

HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: CS/CS/HB 473 Alzheimer's Disease

SPONSOR(S): Health & Human Services Committee; Health & Human Services Access Subcommittee; Hudson and others

TIED BILLS: **IDEN./SIM. BILLS:** SB 682

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR or BUDGET/POLICY CHIEF
1) Health & Human Services Access Subcommittee	15 Y, 0 N, As CS	Guzzo	Schoolfield
2) Health & Human Services Committee	17 Y, 0 N, As CS	Guzzo	Gormley

SUMMARY ANALYSIS

The 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 assess the current and future impact of Alzheimer's disease and related forms of dementia on the state; examine the existing industries, services, and resources in place that address the needs of individuals with Alzheimer's disease; develop a strategy to mobilize a state response to the Alzheimer's disease epidemic; and provide certain information regarding the development of state policy with respect to individuals with Alzheimer's disease, the role of the state in providing care to those with Alzheimer's disease, and the number of people having Alzheimer's disease in the state.

The bill requires the task force to consist of 18 volunteer, culturally diverse members to serve without compensation or reimbursement for per diem or travel expenses with six members appointed by each the Governor, the Speaker of the House of Representatives and the President of the Senate. The bill requires the members of the task force to be appointed by July 1, 2012.

The bill requires DOEA to convene the task force and provide necessary administrative support.

The bill requires the task force to conduct an interim study regarding state trends with respect to individuals with Alzheimer's disease or a related form of dementia. The interim study must be submitted to the Governor and the legislature by January 30, 2013.

The bill requires the task force to submit a report of its findings and date-specific recommendations in the form of an Alzheimer's disease state plan 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 will terminate on the earlier of the date the report is submitted or August 1, 2013.

The bill has an insignificant fiscal impact which can be absorbed by the Department of Elder Affairs.

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

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. EFFECT OF PROPOSED CHANGES:

Current Situation

Alzheimer's Disease Statistics

There is an estimated 5.4 million people in the United States with Alzheimer's disease, including 5.2 million people aged 65 and older and 200,000 individuals under age 65 who have younger-onset Alzheimer's disease.¹ In addition, there is an estimated 459,806 individuals suffering from Alzheimer's disease in the state of Florida.²

By 2030, the segment of the United States population aged 65 years and older is expected to double, and the estimated 71 million older Americans will make up approximately 20 percent of the total population.³ By 2050, the number of people aged 65 and older with Alzheimer's disease is expected to triple to a projected 16 million people.⁴

State Plans

Currently, 30 states 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 eleven member blue ribbon panel released a report outlining recommendations to deal with Alzheimer's disease 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.⁵ Florida does not currently have a state plan or task force in place to deal with the Alzheimer's disease epidemic. However, the Alzheimer's Disease Initiative (ADI), which was created by the Florida Legislature in 1985, does conduct research and advise the Department of Elder Affairs (DOEA) regarding legislative, programmatic and administrative matters that are related to Alzheimer's disease and their caretakers.⁶

Alzheimer's Disease Initiative

The Alzheimer's Disease Initiative was created to provide a continuum of services to meet the changing needs of individuals with Alzheimer's disease and their families. The Department of Elder Affairs coordinates and develops policy to carry out the statutory requirements for the ADI. In conjunction with a ten-member advisory committee appointed by the Governor, the program includes the following four components:⁷

- Supportive services including counseling, consumable medical supplies and respite for caregiver relief;
- Memory disorder clinics to provide diagnosis, research, treatment, and referral;
- Model day care programs to test new care alternatives; and
- A research database and brain bank to support research.

¹ Alzheimer's Association, 2011 Alzheimer's Disease Fact and Figures, located at http://www.alz.org/alzheimers_disease_facts_and_figures.asp

² Florida Department of Elder Affairs, 2011 Florida State Profile, located at http://elderaffairs.state.fl.us/english/pubs/stats/County_2011Projections/Florida_Map.html

³ Alzheimer's Association, 2011 Alzheimer's Disease Fact and Figures, located at http://www.alz.org/alzheimers_disease_facts_and_figures.asp

⁴ Id.

⁵ Alzheimer's Association, *Issue Kit: State Government Alzheimer's Disease Plans*

⁶ Florida Department of Elder Affairs, see <http://elderaffairs.state.fl.us/english/alz.php> (last visited November 30, 2011).

⁷ Id.

