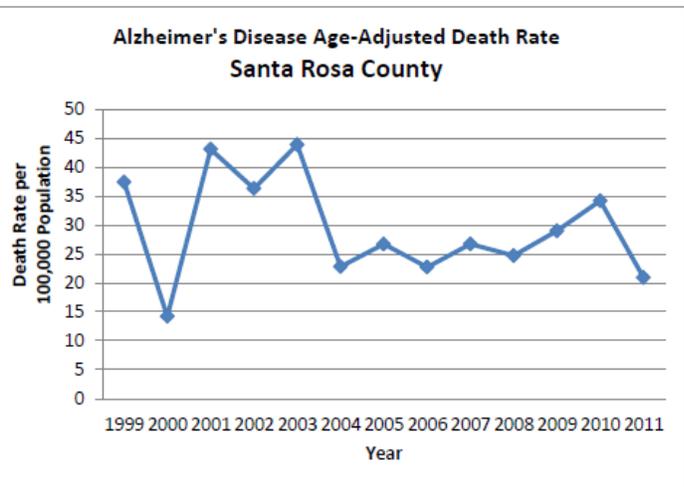
Data Source: [www.floridacharts.com](http://www.floridacharts.com)

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 32.0%  
The rate of alzheimer's disease age-adjusted deaths increased 64.3%

County Website	<a href="http://www.stlucieco.gov">www.stlucieco.gov</a>
Emergency Management Page	<a href="http://www.stlucieco.gov/eoc/situation_report.htm">www.stlucieco.gov/eoc/situation_report.htm</a>
Special Needs Page	PDF file
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	Yes
Status	Average
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Santa Rosa					
Years	65-85+	% of Pop	Population	Count	Rate
1999	12,626	10.9%	115,333	28	37.4
2000	13,122	11.1%	118,605	12	14.2
2001	13,700	11.2%	122,019	34	43.1
2002	14,728	11.6%	127,137	32	36.3
2003	15,183	11.5%	131,774	39	43.9
2004	15,634	11.4%	136,838	24	22.8
2005	16,594	11.8%	140,490	29	26.7
2006	17,129	12.0%	143,006	27	22.7
2007	17,703	12.1%	145,943	32	26.7
2008	18,292	12.3%	148,183	32	24.7
2009	18,778	12.5%	149,677	39	29
2010	19,740	13.0%	152,174	40	34.2
2011	20,520	13.2%	155,720	25	20.9



1999-2011      62.5%      20.4%      35.0%      -44.1%

Data Source: www.floridacharts.com

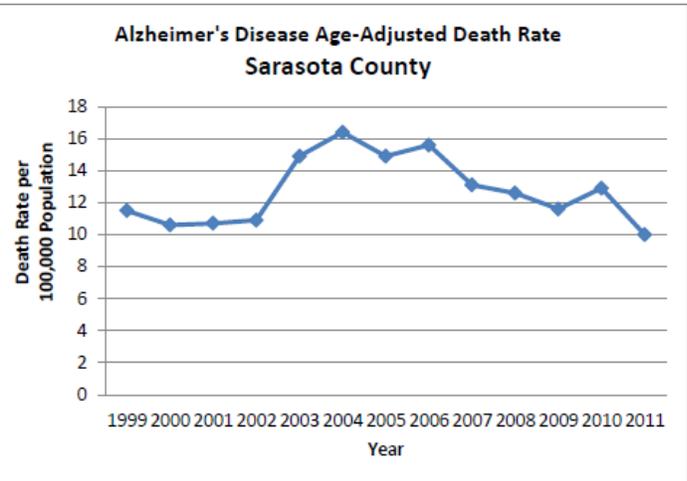
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 62.5%

The rate of alzheimer's disease age-adjusted deaths decreased 44.1%

County Website	<a href="http://www.santarosa.fl.gov">www.santarosa.fl.gov</a>
Emergency Management Page	<a href="http://www.santarosa.fl.gov/emergency/">www.santarosa.fl.gov/emergency/</a>
Special Needs Page	<a href="http://www.santarosa.fl.gov/emergency/specialneeds.html">www.santarosa.fl.gov/emergency/specialneeds.html</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	Yes; very basic
Status	Average
Recommendations	Add contact information to webpage and enhance registration form

