

**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 Budget Subcommittee on Health and Human Services Appropriations

BILL: CS/CS/SB 682

INTRODUCER: Governmental Oversight and Accountability Committee, Children, Families, and Elder Affairs Committee, Senator Richter and others

SUBJECT: Alzheimer's Disease

DATE: February 2, 2012      REVISED: \_\_\_\_\_

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	<u>Daniell</u>	<u>Farmer</u>	<u>CF</u>	<b>Fav/CS</b>
2.	<u>Jenkins</u>	<u>Roberts</u>	<u>GO</u>	<b>Fav/CS</b>
3.	<u>Brown</u>	<u>Hendon</u>	<u>BHA</u>	<b>Pre-meeting</b>
4.	_____	_____	<u>BC</u>	_____
5.	_____	_____	_____	_____
6.	_____	_____	_____	_____

**Please see Section VIII. for Additional Information:**

- |                              |                                     |   |
|------------------------------|-------------------------------------|---|
| A. COMMITTEE SUBSTITUTE..... | <input checked="" type="checkbox"/> | Statement of Substantial Changes        |
| B. AMENDMENTS.....           | <input type="checkbox"/>            | Technical amendments were recommended   |
|                              | <input type="checkbox"/>            | Amendments were recommended             |
|                              | <input type="checkbox"/>            | Significant amendments were recommended |

**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; examine the needs of persons of all cultural backgrounds having Alzheimer's disease; develop a strategy to mobilize a state response to the Alzheimer's disease epidemic; hold public meetings; 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.

The bill has no fiscal impact on government.

The bill creates an unnumbered section of the Florida Statutes.

The bill takes effect upon becoming a law.

## 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.<sup>1</sup>

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.<sup>2</sup>

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.<sup>3</sup> 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.<sup>4</sup> That number is expected to rise to 959,000 new cases of Alzheimer's disease by 2050, a 130 percent increase from 2000.<sup>5</sup> 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.<sup>6</sup>

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.<sup>7</sup> 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.<sup>8</sup> The total Medicaid spending for people with Alzheimer's disease (and other dementia) was estimated to be \$37 billion in 2011.<sup>9</sup>

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

<sup>2</sup> Michael Plontz, *A Brief History of Alzheimer's Disease*, TODAY'S CAREGIVER, [http://www.caregiver.com/channels/alz/articles/a\\_brief\\_history.htm](http://www.caregiver.com/channels/alz/articles/a_brief_history.htm) (last visited Aug. 2, 2011).

<sup>3</sup> 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](http://www.alz.org/documents_custom/2011_Facts_Figures_Fact_Sheet.pdf) (last visited Aug. 3, 2011).

<sup>4</sup> Alzheimer's Assn., *2011 Alzheimer's Disease Facts and Figures*, 7 ALZHEIMER'S & DEMENTIA (Issue 2) at 17, available at [http://www.alz.org/downloads/Facts\\_Figures\\_2011.pdf](http://www.alz.org/downloads/Facts_Figures_2011.pdf) (last visited Jan. 10, 2012).

<sup>5</sup> *Id.*

<sup>6</sup> *Id.* at 18.

<sup>7</sup> *Id.* at 35.

<sup>8</sup> *Id.*

<sup>9</sup> *Id.* at 44.

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.<sup>10</sup> In 2010, there were 960,037 caregivers in Florida with an estimated value of unpaid care reaching nearly \$13.5 million.<sup>11</sup>

### **Alzheimer's Disease Initiative**

In 1985, the Florida Legislature put into place the Alzheimer's Disease Initiative (ADI or 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.<sup>12</sup> There are 15 memory disorder clinics throughout the state, 13 of which are state funded.<sup>13</sup> 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.<sup>14</sup> 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.<sup>15</sup>

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.<sup>16</sup>

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

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<sup>10</sup> 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.

<sup>11</sup> *Id.* at 32.

<sup>12</sup> Fla. Dep't of Elder Affairs, *Alzheimer's Disease Initiative*, <http://elderaffairs.state.fl.us/english/alz.php> (last visited Aug. 16, 2011).

<sup>13</sup> *Id.*

<sup>14</sup> Section 430.502(2), F.S.

<sup>15</sup> 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](http://elderaffairs.state.fl.us/english/pubs/pubs/sops2011/Files/2011_SOPS_full%20web.pdf) (last visited Aug. 16, 2011).

