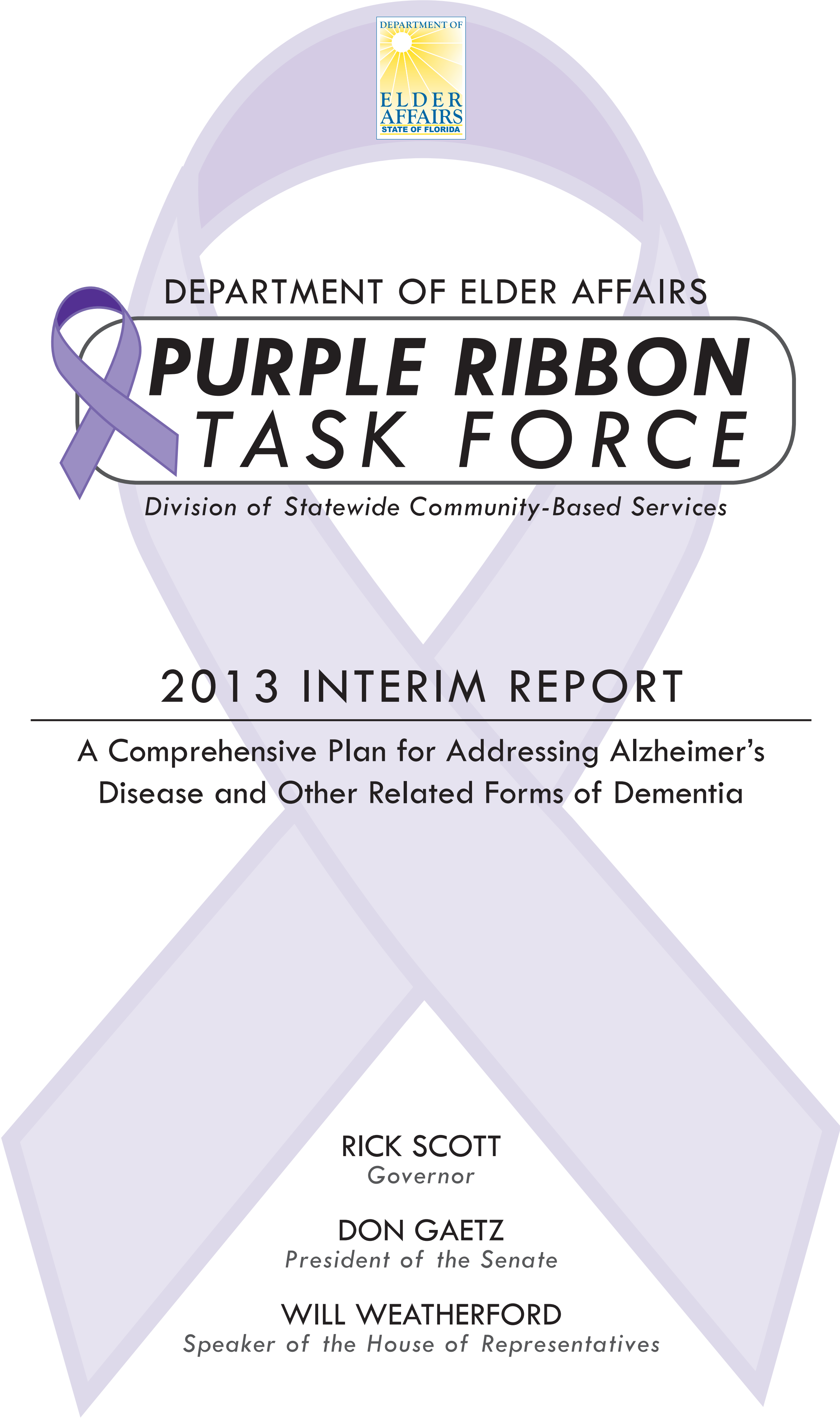

DEPARTMENT OF ELDER AFFAIRS

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

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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 Aβ 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 it 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 recue 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 mission 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 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

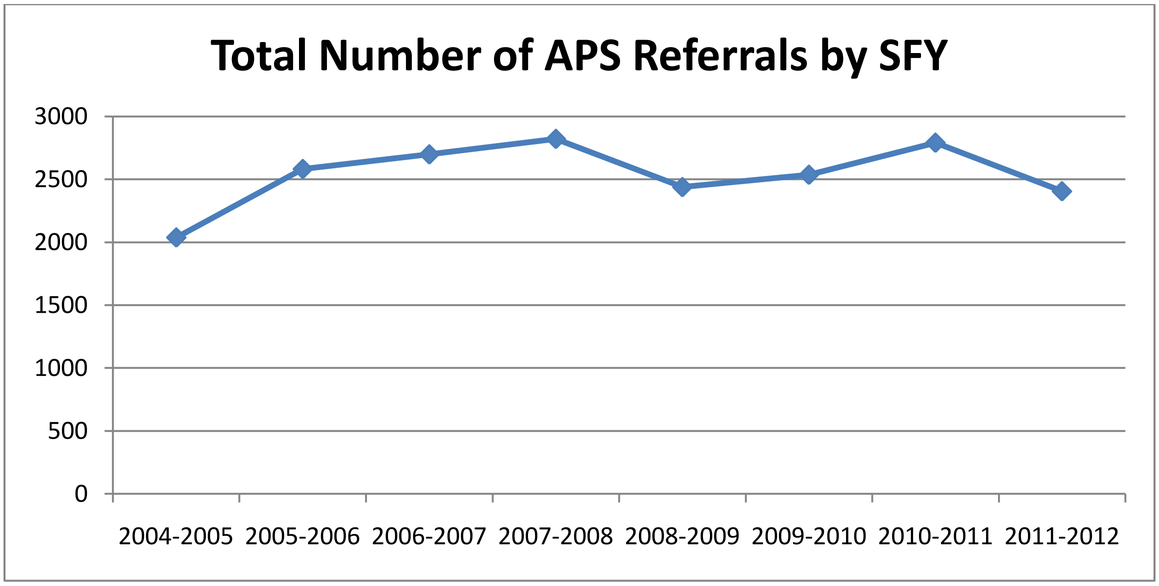
	State Fiscal Year								
Risk Level	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011	2011-2012	*2012-2013* *(as of Nov 2012)*
Low	208	278	319	259	257	235	282	237	*92*
Medium	751	884	1030	991	851	916	1047	732	*328*
High	1079	1420	1349	1571	1330	1385	1462	1436	*585*
Total	**2038**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

% 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	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	***100%***

% 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 age18 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 programing 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.[1]

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 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

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[1] 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 Statues. 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."[2] 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,

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[2] 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.[3] 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.”[4] 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.[5] 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

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[3] 744.1012 et seq., Fla. Stat.

[4] “Who will mind Mom?” Rachel Silverman, The Wall Street Journal (Sept. 7, 2006)

[5] 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 issued 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).

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