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Sarasota					
Years	65-85+	% of Pop	Population	Count	Rate
1999	101,550	31.7%	319,980	94	11.5
2000	103,068	31.4%	328,135	91	10.6
2001	104,019	31.2%	333,830	93	10.7
2002	106,715	31.3%	340,755	101	10.9
2003	108,641	31.2%	348,370	139	14.9
2004	105,257	29.4%	357,787	162	16.4
2005	112,035	30.6%	366,352	160	14.9
2006	113,694	30.6%	371,081	170	15.6
2007	114,848	30.6%	374,721	148	13.1
2008	116,417	30.9%	376,698	151	12.6
2009	117,309	31.1%	377,778	141	11.6
2010	119,077	31.4%	379,741	140	12.9
2011	120,298	31.5%	381,832	110	10



1999-2011    18.5%    -0.7%    19.3%    -13.0%

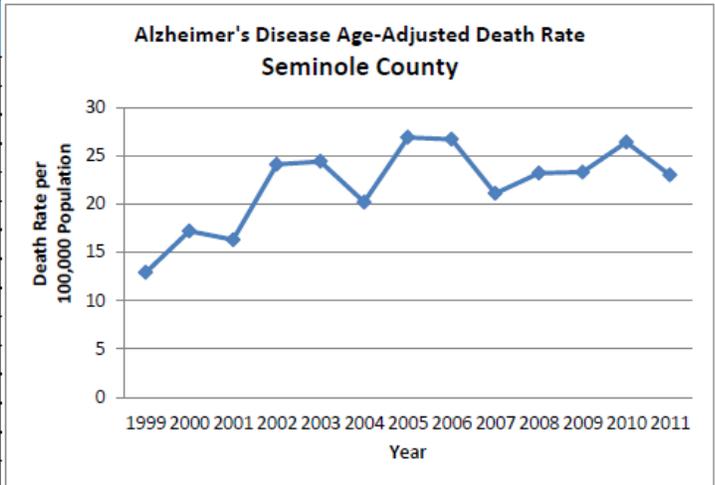
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 18.5%  
The rate of alzheimer's disease age-adjusted deaths decreased 13.0%

County Website	<a href="http://www.scgov.net">www.scgov.net</a>
Emergency Management Page	<a href="http://www.scgov.net/AllHazards/Pages/default.aspx">www.scgov.net/AllHazards/Pages/default.aspx</a>
Special Needs Page	<a href="http://www.scgov.net/AllHazards/Pages/PSN.aspx">www.scgov.net/AllHazards/Pages/PSN.aspx</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Make contact information more prevalent; Add registration form

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Seminole					
Years	65-85+	% of Pop	Population	Count	Rate
1999	38,168	10.7%	357,714	35	12.9
2000	39,115	10.6%	368,231	47	17.2
2001	39,867	10.5%	378,062	47	16.3
2002	41,186	10.7%	386,280	74	24.1
2003	41,619	10.6%	392,696	77	24.4
2004	42,520	10.6%	400,335	67	20.2
2005	43,423	10.6%	409,219	87	26.9
2006	44,894	10.8%	416,184	91	26.7
2007	45,816	10.9%	419,603	74	21.1
2008	46,866	11.1%	420,645	86	23.2
2009	47,624	11.3%	421,438	90	23.3
2010	51,900	12.3%	422,979	112	26.4
2011	53,627	12.6%	425,135	101	23.8



1999-2011      40.5%      18.2%      18.8%      **78.3%**

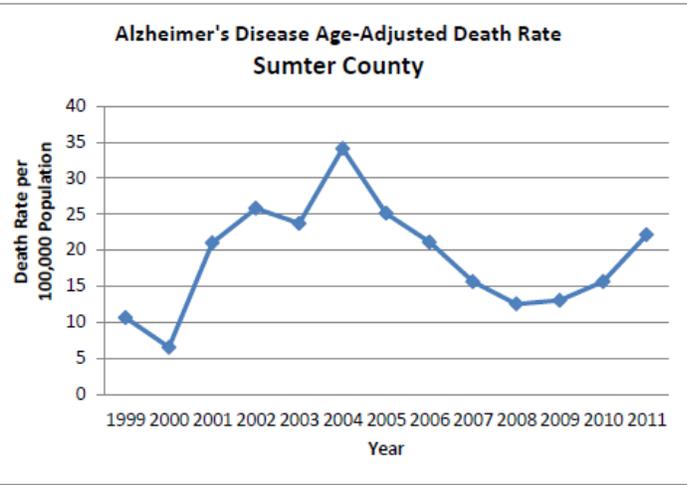
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 40.5%  
The rate of alzheimer's disease age-adjusted deaths increased 78.3%

