

By the Committees on Budget Subcommittee on Health and Human Services Appropriations; Governmental Oversight and Accountability; and Children, Families, and Elder Affairs; and Senators Richter, Sachs, Latvala, Joyner, Bennett, Gibson, and Dockery

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1 A bill to be entitled

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

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18 WHEREAS, Alzheimer's disease is a slow, progressive
19 disorder of the brain that results in loss of memory and other
20 cognitive functions and eventually death, and

21 WHEREAS, because Alzheimer's disease is accompanied by
22 memory loss, poor judgment, changes in personality and behavior,
23 and a tendency to wander or become lost, a person with this
24 disease is at an increased risk for accidental injury, abuse,
25 neglect, and exploitation, and

26 WHEREAS, approximately one in eight Americans 65 years of
27 age or older and almost half of Americans 85 years of age or
28 older develop Alzheimer's disease or a related form of dementia,
29 and

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

33 WHEREAS, Alzheimer's disease takes an enormous toll on
34 family members, with an estimated one in four family members
35 providing caregiving support for individuals with the disease,
36 and

37 WHEREAS, caregivers for persons having Alzheimer's disease
38 witness the deteriorating effects of the disease and often
39 suffer more emotional stress, depression, and health problems
40 than caregivers of people having other illnesses, which can
41 negatively affect such caregivers' employment, income, and
42 financial security, and

43 WHEREAS, younger-onset Alzheimer's disease is a form of
44 Alzheimer's disease that strikes a person who is younger than 65
45 years of age when symptoms first appear, but younger-onset
46 Alzheimer's disease can strike persons as early as 30, 40, or 50
47 years of age, with new data showing that there may be as many as
48 500,000 Americans under the age of 65 who have dementia or
49 cognitive impairment at a level of severity consistent with
50 dementia, and

51 WHEREAS, the state needs to assess the current and future
52 impact of Alzheimer's disease on Floridians and the state's
53 health care system, programs, resources, and services to ensure
54 the continued development and implementation of a more
55 inclusive, integrated, comprehensive, coordinated, and current
56 strategy to address the needs of the growing number of
57 Floridians having Alzheimer's disease or a related form of
58 dementia and the corresponding needs of their caregivers, NOW,

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59 THEREFORE,

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61 Be It Enacted by the Legislature of the State of Florida:62
63 Section 1. The Purple Ribbon Task Force.—The Purple Ribbon
64 Task Force is established within the Department of Elderly
65 Affairs.66 (1) The task force shall consist of 18 volunteer,
67 culturally diverse members, of whom six shall be appointed by
68 the Governor, six shall be appointed by the Speaker of the House
69 of Representatives, and six shall be appointed by the President
70 of the Senate, as follows:71 (a) A member of the House of Representatives.72 (b) A member of the Senate.73 (c) A representative from the Alzheimer's Association.74 (d) At least one person having Alzheimer's disease or a
75 related form of dementia.76 (e) At least one family caregiver or former family
77 caregiver of a person having Alzheimer's disease or a related
78 form of dementia.79 (f) A representative from the Alzheimer's Disease Advisory
80 Committee.81 (g) A representative of law enforcement with knowledge
82 about the disappearance and recovery, self-neglect, abuse,
83 exploitation, and suicide of persons having Alzheimer's disease
84 or a related form of dementia.85 (h) A representative who has knowledge of and experience
86 with the Baker Act and its impact on persons having Alzheimer's
87 disease or a related form of dementia.

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

91 (j) A representative of a health care facility or hospice
92 that serves persons with Alzheimer's disease.

93 (k) A representative of the adult day care services
94 industry.

95 (l) A representative of health care practitioners
96 specializing in the treatment of persons having Alzheimer's
97 disease or a related form of dementia.

98 (m) A Florida board-certified elder law attorney.

99 (n) A representative of the area agencies on aging or aging
100 and disability resource centers.

101 (o) A person who is an Alzheimer's disease researcher.

