

The Florida Senate
BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

Prepared By: The Professional Staff of the Children, Families, and Elder Affairs Committee

BILL: SB 682

INTRODUCER: Senator Richter

SUBJECT: Alzheimer's Disease

DATE: January 11, 2011

REVISED: _____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Daniell	Farmer	CF	Pre-meeting
2.			GO	
3.			BC	
4.				
5.				
6.				

I. Summary:

This bill creates the Purple Ribbon Task Force within the Department of Elder Affairs to develop a comprehensive state plan to address the needs of individuals with Alzheimer's disease and their caregivers.

The purpose of the task force is to assess the current and future impact of Alzheimer's disease on Florida; 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 additional information.

The task force shall consist of 18 members appointed by the Governor, President of the Senate, and Speaker of the House of Representatives, and the task force must submit a report and its recommendations for an Alzheimer's disease state strategy by August 1, 2013.

This bill creates an unnumbered section of the Florida Statutes.

II. Present Situation:

Alzheimer's Disease

Alzheimer's disease is a progressive, degenerative disorder that attacks the brain's nerve cells and results in loss of memory, thinking, and language skills, and behavioral changes.¹

¹ Alzheimer's Foundation of America, *About Alzheimer's, Definition of Alzheimer's*, <http://www.alzfdn.org/AboutAlzheimers/definition.html> (last visited Aug. 2, 2011).

Alzheimer's disease was named after Dr. Alois Alzheimer, a German physician, who in the early 1900's cared for a 51-year-old woman suffering from severe dementia. Upon the woman's death, Dr. Alzheimer conducted a brain autopsy and found bundles of neurofibers and plaques in her brain, which are distinguishing characteristics of what we call Alzheimer's disease today.²

There are approximately 5.4 million Americans currently living with Alzheimer's disease, and that number is projected to rise to 16 million by 2050.³ As the life expectancy for Americans has continued to rise, so has the number of new cases of Alzheimer's disease. For instance, in 2000 there were an estimated 411,000 new cases of Alzheimer's disease in the United States, and in 2010 that number was estimated to be 454,000 – a 10 percent increase.⁴ That number is expected to rise to 959,000 new cases of Alzheimer's disease by 2050, a 130-percent increase from 2000.⁵ Specifically in Florida, approximately 360,000 people age 65 or older had Alzheimer's disease in 2000 and in 2010, that number had risen to 450,000.

As the number of people with Alzheimer's disease increases, so does the cost of caring for these individuals. In 2011, the aggregate cost for health care, long-term care, and hospice for persons with Alzheimer's and other dementias was estimated to be \$183 billion. That number is projected to be \$1.1 trillion by 2050.⁶ A major contributing factor to the cost of care for persons with Alzheimer's is that these individuals have more hospital stays, skilled nursing home stays, and home healthcare visits than older persons who do not have Alzheimer's. Research shows that 22 percent of individuals with Alzheimer's disease who have Medicare also have Medicaid coverage, which pays for nursing home care and other long-term care services.⁷ The total Medicaid spending for people with Alzheimer's disease (and other dementia) was estimated to be \$37 billion in 2011.⁸

In addition to the cost of health care, there is a significant cost associated with unpaid caregivers. An unpaid caregiver is primarily a family member, but can also be other relatives or friends. Such caregivers often provide assistance with daily activities, such as shopping for groceries, preparing meals, bathing, dressing, grooming, assisting with mobility, helping the person take medications, making arrangements for medical care, and performing other household chores. In 2010, nearly 15 million unpaid caregivers provided an estimated 17 billion hours of unpaid care, valued at \$202.6 billion.⁹ In 2010, there were 960,037 caregivers in Florida with an estimated value of unpaid care reaching nearly \$13.5 million.¹⁰

Alzheimer's Disease Initiative

In 1985, the Florida Legislature put into place the Alzheimer's Disease Initiative (ADI or

² Michael Plontz, *A Brief History of Alzheimer's Disease*, TODAY'S CAREGIVER, http://www.caregiver.com/channels/alz/articles/a_brief_history.htm (last visited Aug. 2, 2011).

³ Alzheimer's Assn., *Fact Sheet: 2011 Alzheimer's Disease Facts and Figures* (March 2011), available at http://www.alz.org/documents_custom/2011_Facts_Figures_Fact_Sheet.pdf (last visited Aug. 3, 2011).

⁴ *Id.* at 17.

⁵ *Id.*

⁶ *2011 Alzheimer's Disease Facts and Figures*, *supra* note 4, at 35.

⁷ *Id.*

⁸ *Id.* at 44.

⁹ This number was established by using an average of 21.9 hours of care a week with a value of \$11.93 per hour. *Id.* at 27.

¹⁰ *Id.* at 32.