County Website	<a href="http://www.seminolecountyfl.gov">www.seminolecountyfl.gov</a>
Emergency Management Page	<a href="http://www.prepareseminole.com/prepare/">www.prepareseminole.com/prepare/</a>
Special Needs Page	<a href="http://www.prepareseminole.com/prepare/special_needs.asp">www.prepareseminole.com/prepare/special_needs.asp</a>
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	No; Memory Impaired
Registration Form	Yes
Status	Good
Recommendations	Very comprehensive Special Needs Disaster Guide; Make form, guides, and contact information more prevalent

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Sumter					
Years	65-85+	% of Pop	Population	Count	Rate
1999	13,756	27.2%	50,539	6	10.6
2000	14,920	27.5%	54,203	5	6.5
2001	15,789	27.9%	56,592	18	21
2002	17,132	28.6%	59,799	23	25.8
2003	17,607	28.5%	61,727	20	23.7
2004	19,631	30.2%	64,926	33	34.1
2005	21,733	30.7%	70,846	33	25.1
2006	24,220	31.1%	77,858	34	21.1
2007	26,269	31.5%	83,492	30	15.6
2008	28,047	32.1%	87,432	27	12.5
2009	29,552	32.5%	90,977	31	13
2010	41,314	43.8%	94,234	33	15.6
2011	43,726	44.9%	97,432	44	22.1



1999-2011    217.9%    64.9%    92.8%    **108.5%**

Data Source: www.floridacharts.com

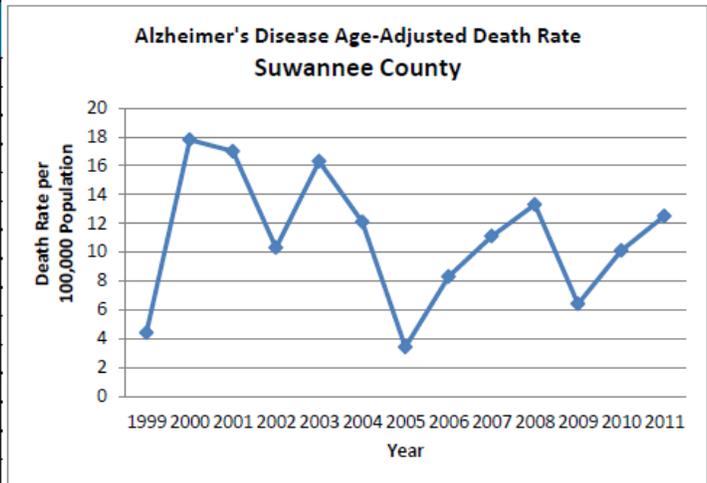
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 217.9%

The rate of alzheimer's disease age-adjusted deaths increased 108.5%

County Website	<a href="http://sumtercountyfl.gov">http://sumtercountyfl.gov</a>
Emergency Management Page	<a href="http://sumtercountyfl.gov/index.aspx?nid=718">http://sumtercountyfl.gov/index.aspx?nid=718</a>
Special Needs Page	<a href="http://sumtercountyfl.gov/index.aspx?NID=723">http://sumtercountyfl.gov/index.aspx?NID=723</a>
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Add contact phone number to webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Suwannee					
Years	65-85+	% of Pop	Population	Count	Rate
1999	5,852	17.1%	34,226	2	4.4
2000	5,951	17.0%	35,091	8	17.8
2001	6,140	17.2%	35,755	8	17
2002	6,377	17.6%	36,170	5	10.3
2003	6,449	17.5%	36,804	8	16.3
2004	6,364	17.0%	37,536	6	12.1
2005	6,953	18.1%	38,442	2	3.4
2006	7,256	18.5%	39,325	5	8.3
2007	7,428	18.4%	40,369	7	11.1
2008	7,574	18.5%	41,047	9	13.3
2009	7,645	18.6%	41,118	4	6.4
2010	7,994	19.1%	41,883	6	10.1
2011	8,352	19.2%	43,578	8	12.5



