

By the Committees on Appropriations; and Health Policy; and
Senators Richter and Soto

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1 A bill to be entitled
2 An act relating to Alzheimer's disease; amending s.
3 252.355, F.S.; requiring the Division of Emergency
4 Management, in coordination with local emergency
5 management agencies, to maintain a registry of persons
6 with special needs; requiring the division to develop
7 and maintain a special needs shelter registration
8 program by a specified date; requiring specified
9 agencies and authorizing specified health care
10 providers to provide registration information to
11 special needs clients or their caregivers and to
12 assist emergency management agencies in registering
13 persons for special needs shelters; amending s.
14 381.0303, F.S.; providing additional staffing
15 requirements for special needs shelters; requiring
16 special needs shelters to establish designated shelter
17 areas for persons with Alzheimer's disease or related
18 forms of dementia; authorizing the Department of
19 Health, in coordination with the division, to adopt
20 rules relating to standards for the special needs
21 registration program; creating s. 381.82, F.S.;
22 establishing the Ed and Ethel Moore Alzheimer's
23 Disease Research Program within the department;
24 requiring the program to provide grants and
25 fellowships for research relating to Alzheimer's
26 disease; creating the Alzheimer's Disease Research
27 Grant Advisory Board; providing for appointment and
28 terms of members; providing for organization, duties,
29 and operating procedures of the board; requiring the

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30 department to provide staff to assist the board in
31 carrying out its duties; requiring the board to
32 annually submit recommendations for proposals to be
33 funded; requiring a report be submitted to the
34 Governor, Legislature, and State Surgeon General;
35 exempting certain activities of the board from the
36 Administrative Procedures Act; authorizing the
37 department to adopt rules; providing that
38 implementation of the program is subject to
39 appropriation; amending s. 430.502, F.S.; updating the
40 name of the memory disorder clinic established in
41 Brevard County; requiring the Department of Elderly
42 Affairs to develop minimum performance standards for
43 memory disorder clinics to receive base-level annual
44 funding; requiring the department to provide
45 incentive-based funding, subject to appropriation, for
46 certain memory disorder clinics; providing an
47 effective date.

48
49 Be It Enacted by the Legislature of the State of Florida:

50
51 Section 1. Section 252.355, Florida Statutes, is amended to
52 read:

53 252.355 Registry of persons with special needs; notice;
54 registration program.—

55 (1) In order to meet the special needs of persons who would
56 need assistance during evacuations and sheltering because of
57 physical, mental, cognitive impairment, or sensory disabilities,
58 the division, in coordination with each local emergency

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59 management agency in the state, shall maintain a registry of
60 persons with special needs located within the jurisdiction of
61 the local agency. The registration shall identify those persons
62 in need of assistance and plan for resource allocation to meet
63 those identified needs.

64 (2) In order to ensure that all persons with special needs
65 may register, the division shall develop and maintain a special
66 needs shelter registration program. The registration program
67 must be developed by January 1, 2015, and fully implemented by
68 March 1, 2015.

69 (a) The registration program shall include, at a minimum, a
70 uniform electronic registration form and a database for
71 uploading and storing submitted registration forms which may be
72 accessed by the appropriate local emergency management agency.
73 The link to the registration form shall be easily accessible on
74 each local emergency management agency's website. Upon receipt
75 of a paper registration form, the local emergency management
76 agency shall enter the person's registration information into
77 the database.

78 (b) To assist the local emergency management agency in
79 identifying such persons with special needs, home health
80 agencies, hospices, nurse registries, home medical equipment
81 providers, the Department of Children and Families Family
82 Services, the Department of Health, the Agency for Health Care
83 Administration, the Department of Education, the Agency for
84 Persons with Disabilities, the and Department of Elderly
85 Affairs, and memory disorder clinics shall, and any physician
86 licensed under chapter 458 or chapter 459 and any pharmacy
87 licensed under chapter 465 may, annually shall provide

