By the Committee on Children, Families, and Elder Affairs; and Senators Richter, Sachs, Latvala, Joyner, Bennett, and Gibson

586-01856-12 2012682c1

A bill to be entitled

An act relating to Alzheimer's disease; establishing the Purple Ribbon Task Force within the Department of Elderly Affairs; providing for membership; providing that members shall serve without compensation or reimbursement for per diem or travel expenses; requiring the department to provide administrative support; providing duties of the task force; authorizing the task force to hold meetings by teleconference or other electronic means, or in person without compensation or reimbursement for per diem or travel expenses; requiring the task force to submit a report in the form of an Alzheimer's disease state plan to the Governor and Legislature; providing for termination of the task force; providing an effective date.

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, and

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, and

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, and

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WHEREAS, there are 459,806 probable cases of Alzheimer's disease in this state in 2011, which population is expected to triple by the year 2050, and

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 the disease, and

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, and

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 a more inclusive, 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, NOW,

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59 THEREFORE,

Be It Enacted by the Legislature of the State of Florida:

- Section 1. The Purple Ribbon Task Force.—The Purple Ribbon Task Force is established within the Department of Elderly Affairs.
- (1) The task force shall consist of 18 volunteer members, of whom six shall be appointed by the Governor, six shall be appointed by the Speaker of the House of Representatives, and six shall be appointed by the President of the Senate, as follows:
 - (a) A member of the House of Representatives.
 - (b) A member of the Senate.
 - (c) A representative from the Alzheimer's Association.
- (d) At least one person having Alzheimer's disease or a related form of dementia.
- (e) At least one family caregiver or former family caregiver of a person having Alzheimer's disease or a related form of dementia.
- (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 having Alzheimer's disease or a related form of dementia.
- (h) 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.

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(i) An expert on disaster preparedness and response for persons having Alzheimer's disease or a related form of dementia.

- (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.
- (1) A representative of health care practitioners specializing in the treatment of persons having Alzheimer's disease or a related form of dementia.
 - (m) A Florida board-certified elder law attorney.
- (n) A representative of the area agencies on aging or aging and disability resource centers.
 - (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.
- (r) A representative of the skilled nursing facility industry.
- (2) Initial appointments to the task force shall be made by July 1, 2012. A vacancy on the task force shall be filled for the unexpired portion of the term in the same manner as the original appointment.
- (3) Members shall serve on the task force without compensation and may not receive reimbursement for per diem or travel expenses.
- (4) The Department of Elderly Affairs shall convene the task force and provide necessary administrative support.
 - (5) The task force shall:

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

- (b) 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.
- (c) 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.
- (d) Develop a strategy to mobilize a state response to this public health crisis.
 - (e) Provide information regarding:
- 1. State trends with respect to persons having Alzheimer's disease or a related form of dementia and their needs, including, but not limited to:
- a. The role of the state in providing community-based care, long-term care, and family caregiver support, including respite, education, and assistance to persons who are in the early stages of Alzheimer's disease, who have younger-onset Alzheimer's disease, or who have a related form of dementia.
- b. The development of state policy with respect to persons having Alzheimer's disease or a related form of dementia.
- c. 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 at present and projected population levels.
- 2. Existing services, resources, and capacity, including, but not limited to:

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a. The type, cost, and availability of dementia-specific services throughout the state.

- b. Policy requirements and effectiveness for dementiaspecific training for professionals providing care.
- c. Quality care measures employed by providers of care, including providers of respite, adult day care, assisted living facility, skilled nursing facility, and hospice services.
- d. The capability of public safety workers and law enforcement officers to respond to persons having Alzheimer's disease or a related form of dementia, including, but not limited to, responding to their disappearance, search and rescue, abuse, elopement, exploitation, or suicide.
- e. The availability of home and community-based services and respite care for persons having Alzheimer's disease or a related form of dementia and education and support services to assist their families and caregivers.
- <u>f. An inventory of long-term care facilities and community-based services serving persons having Alzheimer's disease or a related form of dementia.</u>
- g. The adequacy and appropriateness of geriatricpsychiatric units for persons having behavior disorders associated with Alzheimer's disease or a related form of dementia.
- h. Residential assisted living options for persons having Alzheimer's disease or a related form of dementia.
- i. 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 their caregivers and families.

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3. Needed state policies or responses, including, but not limited to, directions for the provision of clear and coordinated care, services, and support to persons having Alzheimer's disease or a related form of dementia and their caregivers and families and strategies to address any identified gaps in the provision of services.

- (f) 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, their caregivers and families, and the general public. Meetings of the task force may be held in person without compensation or reimbursement for travel expenses, by teleconference, or by other electronic means.
- (6) The task force shall 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 shall terminate on the earlier of the date the report is submitted or August 1, 2013.

Section 2. This act shall take effect upon becoming a law.