102 (p) A representative from a memory disorder clinic.

103 (q) A representative of the assisted living facility
104 industry.

105 (r) A representative of the skilled nursing facility
106 industry.

107 (2) Initial appointments to the task force shall be made by
108 July 1, 2012. A vacancy on the task force shall be filled for
109 the unexpired portion of the term in the same manner as the
110 original appointment.

111 (3) Members shall serve on the task force without
112 compensation and may not receive reimbursement for per diem or
113 travel expenses.

114 (4) The Department of Elderly Affairs shall convene the
115 task force and provide necessary administrative support.

116 (5) The task force shall:

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117 (a) Submit to the Governor, the President of the Senate,
118 and the Speaker of the House of Representatives by January 30,
119 2013, an interim study regarding state trends with respect to
120 persons having Alzheimer's disease or a related form of dementia
121 and their needs.

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

124 (c) Examine the existing industries, services, and
125 resources addressing the needs of persons having Alzheimer's
126 disease or a related form of dementia and their family
127 caregivers.

128 (d) Examine the needs of persons of all cultural
129 backgrounds having Alzheimer's disease or a related form of
130 dementia and how their lives are affected by the disease from
131 younger-onset, through mid-stage, to late-stage.

132 (e) Develop a strategy to mobilize a state response to this
133 public health crisis.

134 (f) Provide information regarding:

135 1. State trends with respect to persons having Alzheimer's
136 disease or a related form of dementia and their needs,
137 including, but not limited to:

138 a. The role of the state in providing community-based care,
139 long-term care, and family caregiver support, including respite,
140 education, and assistance to persons who are in the early stages
141 of Alzheimer's disease, who have younger-onset Alzheimer's
142 disease, or who have a related form of dementia.

143 b. The development of state policy with respect to persons
144 having Alzheimer's disease or a related form of dementia.

145 c. The surveillance of persons having Alzheimer's disease

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146 or a related form of dementia for the purpose of accurately
147 estimating the number of such persons in the state at present
148 and projected population levels.

149 2. Existing services, resources, and capacity, including,
150 but not limited to:

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

153 b. Policy requirements and effectiveness for dementia-
154 specific training for professionals providing care.

155 c. Quality care measures employed by providers of care,
156 including providers of respite, adult day care, assisted living
157 facility, skilled nursing facility, and hospice services.

158 d. The capability of public safety workers and law
159 enforcement officers to respond to persons having Alzheimer's
160 disease or a related form of dementia, including, but not
161 limited to, responding to their disappearance, search and
162 rescue, abuse, elopement, exploitation, or suicide.

163 e. The availability of home and community-based services
164 and respite care for persons having Alzheimer's disease or a
165 related form of dementia and education and support services to
166 assist their families and caregivers.

167 f. An inventory of long-term care facilities and community-
168 based services serving persons having Alzheimer's disease or a
169 related form of dementia.

170 g. The adequacy and appropriateness of geriatric-
171 psychiatric units for persons having behavior disorders
172 associated with Alzheimer's disease or a related form of
173 dementia.

174 h. Residential assisted living options for persons having

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175 Alzheimer's disease or a related form of dementia.

176 i. The level of preparedness of service providers before,
177 during, and after a catastrophic emergency involving persons
178 having Alzheimer's disease or a related form of dementia and
179 their caregivers and families.

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

186 (g) Hold public meetings and employ technological means to
187 gather feedback on the recommendations submitted by persons
188 having Alzheimer's disease or a related form of dementia, their
189 caregivers and families, and the general public. Meetings of the
190 task force may be held in person without compensation or
191 reimbursement for travel expenses, by teleconference, or by
192 other electronic means.

193 (6) The task force shall submit a report of its findings
194 and date-specific recommendations in the form of an Alzheimer's
195 disease state plan to the Governor, the Speaker of the House of
196 Representatives, and the President of the Senate no later than
197 August 1, 2013. The task force shall terminate on the earlier of
198 the date the report is submitted or August 1, 2013.

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