1999-2011      42.7%      12.1%      27.3%      **184.1%**

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

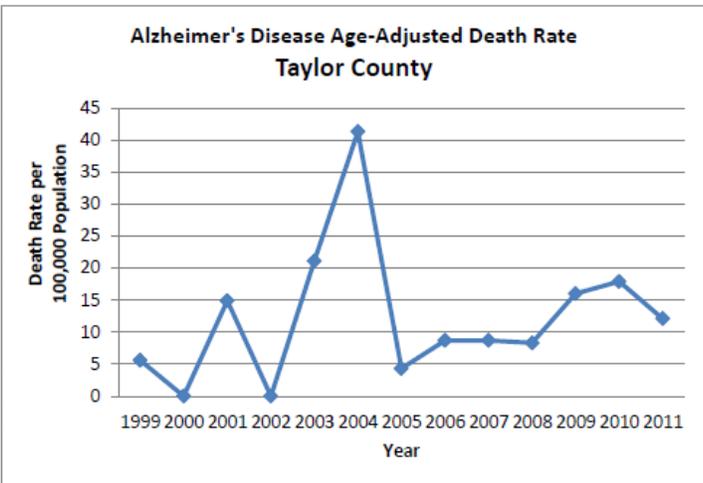
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 42.7%

The rate of alzheimer's disease age-adjusted deaths increased 184.1%

County Website	<a href="http://www.suwcounty.org">www.suwcounty.org</a>
Emergency Management Page	<a href="http://www.suwcounty.org/index.php?option=com_content&amp;view=article&amp;id=34&amp;Itemid=26">www.suwcounty.org/index.php?option=com_content&amp;view=article&amp;id=34&amp;Itemid=26</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Taylor					
Years	65-85+	% of Pop	Population	Count	Rate
1999	2,667	13.8%	19,264	1	5.6
2000	2,719	14.1%	19,297	0	0
2001	2,744	14.1%	19,509	3	14.9
2002	2,831	14.3%	19,753	0	0
2003	2,856	14.1%	20,255	4	21.1
2004	2,810	13.8%	20,315	9	41.3
2005	2,856	13.9%	20,576	1	4.3
2006	2,977	14.2%	20,981	2	8.7
2007	3,112	14.2%	21,968	2	8.7
2008	3,183	14.2%	22,449	2	8.3
2009	3,245	14.4%	22,526	4	16
2010	3,579	15.9%	22,529	4	17.9
2011	3,668	16.3%	22,491	3	12.1



1999-2011      37.5%      17.8%      16.8%      **116.1%**

Data Source: www.floridacharts.com

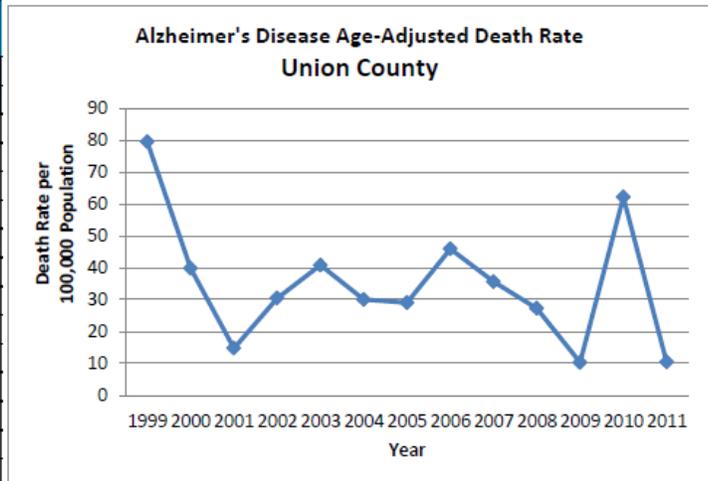
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 37.5%

The rate of alzheimer's disease age-adjusted deaths increased 116.1%

County Website	<a href="http://www.taylorcountygov.com">www.taylorcountygov.com</a>
Emergency Management Page	<a href="http://www.taylorcountygov.com/em/index.htm">www.taylorcountygov.com/em/index.htm</a>
Special Needs Page	PDF file
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	No; Memory Impaired
Registration Form	Yes
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Union					
Years	65-85+	% of Pop	Population	Count	Rate
1999	958	7.2%	13,335	4	79.5
2000	1,011	7.5%	13,473	2	39.8
2001	1,044	7.7%	13,577	1	14.7
2002	1,092	8.0%	13,618	2	30.4
2003	1,099	8.0%	13,777	3	40.8
2004	1,041	7.2%	14,559	2	30
2005	1,117	7.5%	14,812	2	29
2006	1,179	7.9%	14,933	4	45.9
2007	1,268	8.2%	15,504	3	35.6
2008	1,324	8.5%	15,584	3	27.2
2009	1,366	8.9%	15,367	1	10.3
2010	1,607	10.3%	15,567	5	62.1
2011	1,624	10.5%	15,455	1	10.4