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88 registration information to all of their special needs clients
89 or their caregivers and ~~to all persons with special needs who~~
90 ~~receive services.~~ The division shall develop a brochure that
91 provides information regarding special needs shelter
92 registration procedures. The brochure shall be published on the
93 division's website. All appropriate agencies and community-based
94 service providers, including aging and disability resource
95 centers, memory disorder clinics, home health care providers,
96 hospices, nurse registries, and home medical equipment providers
97 shall, and any physician licensed under chapter 458 or chapter
98 459 may, assist emergency management agencies by annually
99 registering persons with special needs for special needs
100 shelters, collecting registration information for persons with
101 special needs as part of the program intake process, and
102 establishing programs to educate clients about the registration
103 process and disaster preparedness safety procedures. A client of
104 a state-funded or federally funded service program who has a
105 physical, mental, or cognitive impairment or sensory disability
106 and who needs assistance in evacuating or while in a shelter
107 must register as a person with special needs. ~~The registry shall~~
108 ~~be updated annually.~~ The registration program shall give persons
109 with special needs the option of preauthorizing emergency
110 response personnel to enter their homes during search and rescue
111 operations if necessary to ensure ~~assure~~ their safety and
112 welfare following disasters.

113 (c) (2) The division shall be the designated lead agency
114 responsible for community education and outreach to the public,
115 including special needs clients, regarding registration and
116 special needs shelters and general information regarding shelter

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117 stays.

118 (d)~~(4)~~~~(a)~~ On or before May 31 of each year, each electric
119 utility in the state shall annually notify residential customers
120 in its service area of the availability of the registration
121 program available through their local emergency management
122 agency by:

123 1. An initial notification upon the activation of new
124 residential service with the electric utility, followed by one
125 annual notification between January 1 and May 31; or

126 2. Two separate annual notifications between January 1 and
127 May 31.

128
129 ~~(b)~~ The notification may be made by any available means,
130 including, but not limited to, written, electronic, or verbal
131 notification, and may be made concurrently with any other
132 notification to residential customers required by law or rule.

133 (3) A person with special needs must be allowed to bring
134 his or her service animal into a special needs shelter in
135 accordance with s. 413.08.

136 (4)~~(5)~~ All records, data, information, correspondence, and
137 communications relating to the registration of persons with
138 special needs as provided in subsection (1) are confidential and
139 exempt from ~~the provisions of~~ s. 119.07(1), except that such
140 information shall be available to other emergency response
141 agencies, as determined by the local emergency management
142 director. Local law enforcement agencies shall be given complete
143 shelter roster information upon request.

144 ~~(6) All appropriate agencies and community-based service~~
145 ~~providers, including home health care providers, hospices, nurse~~

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146 ~~registries, and home medical equipment providers, shall assist~~
147 ~~emergency management agencies by collecting registration~~
148 ~~information for persons with special needs as part of program~~
149 ~~intake processes, establishing programs to increase the~~
150 ~~awareness of the registration process, and educating clients~~
151 ~~about the procedures that may be necessary for their safety~~
152 ~~during disasters. Clients of state or federally funded service~~
153 ~~programs with physical, mental, cognitive impairment, or sensory~~
154 ~~disabilities who need assistance in evacuating, or when in~~
155 ~~shelters, must register as persons with special needs.~~

156 Section 2. Present subsections (3) through (7) of section
157 381.0303, Florida Statutes, are redesignated as subsections (4)
158 through (8), respectively, paragraph (b) of subsection (2) and
159 present subsection (6) are amended, and a new subsection (3) is
160 added to that section, to read:

161 381.0303 Special needs shelters.-

162 (2) SPECIAL NEEDS SHELTER PLAN; STAFFING; STATE AGENCY
163 ASSISTANCE.-If funds have been appropriated to support disaster
164 coordinator positions in county health departments:

165 (b) County health departments ~~shall~~, in conjunction with
166 the local emergency management agencies, have the lead
167 responsibility for coordination of the recruitment of health
168 care practitioners to staff local special needs shelters. County
169 health departments shall assign their employees to work in
170 special needs shelters when those employees are needed to
171 protect the health and safety of persons with special needs.
172 County governments shall assist the department with nonmedical
173 staffing and the operation of special needs shelters. The local
174 health department and emergency management agency shall

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175 coordinate these efforts to ensure appropriate staffing in
176 special needs shelters, including a staff member who is familiar
177 with the needs of persons with Alzheimer's disease.