Initiative). The Initiative has four objectives: (1) to provide supportive services; (2) to establish memory disorder clinics; (3) to provide model day care programs to test new care alternatives; and (4) to establish a research database and brain bank to support research.¹¹ There are 15 memory disorder clinics throughout the state, 13 of which are state funded.¹² The purpose of these clinics is to conduct research related to diagnostic technique, therapeutic interventions, and supportive services for persons with Alzheimer's disease and to develop caregiver-training materials.¹³ According to ADI, the memory disorder clinics are required to:

- Provide services to persons suspected of having Alzheimer's disease or other related dementia;
- Provide four hours of in-service training during the contract year to all ADI respite and model day care service providers and develop and disseminate training models to service providers and the Department of Elder Affairs;
- Develop training materials and educational opportunities for lay and professional caregivers and provide specialized training for caregivers and caregiver organizations;
- Conduct service-related applied research;
- Establish a minimum of one annual contact with each respite care and model day care service provider to discuss, plan, develop, and conduct service-related research projects; and
- Plan for the public dissemination of research findings through professional papers and to the general public.¹⁴

Individuals diagnosed with or suspected of having Alzheimer's disease are eligible for memory disorder clinic services. In fiscal year 2009-2010, Florida's memory disorder clinics received nearly \$3 million in state funds and served just over 5,000 clients.¹⁵

Model day care programs have been established in conjunction with memory disorder clinics to test therapeutic models and provide day care services. These programs provide a safe environment where Alzheimer's patients can socialize with each other, as well as receive therapeutic interventions designed to maintain or improve their cognitive functioning. Model day care programs also provide training for health care and social service personnel in the care of individuals with Alzheimer's disease or related memory disorders. There are currently four model day care programs in the state.¹⁶

The ADI also includes respite care services, which includes in-home, facility-based, emergency and extended care respite for caregivers who serve individuals with memory disorders.¹⁷ In addition to respite care services, caregivers and consumers may receive supportive services essential to maintaining individuals with Alzheimer's disease or related dementia in their own

¹¹ Fla. Dep't of Elder Affairs, *Alzheimer's Disease Initiative*, <http://elderaffairs.state.fl.us/english/alz.php> (last visited Aug. 16, 2011).

¹² *Id.*

¹³ Section 430.502(2), F.S.

¹⁴ Fla. Dep't of Elder Affairs, *Summary of Programs and Services*, 87-88 (Feb. 2011), available at http://elderaffairs.state.fl.us/english/pubs/pubs/sops2011/Files/2011_SOPS_full%20web.pdf (last visited Aug. 16, 2011).

¹⁵ *Id.* at 91.

¹⁶ Fla. Dep't of Elder Affairs, *supra* note 11.

¹⁷ *Id.*

homes. The supportive services may include caregiver training and support groups, counseling, consumable medical supplies and nutritional supplements. Services are authorized by a case manager based on a comprehensive assessment. Alzheimer's Respite Care programs are established in all of Florida's 67 counties.¹⁸

Alzheimer's Disease State Plans¹⁹

Currently, 30 states and the District of Columbia have developed or are in the process of developing state plans to deal with the Alzheimer's disease epidemic. In 2009, the Alzheimer's Study Group (ASG), an 11 member blue ribbon panel, released a report outlining recommendations to deal with Alzheimer's disease related issues and policy. These recommendations included:

- Expanding the type, pace, and level of funding of Alzheimer's research;
- Instituting value-based payments to reimburse providers who care for individuals with Alzheimer's; and
- Creating an Alzheimer's Solutions Project Office within the federal government to coordinate and oversee implementation of Alzheimer's-related issues and policy.

In response to the ASG report, Congress passed the National Alzheimer's Project Act (NAPA). NAPA requires the federal Department of Health and Human Services to create a national strategic plan to coordinate Alzheimer's disease efforts across the federal government.

Florida does not currently have a state plan in place to deal with the Alzheimer's disease crisis. Developing and implementing a state plan is a four-phase process.²⁰ The first phase is a state mandate that puts the weight of state government behind the development of an Alzheimer's disease state plan through the creation of a state plan task force. This bill would accomplish the first phase of the state plan process.

III. Effect of Proposed Changes:

This bill creates the Purple Ribbon Task Force within the Department of Elder Affairs (DOEA) to develop a comprehensive state plan to address the needs of individuals with Alzheimer's disease and their caregivers.

The purpose of the task force is to:

- Assess the current and future impact of Alzheimer's disease and related forms of dementia on the state.

¹⁸ *Id.*

¹⁹ Alzheimer's Association, *Issue Kit: State Government Alzheimer's Disease Plans*, 4 (on file with the Senate Committee on Children, Families, and Elder Affairs).

²⁰ The first phase involves creating a state task force to develop an Alzheimer's disease state plan. The second phase involves the development of the state plan as mandated by the task force. Phase three is translating the vision of the state plan into actual public policy. And phase four focuses on executing the programs and enforcement of the policies outlined in the state plan. *Id.* at 5.

- Examine the existing industries, services, and resources addressing the needs of persons having Alzheimer's disease or a related form of dementia and their family caregivers.
- Develop a strategy to mobilize a state response to Alzheimer's disease.
- Hold public meetings to gather feedback on the recommendations submitted by persons having Alzheimer's disease or a related form of dementia and their family caregivers and by the general public.