1999-2011      69.5%      46.3%      15.9%      -86.9%

Data Source: www.floridacharts.com

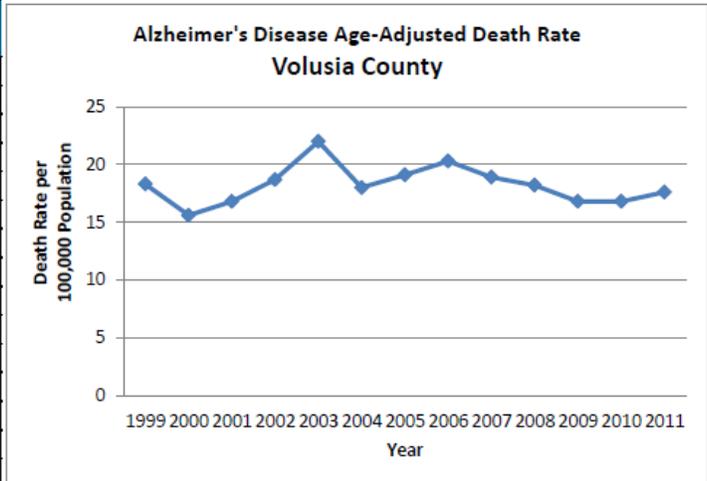
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 69.5%

The rate of alzheimer's disease age-adjusted deaths decreased 86.9%

County Website	<a href="http://www.unionsheriff.us">www.unionsheriff.us</a> no central county website - Union County Sheriff site
Emergency Management Page	<a href="http://www.unionsheriff.us/emergency_management.html">www.unionsheriff.us/emergency_management.html</a>
Special Needs Page	<a href="http://www.unionsheriff.us/special_needs.html">www.unionsheriff.us/special_needs.html</a>
Number of Clicks	1
Special Needs Info	No
Lists Alzheimer's	No; Memory Impaired
Registration Form	Yes
Status	Poor
Recommendations	Add Special Needs information to webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Volusia					
Years	65-85+	% of Pop	Population	Count	Rate
1999	97,014	22.2%	436,218	138	18.3
2000	98,077	22.0%	445,676	119	15.6
2001	98,241	21.7%	451,925	130	16.8
2002	100,319	21.9%	459,069	150	18.7
2003	101,593	21.7%	467,705	179	22
2004	98,778	20.7%	477,957	157	18
2005	101,333	20.8%	486,800	170	19.1
2006	103,343	20.9%	494,717	186	20.3
2007	104,177	20.9%	499,139	175	18.9
2008	105,007	21.1%	498,789	177	18.2
2009	104,911	21.2%	495,754	169	16.8
2010	105,785	21.4%	494,617	151	16.8
2011	107,088	21.6%	495,758	162	17.6



1999-2011    10.4%    -2.9%    13.6%    -3.8%

Data Source: www.floridacharts.com

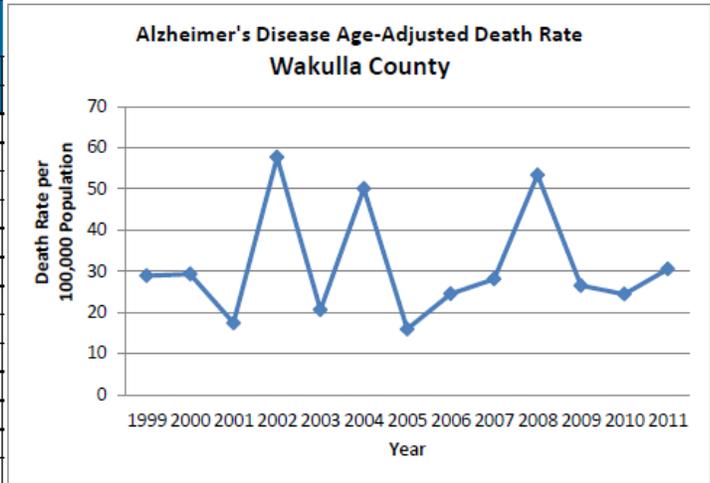
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 10.4%

The rate of alzheimer's disease age-adjusted deaths decreased 3.8%

County Website	<a href="http://www.volusia.org">www.volusia.org</a>
Emergency Management Page	<a href="http://www.volusia.org/services/public-protection/emergency-management/">www.volusia.org/services/public-protection/emergency-management/</a>
Special Needs Page	<a href="http://www.volusia.org/services/public-protection/emergency-management/before-a-disaster/special-needs.shtml">www.volusia.org/services/public-protection/emergency-management/before-a-disaster/special-needs.shtml</a>
Number of Clicks	2
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Good
Recommendations	Make link to registration form more prevalent