178 (3) SPECIAL CARE FOR PERSONS WITH ALZHEIMER'S DISEASE OR
179 RELATED FORMS OF DEMENTIA.—All special needs shelters must
180 establish designated shelter areas for persons with Alzheimer's
181 disease or related forms of dementia to enable those persons to
182 maintain their normal habits and routines to the greatest extent
183 possible.

184 (7)(6) RULES.—The department, in coordination with the
185 Division of Emergency Management, may ~~has the authority to~~ adopt
186 rules ~~necessary~~ to implement this section. Rules shall include:

187 (a) The definition of a "person with special needs,"
188 including eligibility criteria for individuals with physical,
189 mental, cognitive impairment, or sensory disabilities and the
190 services a person with special needs can expect to receive in a
191 special needs shelter.

192 (b) The process for special needs shelter health care
193 practitioners and facility reimbursement for services provided
194 in a disaster.

195 (c) Guidelines for special needs shelter staffing levels to
196 provide services.

197 (d) The definition of and standards for special needs
198 shelter supplies and equipment, including durable medical
199 equipment.

200 (e) Standards for the special needs shelter registration
201 program process, including all necessary forms and guidelines
202 for addressing the needs of unregistered persons in need of a
203 special needs shelter.

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204 (f) Standards for addressing the needs of families where
205 only one dependent is eligible for admission to a special needs
206 shelter and the needs of adults with special needs who are
207 caregivers for individuals without special needs.

208 (g) The requirement of the county health departments to
209 seek the participation of hospitals, nursing homes, assisted
210 living facilities, home health agencies, hospice providers,
211 nurse registries, home medical equipment providers, dialysis
212 centers, and other health and medical emergency preparedness
213 stakeholders in pre-event planning activities.

214 Section 3. Section 381.82, Florida Statutes, is created to
215 read:

216 381.82 Ed and Ethel Moore Alzheimer's Disease Research
217 Program.-

218 (1) There is established the Ed and Ethel Moore Alzheimer's
219 Disease Research Program within the Department of Health. The
220 purpose of the program is to fund research leading to prevention
221 of or a cure for Alzheimer's disease. The long-term goals of the
222 program are to:

223 (a) Enhance the health of Floridians by researching
224 improved prevention, diagnosis, treatment, and cure of
225 Alzheimer's disease.

226 (b) Expand the foundation of knowledge relating to the
227 prevention, diagnosis, treatment, and cure of Alzheimer's
228 disease.

229 (c) Stimulate economic activity in the state in areas
230 related to Alzheimer's disease research.

231 (2) (a) Funds appropriated for the Ed and Ethel Moore
232 Alzheimer's Disease Research Program shall be used exclusively

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233 for the award of grants and fellowships through a competitive
234 process for research relating to the prevention, diagnosis,
235 treatment, and cure of Alzheimer's disease and for expenses
236 incurred in the administration of this section. Priority shall
237 be granted to research designed to prevent or cure Alzheimer's
238 disease.

239 (b) Applications for Alzheimer's disease research funding
240 under the program may be submitted from any university or
241 established research institute in the state. All qualified
242 investigators in the state, regardless of institution
243 affiliation, shall have equal access and opportunity to compete
244 for research funding. The following types of applications may be
245 considered for funding:

- 246 1. Investigator-initiated research grants.
- 247 2. Institutional research grants.
- 248 3. Predoctoral and postdoctoral research fellowships.
- 249 4. Collaborative research grants, including those that
250 advance the finding of cures through basic or applied research.

251 (3) There is created the Alzheimer's Disease Research Grant
252 Advisory Board within the Department of Health.