Additionally, the bill requires the task force to provide information regarding state trends with respect to people with Alzheimer's disease or a related form of dementia and their needs, including, but not limited to:

- The role of the state in providing long-term care, family caregiver support, and assistance to persons who are in the early stages of Alzheimer's disease, who have early-onset Alzheimer's disease, or who have a related form of dementia;
- The development of state policy with respect to persons having Alzheimer's disease or a related form of dementia;
- Surveillance of persons having Alzheimer's disease or a related form of dementia for the purpose of accurately estimating the number of such persons in the state;
- Existing services, resources, and capacity;
- The type, cost, and availability of dementia services in the state;
- Requirements for dementia-specific training for professionals providing care;
- Quality care measures employed by long-term care facilities;
- The capability of public safety workers and law enforcement officers to respond to persons having Alzheimer's disease or a related form of dementia;
- The availability of home and community-based services for persons having Alzheimer's disease or a related form of dementia and respite care to assist their families;
- An inventory of long-term care facilities serving persons having Alzheimer's disease or a related form of dementia;
- The adequacy and appropriateness of geriatric-psychiatric units for persons having behavior disorders associated with Alzheimer's disease or other dementia;
- Residential assisted living options for persons having Alzheimer's disease or a related form of dementia;
- The level of preparedness of service providers before, during, and after a catastrophic emergency involving a person having Alzheimer's disease or a related form of dementia;
- Needed state policies or responses.

The task force shall consist of 18 members, six appointed by the Governor, six appointed by the President of the Senate, and six appointed by the Speaker of the House of Representatives. The members of the task force shall be as follows:

- A member of the House of Representatives;
- A member of the Senate;
- A representative from the Alzheimer's Association;
- At least one person having Alzheimer's disease or a related form of dementia;
- At least one family caregiver or former family caregiver of a person having Alzheimer's disease or a related form of dementia;

- A representative from the Alzheimer’s Disease Advisory Committee or a state memory disorder clinic;
- A representative of law enforcement with knowledge about the disappearance, abuse, exploitation, and suicide of persons having Alzheimer’s disease or a related form of dementia;
- An expert on the Baker Act;
- An expert on emergency preparedness for persons having Alzheimer’s disease or a related form of dementia;
- A representative of a health care facility that serves persons with Alzheimer’s disease;
- A representative of the adult day care services industry;
- A representative of health care practitioners specializing in the treatment of persons having Alzheimer’s disease or related dementias;
- An elder-law attorney;
- A representative of the area agencies on aging or aging resource centers; and
- A person who is an Alzheimer’s disease researcher.

Task force appointments must be made by July 1, 2012, and members of the task force are to serve without compensation and may not receive reimbursement for per diem or travel expenses.

Finally, the task force must submit a report of its findings and date-specific recommendations in the form of an Alzheimer’s disease state strategy and policy recommendations to the Governor and Legislature by August 1, 2013. The task force will terminate on the earlier of the date the report is submitted or August 1, 2013.

The bill provides an effective date of July 1, 2012.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

V. Fiscal Impact Statement:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

This bill creates the Purple Ribbon Task Force comprising of 18 members. These members are to serve on the task force without compensation and may not receive reimbursement for per diem or travel expenses. Accordingly, any costs that may be incurred as a result of participating on the task force will be borne by the individual.

C. Government Sector Impact:

The bill creates the Purple Ribbon Task Force within the Department of Elder Affairs (DOEA or department) and provides that the department shall provide any necessary administrative support for the task force. According to a representative from the department, this bill should have an insignificant impact on DOEA because any potential fiscal impact is expected to be absorbed with existing resources.²¹

VI. Technical Deficiencies:

The bill provides that initial appointments to the task force are to be made by July 1, 2012. The effective date of the bill is also July 1, 2012. The bill may not provide enough time for the Governor, President of the Senate, and Speaker of the House of Representatives to appoint the 18 members of the task force due to the fact the effective date of the bill coincides with the date the members of the task force are supposed to be appointed.

Lines 163-168 of the bill provide that the task force is to hold public meetings and gather recommendations from the public, however, the bill does not specify what the purpose of the public meetings is or what type of recommendations the task force should be collecting from the public.

VII. Related Issues:

None.

VIII. Additional Information:**A. Committee Substitute – Statement of Substantial Changes:**

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

None.

B. Amendments:

None.

This Senate Bill Analysis does not reflect the intent or official position of the bill's introducer or the Florida Senate.

²¹ Health & Human Servs. Access Subcommittee, The Florida House of Representatives, *HB 473, Alzheimer's Disease*, 6, available at <http://www.flsenate.gov/Session/Bill/2012/0473/Analyses/YluJKpGJO1ZB6M7smYBwSel=PL=rCo=%7C11/Public/Bills/0400-0499/0473/Analysis/h0473a.HSAS.PDF> (last visited Jan. 9, 2012).