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Wakulla					
Years	65-85+	% of Pop	Population	Count	Rate
1999	2,271	10.4%	21,917	4	28.9
2000	2,387	10.3%	23,150	5	29.3
2001	2,497	10.5%	23,744	3	17.4
2002	2,657	10.9%	24,417	9	57.7
2003	2,702	10.8%	25,066	4	20.6
2004	2,623	10.2%	25,796	9	50.1
2005	2,937	11.0%	26,673	3	15.9
2006	3,176	11.5%	27,698	5	24.5
2007	3,361	11.8%	28,473	6	28.1
2008	3,688	12.6%	29,217	13	53.4
2009	3,911	12.9%	30,392	7	26.5
2010	3,395	11.0%	30,818	5	24.4
2011	3,511	11.4%	30,889	6	30.5



1999-2011      54.6%      9.7%      40.9%      5.5%

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

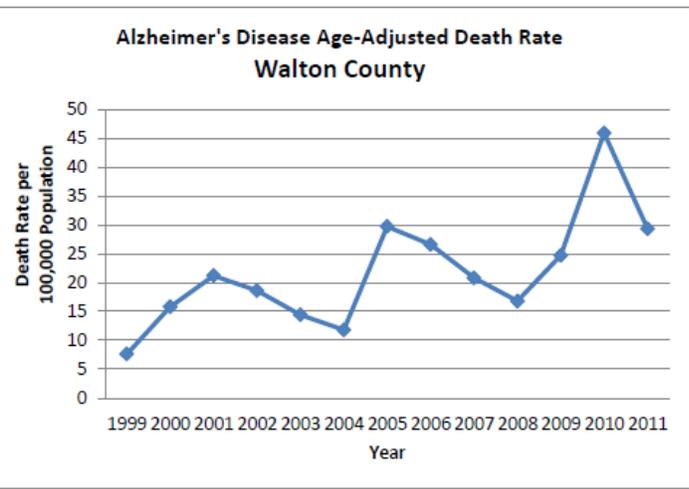
**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 54.6%

The rate of alzheimer's disease age-adjusted deaths increased 5.5%

County Website	<a href="http://www.mywakulla.com">www.mywakulla.com</a>
Emergency Management Page	<a href="http://www.wcso.org/index.php?option=com_content&amp;task=view&amp;id=15&amp;Itemid=52">www.wcso.org/index.php?option=com_content&amp;task=view&amp;id=15&amp;Itemid=52</a>
Special Needs Page	None
Number of Clicks	None
Special Needs Info	No
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Create Special Needs webpage

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Walton					
Years	65-85+	% of Pop	Population	Count	Rate
1999	6,221	15.8%	39,387	3	7.6
2000	6,526	15.9%	40,990	6	15.8
2001	7,042	16.4%	42,879	10	21.2
2002	7,669	17.1%	44,732	10	18.6
2003	7,903	17.1%	46,312	7	14.4
2004	7,338	15.2%	48,429	6	11.8
2005	8,773	17.5%	50,118	18	29.7
2006	9,229	17.8%	51,833	18	26.6
2007	9,589	18.0%	53,203	15	20.8
2008	9,969	18.4%	54,279	13	16.8
2009	10,218	18.6%	54,794	20	24.7
2010	9,044	16.4%	55,060	28	45.9
2011	9,226	16.6%	55,599	18	29.3



1999-2011      48.3%      5.1%      41.2%      **285.5%**

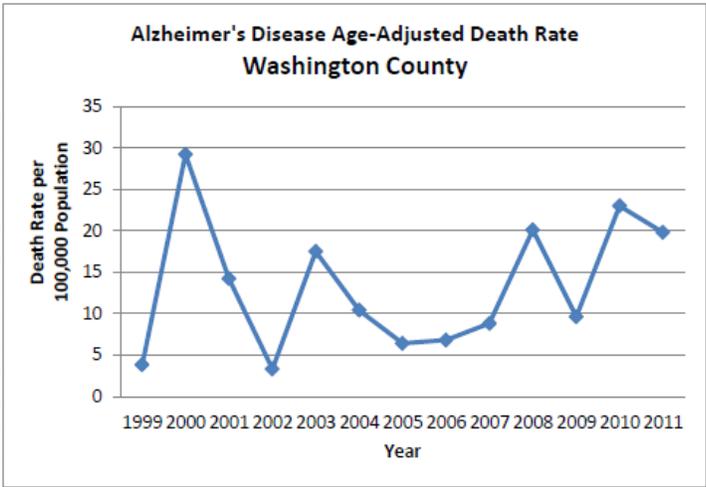
Data Source: www.floridacharts.com

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 48.3%  
The rate of alzheimer's disease age-adjusted deaths increased 285.5%