253 (a) The board shall consist of 11 members appointed by the
254 State Surgeon General. The board shall be composed of two
255 gerontologists, two geriatric psychiatrists, two geriatricians,
256 two neuroscientists, and three neurologists. Initial
257 appointments to the board shall be made by October 1, 2014. The
258 board members shall serve 4-year terms, except that, to provide
259 for staggered terms, five of the initial appointees shall serve
260 2-year terms and six shall serve 4-year terms. All subsequent
261 appointments shall be for 4-year terms. The chair of the board

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262 shall be elected from the membership of the board and shall
263 serve as chair for 2 years. An appointed member may not serve
264 more than two consecutive terms. Appointed members must have
265 experience in Alzheimer's disease or related biomedical
266 research. The board shall adopt internal organizational
267 procedures as necessary for its organization. The board shall
268 establish and follow guidelines for ethical conduct and adhere
269 to a policy established to avoid conflicts of interest. A member
270 of the board may not participate in any discussion or decision
271 of the board or a panel with respect to a research proposal by
272 any firm, entity, or agency with which the member is associated
273 as a member of the governing body or as an employee or with
274 which the member has entered into a contractual arrangement.

275 (b) The department shall provide such staff, information,
276 and other assistance as necessary to assist the board in
277 carrying out its responsibilities. Members of the board shall
278 serve without compensation and may not receive reimbursement for
279 per diem or travel expenses.

280 (c) The board shall advise the State Surgeon General as to
281 the scope of the research program and shall submit its
282 recommendations for proposals to be funded to the State Surgeon
283 General by December 15 of each year. Grants and fellowships
284 shall be awarded by the State Surgeon General, after
285 consultation with the board, on the basis of scientific merit.
286 Other responsibilities of the board may include, but are not
287 limited to, providing advice on program priorities and emphases;
288 assisting in the development of appropriate linkages to
289 nonacademic entities, such as voluntary organizations, health
290 care delivery institutions, industry, government agencies, and

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291 public officials; and developing and providing oversight
292 regarding mechanisms for the dissemination of research results.

293 (4) The board shall submit a fiscal-year progress report on
294 the programs under its purview to the Governor, the President of
295 the Senate, the Speaker of the House of Representatives, and the
296 State Surgeon General by February 15 of each year. The report
297 must include:

298 (a) A list of research projects supported by grants or
299 fellowships awarded under the program.

300 (b) A list of recipients of program grants or fellowships.

301 (c) A list of publications in peer-reviewed journals
302 involving research supported by grants or fellowships awarded
303 under the program.

304 (d) The state ranking and total amount of Alzheimer's
305 disease research funding allocated to the state from the
306 National Institutes of Health.

307 (e) New grants for Alzheimer's disease research which were
308 funded based on research supported by grants or fellowships
309 awarded under the program.

310 (f) Progress toward programmatic goals, particularly in the
311 prevention, diagnosis, treatment, and cure of Alzheimer's
312 disease.

313 (g) Recommendations to further the mission of the program.

314 (5) Activities of the board provided in subsection (3) are
315 exempt from chapter 120.

316 (6) The department may adopt rules to implement this
317 section.

318 (7) Implementation of the Ed and Ethel Moore Alzheimer's
319 Disease Research Program is subject to legislative

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320 appropriation.

321 Section 4. Present subsections (3) through (9) of section
322 430.502, Florida Statutes, are redesignated as subsections (6)
323 through (12), respectively, new subsections (3), (4), and (5)
324 are added to that section, and present subsections (1), (4),
325 (5), (8), and (9) of that section are amended, to read:

326 430.502 Alzheimer's disease; memory disorder clinics and
327 day care and respite care programs.—

328 (1) There is established:

329 (a) A memory disorder clinic at each of the three medical
330 schools in this state;

331 (b) A memory disorder clinic at a major private nonprofit
332 research-oriented teaching hospital, and may fund a memory
333 disorder clinic at any of the other affiliated teaching
334 hospitals;

335 (c) A memory disorder clinic at the Mayo Clinic in
336 Jacksonville;

337 (d) A memory disorder clinic at the West Florida Regional
338 Medical Center;

339 (e) A memory disorder clinic operated by Health First ~~The~~
340 ~~Memory Disorder Clinic, Inc., operating~~ in Brevard County;

341 (f) A memory disorder clinic at the Orlando Regional
342 Healthcare System, Inc.;

343 (g) A memory disorder center located in a public hospital
344 that is operated by an independent special hospital taxing
345 district that governs multiple hospitals and is located in a
346 county with a population greater than 800,000 persons;