<sup>16</sup> *Id.* at 91.

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.<sup>17</sup>

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.<sup>18</sup> 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 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.<sup>19</sup>

### **Alzheimer's Disease State Plans<sup>20</sup>**

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.<sup>21</sup> 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.

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<sup>17</sup> Fla. Dep't of Elder Affairs, *supra* note 12.

<sup>18</sup> *Id.*

<sup>19</sup> *Id.*

<sup>20</sup> Alzheimer's Assn., *Issue Kit: State Government Alzheimer's Disease Plans*, 4 (on file with the Senate Committee on Children, Families, and Elder Affairs).

<sup>21</sup> 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. Phase four focuses on executing the programs and enforcement of the policies outlined in the state plan. *Id.* at 5.

### 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 bill requires the task force to:

- Submit an interim study regarding state trends with respect to persons having Alzheimer's disease or a related form of dementia and their needs to the Governor, the President of the Senate, and the Speaker of the House of Representatives by January 30, 2013;
- 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;
- Examine the needs of persons of all cultural backgrounds having Alzheimer's disease or a related form of dementia and how their lives are affected by the disease from younger-onset, through mid-stage, to late-stage;
- Develop a strategy to mobilize a state response to Alzheimer's disease; and
- Hold public meetings and employ technological means 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 community-based care, long-term care, family caregiver support, and assistance 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;
- 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;
- Policy requirements and effectiveness for dementia-specific training for professionals providing care;
- Quality care measures employed by providers of care;
- 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 and respite care for persons having Alzheimer's disease or a related form of dementia and education and support services to assist their families and caregivers;
- An inventory of long-term care facilities and community-based services 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; and
- Needed state policies or responses.

The task force shall consist of 18 volunteer, culturally diverse members, six of whom shall be 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;
- 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;
- A representative who has knowledge of and experience with the Baker Act and its impact on persons having Alzheimer's disease or a related form of dementia;
- An expert on disaster preparedness and response for persons having Alzheimer's disease or a related form of dementia;
- A representative of a health care facility or hospice 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;
- A Florida board-certified elder law attorney;
- A representative of the area agencies on aging or aging and disability resource centers;
- A person who is an Alzheimer's disease researcher;
- A representative from a memory disorder clinic;
- A representative of the assisted living facility industry; and
- A representative of the skilled nursing facility industry.

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 final date-specific recommendations in the form of an Alzheimer's disease state plan 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 shall take effect upon becoming a law.

**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 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, costs that may be incurred as a result of participating on the task force will be borne by each individual member.

## 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. This bill should have an insignificant impact on DOEA because any potential fiscal impact is expected to be absorbed with existing resources.<sup>22</sup>

**VI. Technical Deficiencies:**

None.

**VII. Related Issues:**

None.

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<sup>22</sup> Health & Human Services. 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).

**VIII. Additional Information:**

- A. **Committee Substitute – Statement of Substantial Changes:**  
(Summarizing differences between the Committee Substitute and the prior version of the bill.)

**CS/CS by Government Oversight and Accountability on January 26, 2012:**

The committee substitute:

- Provides that the task force shall consist of 18 volunteer, culturally diverse members.
- Adds a requirement that the task force to submit an interim study regarding state trends with respect to persons having Alzheimer’s disease or a related form of dementia and their needs to the Governor, Speaker of the House of Representatives, and the President of the Senate by January 30, 2013.

**CS by Children, Families, and Elder Affairs on January 12, 2012:**

The committee substitute:

- Specifies additional members of the task force (a representative from a memory disorder clinic, the assisted living facility industry, and the skilled nursing facility industry) and provides hospice and Aging and Disability Resource Centers the opportunity to be represented;
- Requires the task force to examine the needs of persons of all cultural backgrounds having Alzheimer’s disease or a related form of dementia;
- Includes reference to alternative avenues of care, such as community-based care, respite, adult day care, and hospice services;
- Clarifies that task force meetings may be held in person (not just electronically or by teleconference);
- Provides in the whereas clauses the most current numbers on the Alzheimer’s disease population in the state;
- Changes the effective date from July 1, 2012, to upon becoming a law; and
- Makes technical changes.

- B. **Amendments:**

None.