County Website	<a href="http://www.co.walton.fl.us">www.co.walton.fl.us</a>
Emergency Management Page	<a href="http://www.co.walton.fl.us/index.aspx?NID=449">www.co.walton.fl.us/index.aspx?NID=449</a>
Special Needs Page	<a href="http://www.co.walton.fl.us/index.aspx?NID=554">www.co.walton.fl.us/index.aspx?NID=554</a>
Number of Clicks	1
Special Needs Info	Yes; very limited
Lists Alzheimer's	No
Registration Form	No
Status	Poor
Recommendations	Add Special Needs information, registration form and contact details

Alzheimer's Disease Age-Adjusted Death Rate, Single Year Rates					
Washington					
Years	65-85+	% of Pop	Population	Count	Rate
1999	3,263	15.6%	20,850	1	3.8
2000	3,313	15.7%	21,069	8	29.2
2001	3,363	15.7%	21,419	4	14.2
2002	3,445	16.0%	21,527	1	3.3
2003	3,469	15.9%	21,837	5	17.5
2004	3,348	15.0%	22,309	3	10.4
2005	3,551	15.6%	22,783	2	6.4
2006	3,677	15.8%	23,249	2	6.8
2007	3,847	16.1%	23,945	3	8.8
2008	3,979	16.1%	24,765	7	20.1
2009	4,019	16.2%	24,796	3	9.6
2010	3,870	15.6%	24,862	6	23
2011	3,859	15.7%	24,588	5	19.8



1999-2011    18.3%    0.3%    17.9%    **421.1%**

Data Source: [www.floridacharts.com](http://www.floridacharts.com)

**Summary from 1999 to 2011**

The population of persons age 65-85+ increased 18.3%

The rate of alzheimer's disease age-adjusted deaths increased 421.1%

County Website	<a href="http://www.washingtonfl.com">www.washingtonfl.com</a>
Emergency Management Page	<a href="http://www.washingtonfl.com/emergencymgmt/eoc.htm">www.washingtonfl.com/emergencymgmt/eoc.htm</a>
Special Needs Page	PDF file
Number of Clicks	1
Special Needs Info	Yes
Lists Alzheimer's	Yes
Registration Form	Yes
Status	Average
Recommendations	Create Special Needs webpage with information and links

## Appendix 6: Florida Alzheimer's Disease Initiative Brain Bank

### Florida Alzheimer Disease Initiative Brain Bank

(September 2011 – August 2012)

- **Brains received: 105** (103 with frozen tissue)
  - Orlando Regional Medical Center – 40
  - Other (mostly Clinical Research Recovery) – 37
  - Mount Sinai Medical Center – 26
  - Mayo Clinic – 2
- **Average postmortem delay: 9.5 hours** (range: 2 to 58 hours)
- **Average age: 79 years** (range: 36 to 97 years)
- **Sex: 56 women and 49 men**
- **Race: 96 Caucasian and 9 Hispanic** (no African American)
- **Clinical diagnoses: AD (73); Lewy body dementia (21);**  
**frontal lobe dementia (11), vascular dementia (7)**
- **Neuropathology diagnoses: AD (70); Lewy body disease (41),**  
**frontotemporal dementia (10); vascular disease (38);**  
**other (2 Creutzfeldt-Jakob disease; 4 PSP, 2 CBD)**
  - **Average Braak NFT stage: IV** (range: 0 to VI)
  - **Average brain weight: 1050 grams** (range: 640 to 1460 grams)
- **Average time for final neuropathology report: 38 days** (range: 8 to 90 days)