347 (h) A memory disorder clinic at St. Mary's Medical Center
348 in Palm Beach County;

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- 349 (i) A memory disorder clinic at Tallahassee Memorial
350 Healthcare;
- 351 (j) A memory disorder clinic at Lee Memorial Hospital
352 created by chapter 63-1552, Laws of Florida, as amended;
- 353 (k) A memory disorder clinic at Sarasota Memorial Hospital
354 in Sarasota County;

355 (l) A memory disorder clinic at Morton Plant Hospital,
356 Clearwater, in Pinellas County; and

357 (m) A memory disorder clinic at Florida Atlantic
358 University, Boca Raton, in Palm Beach County,

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360 for the purpose of conducting research and training in a
361 diagnostic and therapeutic setting for persons suffering from
362 Alzheimer's disease and related memory disorders. However,
363 memory disorder clinics funded as of June 30, 1995, shall not
364 receive decreased funding due solely to subsequent additions of
365 memory disorder clinics in this subsection.

366 (3) The department shall develop minimum performance
367 standards for memory disorder clinics and include those
368 standards in each memory disorder clinic contract as a condition
369 for receiving base-level funding. The performance standards must
370 address, at a minimum, quality of care, comprehensiveness of
371 services, and access to services.

372 (4) The department shall develop performance goals that
373 exceed the minimum performance standards developed under
374 subsection (3) which must be achieved in order for a memory
375 disorder clinic to be eligible for incentive funding above the
376 base level, subject to legislative appropriation. Incentive
377 funding shall be based on criteria including, but not limited

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378 to:379 (a) A significant increase in the volume of clinical
380 services.381 (b) A significant increase in public outreach to low-income
382 and minority populations.383 (c) A significant increase in the acceptance of Medicaid
384 and commercial insurance policies.385 (d) Significant institutional financial commitments.386 (5) The department shall measure and score each memory
387 disorder clinic based on minimum performance standards and
388 incentive performance goals.389 (7)~~(4)~~ Pursuant to ~~the provisions of~~ s. 287.057, the
390 department ~~of Elderly Affairs~~ may contract for the provision of
391 specialized model day care programs in conjunction with the
392 memory disorder clinics. The purpose of each model day care
393 program must be to provide service delivery to persons suffering
394 from Alzheimer's disease or a related memory disorder and
395 training for health care and social service personnel in the
396 care of persons having Alzheimer's disease or a related memory
397 disorder disorders.398 (8)~~(5)~~ Pursuant to s. 287.057, the department ~~of Elderly~~
399 ~~Affairs~~ shall contract for the provision of respite care. All
400 funds appropriated for the provision of respite care shall be
401 distributed annually by the department to each funded county
402 according to an allocation formula. In developing the formula,
403 the department shall consider the number and proportion of the
404 county population of individuals who are 75 years of age and
405 older. Each respite care program shall be used as a resource for
406 research and statistical data by the memory disorder clinics

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407 established in this part. In consultation with the memory
408 disorder clinics, the department shall specify the information
409 to be provided by the respite care programs for research
410 purposes.

411 (11)~~(8)~~ The department shall implement the waiver program
412 specified in subsection (10)~~(7)~~. The agency and the department
413 shall ensure the selection of ~~that~~ providers who have a history
414 of successfully serving persons with Alzheimer's disease ~~are~~
415 ~~selected~~. The department and the agency shall develop
416 specialized standards for providers and services tailored to
417 persons in the early, middle, and late stages of Alzheimer's
418 disease and designate a level of care determination process and
419 standard that is most appropriate to this population. The
420 department and the agency shall include in the waiver services
421 designed to assist the caregiver in continuing to provide in-
422 home care. The department shall implement this waiver program
423 subject to a specific appropriation or as provided in the
424 General Appropriations Act.

425 (12)~~(9)~~ Authority to continue the waiver program specified
426 in subsection (10)~~(7)~~ shall be automatically eliminated at the
427 close of the 2010 Regular Session of the Legislature unless
428 further legislative action is taken to continue it before ~~prior~~
429 ~~to~~ such time.

430 Section 5. This act shall take effect July 1, 2014.