Section 430.501, F.S., authorizes DOEA to adopt rules necessary to carry out the duties of the advisory committee. The area agency on aging, under contract with DOEA, is responsible for the planning and administration of respite and model day care services funded under the ADI and must contract with local service providers for the provision of these services.⁸

The ADI is funded by General Revenue and Tobacco Settlement funds. The DOEA allocates General Revenue funding to each of the Area Agencies on Aging, which in turn fund providers of model day care and respite care programs in designated counties.⁹ Provider agencies are responsible for the collection of fees for ADI services. To help pay for services received pursuant to the ADI, a functionally impaired elderly person is assessed a fee based on an overall ability to pay in accordance with Rule 58C-1.007, F.A.C.

Alzheimer's Disease Advisory Committee

The Alzheimer's Disease Advisory Committee is a 10-member panel that advises DOEA regarding legislative, programmatic and administrative matters that are related to Alzheimer's disease victims and their caretakers. Committee members must be Florida residents and reflect the following representation:¹⁰

- At least four of the 10 members must be licensed pursuant to Chapter 458 or 459, F.S., or hold a Ph.D. degree and be currently involved in research of Alzheimer's disease;
- The 10 members must include at least four people who have been caregivers of victims of Alzheimer's disease; and
- Whenever possible, there should be one individual from each of the following professions: a gerontologist, a geriatric psychiatrist, a geriatrician, a neurologist, a social worker and a registered nurse.

Members are appointed to four-year staggered terms. The committee elects one of its members to serve as chair for a one-year term. Committee meetings are held quarterly or as frequently as needed.

The function of the Advisory Committee is to advise DOEA in the performance of its duties under the ADI. As appropriate, and with the approval of DOEA, the Advisory Committee may establish subcommittees.¹¹

Respite Services

Alzheimer's Respite Care programs are established in all of Florida's 67 counties.¹² ADI respite includes in-home, facility-based, emergency and extended care (up to 30 days) respite for caregivers who serve individuals with memory disorders. 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 and on unmet needs identified during that assessment.

Memory Disorder Clinics

There are 15 memory disorder clinics authorized to provide diagnostic and referral services for persons with Alzheimer's disease and related dementia.¹³ The centers, 13 of which are funded by the state, also conduct service-related research and develop caregiver training materials and educational opportunities. Clinics are established at medical schools, teaching hospitals, and public and private not-for-profit hospitals throughout the state in accordance with s. 430.502, F.S.

⁸ Rule 58D-1.005, F.A.C.

⁹ Florida Department of Elder Affairs, *State General Revenue Program Report 2011*.

¹⁰ Section 430.501(3), F.S.

¹¹ *Id.*

¹² Florida Department of Elder Affairs, see <http://elderaffairs.state.fl.us/english/alz.php> (last visited November 18, 2011).

¹³ Section 430.502(1), F.S.

Model Day Care

Model day care programs have been established in conjunction with memory disorder clinics to test therapeutic models and provide day care services. The model day care programs provide a safe environment where Alzheimer's patients congregate for the day and 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 and related memory disorders. There are currently four model day care programs in the state.¹⁴

Brain Bank

The Florida Alzheimer's disease brain bank is a service and research oriented network of statewide regional sites. The intent of the brain bank program is to collect and study the brains of deceased patients who had been clinically diagnosed with dementia. Mt. Sinai Medical Center contracts annually with the state of Florida to operate the primary brain bank. Coordinators at regional brain bank sites in Orlando, Tampa and Pensacola help recruit participants and act as liaisons between the brain bank and participants' families.¹⁵

Effect of Proposed Changes

The bill establishes the Purple Ribbon Task Force within the Department of Elder Affairs and contains the following "whereas clauses:"

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

The bill creates the Purple Ribbon Task Force within DOEA to develop a comprehensive state plan to address the needs of individuals with Alzheimer's disease and their caregivers. The bill does not address or make any changes to the current Alzheimer's Disease Initiative.

¹⁴ Florida Department of Elder Affairs, see <http://elderaffairs.state.fl.us/english/alz.php> (last visited November 30, 2011).

¹⁵ Florida Department of Elder Affairs, *State General Revenue Program Report 2011*.

The bill requires the task force to consist of 18 volunteer, culturally diverse members to serve without compensation or reimbursement for per diem or travel expenses. Six of the members must be appointed by each the Governor, the Speaker of the House of Representatives and the President of the Senate. The bill requires the members of the task force to be appointed by July 1, 2012. The task force must consist of the following:

- 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 of a person with 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 disappearance and recovery, self-neglect, abuse, exploitation, and suicide of persons having Alzheimer's disease or a related form of dementia;
- A representative having knowledge of and expertise with the Baker Act and its impact on individuals with Alzheimer's disease;
- An expert on disaster preparedness and response for individuals with Alzheimer's disease;
- A representative of a health care facility or hospice that serves individuals with Alzheimer's disease;
- A representative of the adult day care services industry;
- A representative of health care practitioners specializing in the treatment of individuals with Alzheimer's disease;
- A Florida board certified elder law attorney;
- A representative of the area agencies on 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.