## Appendix 7: Memory Disorder Clinics Statewide Report 2011-2012

MEMORY DISORDER CLINICS STATEWIDE REPORT - 2011 - 2012*					
Reporting Period: <b>(Check One)</b>	<input type="checkbox"/> <div style="border: 1px solid black; width: 80px; height: 20px; margin: 2px auto;"></div>	<input type="checkbox"/> <div style="border: 1px solid black; width: 80px; height: 20px; margin: 2px auto;"></div>	<input type="checkbox"/> <div style="border: 1px solid black; width: 80px; height: 20px; margin: 2px auto;"></div>	<input type="checkbox"/> <div style="border: 1px solid black; width: 80px; height: 20px; margin: 2px auto;"></div>	
A. SERVICE SUMMARY	QTR 1	QTR 2	QTR 3	QTR 4	YTD
1. Total unduplicated persons seen	1799	1810	1653	1461	6723
2. Total new patients seen this period	782	843	897	813	3335
3. Total evaluations completed (including follow-ups)	1547	1585	1734	1718	6584
4. Total community screenings	211	571	482	309	1573
5. Office visits	2418	2307	2775	2605	10105
Office visit activities					
a. Part of evaluation	1830	1737	1935	1848	7350
b. Medical	560	479	565	479	2083
c. Psychosocial	344	389	474	547	1754
d. Neuropsychological testing	342	369	397	533	1641
e. Other	92	126	105	109	432
6. Phone information/support/counseling	2814	3112	3452	3192	12570
7. Referrals					
a. respite/day care	322	393	406	451	1572
b. support groups	450	480	520	626	2076
c. long-term care placement	109	129	125	159	522
d. counseling	367	429	408	420	1624
e. other social service	855	923	964	1125	3867
f. medical	929	1153	1016	919	4017
g. <b>TOTAL</b>	3032	3507	3439	3700	13678
8. Age groups served					
a. < 60 years	115	113	122	103	453
b. age 60-64	69	106	109	84	368
c. age 65-74	261	232	333	227	1053
d. age 75-84	269	311	338	325	1243
e. age 85 +	131	145	138	151	565

<b>f. TOTAL</b>	845	907	1040	890	3682
9. Race					
a. Asian/Pacific Islander	11	8	5	2	26
b. Black	59	47	52	77	235
c. Caucasian	761	841	965	760	3327
d. Native American	0	2	0	1	3
e. Other	10	7	11	47	75
<b>f. TOTAL</b>	841	905	1033	887	3666
10. Ethnicity					
a. Hispanic	151	159	181	152	643
b. Non-Hispanic	568	633	645	579	2425
c. No response	88	70	85	111	354
<b>d. TOTAL</b>	807	862	911	842	3422
11. Sex					
a. female	521	581	632	541	2275
b. male	324	328	408	346	1406
<b>c. TOTAL</b>	845	909	1040	887	3681
12. No. of volunteers utilized	57	46	43	47	96

<b>B. RESEARCH SUMMARY</b>	<b>QTR 1</b>	<b>QTR 2</b>	<b>QTR 3</b>	<b>QTR 4</b>	<b>YTD</b>
1. Referrals to genetic studies	34	45	48	25	152
2. Referrals to clinical drug trials	91	109	116	82	398
3. Referrals to Brain Bank	86	106	129	191	512
4. Referrals to other research	207	202	253	217	879

**\*not including XZ907 - Brain Bank**

<b>C. CAREGIVER INFORMATION</b>	<b>QTR 1</b>	<b>QTR 2</b>	<b>QTR 3</b>	<b>QTR 4</b>	<b>YTD</b>
1. Unduplicated # of primary caregivers served	528	628	675	619	2450
2. Number of patients providing self-care	261	236	269	234	1000
3. Sex of primary caregiver					
a. female	348	394	414	408	1564
b. male	163	214	241	216	834

c. <b>TOTAL</b>	511	608	660	624	2398
4. Relationship of caregiver to patient					
a. spouse	276	333	379	334	1322
b. child	178	219	190	196	783
c. sibling	10	9	21	24	64
d. other relative	25	23	32	25	105
e. non-relative	23	23	35	30	111
f. <b>TOTAL</b>	512	607	663	609	2385
5. Age of primary caregiver					
a. < 30	11	19	16	10	56
b. age 30-39	14	24	21	32	91
c. age 40-49	81	88	89	81	339
d. age 50-59	132	132	149	131	544
e. age 60-64	60	84	90	108	342
f. age 65-74	114	128	152	123	517
g. age 75-84	85	111	114	100	410
h. age 85 +	13	19	24	29	85
i. <b>TOTAL</b>	510	605	662	614	2391
6. Unduplicated # of caregivers served	692	726	822	694	2934

<b>D. SILVER ALERT INFORMATION</b>	<b>QTR 1</b>	<b>QTR 2</b>	<b>QTR 3</b>	<b>QTR 4</b>	<b>YTD</b>
1. Number of notifications	33	41	31	40	145
2. Number of referrals made to ARC/ADRC	16	25	12	17	70

**\*not including XZ907 - Brain Bank**