The bill requires DOEA to convene the task force and provide necessary administrative support. Meetings of the task force may be held in person without compensation or travel reimbursement, by teleconference or by other electronic means.

The bill requires the task force to perform the following duties:

- Access the current and future impact of Alzheimer's disease on the state;
- Examine the existing industries, services, and resources addressing the needs of people with Alzheimer's disease;
- Examine the needs of individuals with Alzheimer's disease or a related form of dementia and the effects it has from the early-onset, mid-stage, and late stage inclusive of all cultures;
- Develop a strategy to mobilize a state response; and
- Hold public meetings and employ technological means to gather feedback on the recommendations submitted by individuals with Alzheimer's disease or a related form of dementia, their caregivers, and by the general public.

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 including respite, education, and assistance to people 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 individuals with Alzheimer's disease or a related form of dementia;

- Surveillance of people with Alzheimer’s disease for the purpose of accurately estimating the number of such persons in the state at present and projected population;
- Existing services, resources, and capacity;
- The type, cost, and availability of dementia-specific services throughout the state;
- Policy requirements and effectiveness for dementia-specific training for professionals providing care;
- Quality care measures employed by providers of care including respite, adult day care, assisted living facility, skilled nursing facility and hospice;
- The capability of public safety workers and law enforcement officers to respond to people with Alzheimer’s disease or a related form of dementia;
- The availability of home and community-based services and respite care for people with 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 people with Alzheimer’s disease or a related form of dementia;
- The adequacy and appropriateness of geriatric-psychiatric units for people who have behavior disorders associated with Alzheimer’s disease or a related form of dementia;
- Residential assisted living options for people with Alzheimer’s disease or a related form of dementia;
- The level of preparedness of service providers before, during, and after a catastrophic emergency involving people with Alzheimer’s disease or a related form of dementia, their caregivers and families; and
- Needed state policies or responses.

The bill requires the task force to conduct an interim study regarding state trends with respect to individuals with Alzheimer’s disease or a related form of dementia. The interim study must be submitted to the Governor and the legislature by January 30, 2013.

Finally, the bill requires the task force to submit a report of its findings and date-specific recommendations in the form of an Alzheimer’s disease state plan 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 will terminate on the earlier of the date the report is submitted or August 1, 2013.

B. SECTION DIRECTORY:

Section 1. Establishes the Purple Ribbon Task Force within the Department of Elder Affairs in an unnamed section of law.

Section 2. Provides an effective date of July 1, 2012.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

2. Expenditures:

Insignificant impact. Any potential fiscal impact is expected to be absorbed with existing resources at the Department of Elder Affairs.¹⁶

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

¹⁶ Email from Joshua Spagnola, Florida Department of Elder Affairs, November 14, 2011. (On file with committee staff).

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

None.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

Not applicable. This bill does not appear to affect county or municipal governments.

2. Other:

None.

B. RULE-MAKING AUTHORITY:

None.

C. DRAFTING ISSUES OR OTHER COMMENTS:

None.

IV. AMENDMENTS/ COMMITTEE SUBSTITUTE CHANGES

On December 7, 2011, the Health and Human Services Access Subcommittee adopted a strike-all amendment. The amendment:

- Makes several technical changes to provide clarification;
- Requires additional representation of the task force to include a representative from a memory disorder clinic, assisted living facility, and a skilled nursing facility;
- Requires the task force to examine the needs of individuals with Alzheimer's disease or a related form of dementia and the effects it has from the early-onset, mid-state, and late stage inclusive of all cultures;
- Provides that the task force may meet in person without compensation or travel reimbursement; and
- Changes the name of the Alzheimer's disease state strategy and policy recommendations to the Alzheimer's disease state plan.

On February 2, 2012, the Health and Human Services Committee adopted two amendments. The amendments:

- Require the Purple Ribbon Task Force to consist of 18 volunteer, *Culturally diverse*, members; and
- Require the Purple Ribbon Task Force to submit an interim study to the Governor and the legislature by January 30, 2013, regarding state trends with respect to individuals with Alzheimer's disease or a related form of dementia and their needs.

The bill was reported favorably as a Committee Substitute. This analysis reflects the Committee Substitute.