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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



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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
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 to the Governor,
34 Legislature, and State Surgeon General; exempting
35 certain activities of the board from the
36 Administrative Procedure 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:
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51 Section 1. Section 252.355, Florida Statutes, is amended
52 to 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
56 would need assistance during evacuations and sheltering because
57 of physical, mental, cognitive impairment, or sensory
58 disabilities, the division, in coordination with each local
59 emergency management agency in the state, shall maintain a
60 registry of persons with special needs located within the
61 jurisdiction of the local agency. The registration shall
62 identify those persons in need of assistance and plan for
63 resource allocation to meet 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,
70 a uniform electronic registration form and a database for
71 uploading and storing submitted registration forms that 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



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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
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 must be easily accessible
93 on the division's website. All appropriate agencies and
94 community-based service providers, including aging and
95 disability resource centers, memory disorder clinics, home
96 health care providers, hospices, nurse registries, and home
97 medical equipment providers, shall, and any physician licensed
98 under chapter 458 or chapter 459 may, assist emergency
99 management agencies by annually registering persons with special
100 needs for special needs shelters, collecting registration



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101 information for persons with special needs as part of the
102 program intake process, and establishing programs to educate
103 clients about the registration process and disaster preparedness
104 safety procedures. A client of a state-funded or federally
105 funded service program who has a physical, mental, or cognitive
106 impairment or sensory disability and who needs assistance in
107 evacuating, or when in a shelter, must register as a person with
108 special needs. The registry shall be updated annually. The
109 registration program shall give persons with special needs the
110 option of preauthorizing emergency response personnel to enter
111 their homes during search and rescue operations if necessary to
112 ensure ~~assure~~ their safety and 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
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



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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~~
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~~



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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. Subsections (3) through (7) of section
157 381.0303, Florida Statutes, are renumbered 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
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, 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
196 to 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



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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.

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

223 (a) Improve the health of Floridians by researching better
224 prevention and diagnoses of and treatments and cures for
225 Alzheimer's disease.



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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
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 within the Department of Health the
252 Alzheimer's Disease Research Grant Advisory Board.

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
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 efficient organization. The
268 board shall establish and follow rigorous guidelines for ethical
269 conduct and adhere to a strict policy with regard to conflicts
270 of interest. A member of the board may not participate in any
271 discussion or decision of the board or a panel with respect to a
272 research proposal by any firm, entity, or agency with which the
273 member is associated as a member of the governing body or as an
274 employee or with which the member has entered into a contractual
275 arrangement.



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

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

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

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



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

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

305 | (d) The state ranking and total amount of Alzheimer's
306 | disease research funding currently flowing into the state from
307 | the National Institutes of Health.

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

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

314 | (g) Recommendations to further the mission of the program.

315 | (5) The activities of the board provided in subsection (3)
316 | are exempt from chapter 120.

317 | (6) The department may adopt rules as necessary to
318 | implement the provisions of this section.

319 | (7) Implementation of the Ed and Ethel Moore Alzheimer's
320 | Disease Research Program is subject to legislative
321 | appropriation.

322 | Section 4. Subsections (3) through (9) of section 430.502,
323 | Florida Statutes, are renumbered as subsections (6) through
324 | (12), respectively, new subsections (3), (4), and (5) are added
325 | to that section, and paragraph (e) of subsection (1) and present



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326 subsections (4), (5), (8), and (9) of that section are amended,
327 to read:

328 430.502 Alzheimer's disease; memory disorder clinics and
329 day care and respite care programs.—

330 (1) There is established:

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

333 (3) The department shall develop minimum performance
334 standards for memory disorder clinics and include those
335 standards in each memory disorder clinic contract as a condition
336 for receiving base-level funding. The performance standards must
337 address, at a minimum, quality of care, comprehensiveness of
338 services, and access to services.

339 (4) The department shall develop performance goals that
340 exceed the minimum performance standards developed under
341 subsection (3), which goals must be achieved in order for a
342 memory disorder clinic to be eligible for incentive funding
343 above the base level, subject to legislative appropriation.
344 Incentive funding shall be based on criteria including, but not
345 limited to:

346 (a) Significant increase in the volume of clinical
347 services.

348 (b) Significant increase in public outreach to low-income
349 and minority populations.

350 (c) Significant increase in acceptance of Medicaid and



351 commercial insurance policies.

352 (d) Significant institutional financial commitments.

353 (5) The department shall measure and score each memory
354 disorder clinic based on minimum performance standards and
355 incentive performance goals.

356 (7)~~(4)~~ Pursuant to ~~the provisions of~~ s. 287.057, the
357 department ~~of Elderly Affairs~~ may contract for the provision of
358 specialized model day care programs in conjunction with the
359 memory disorder clinics. The purpose of each model day care
360 program must be to provide service delivery to persons suffering
361 from Alzheimer's disease or a related memory disorder and
362 training for health care and social service personnel in the
363 care of persons having Alzheimer's disease or related memory
364 disorders.

365 (8)~~(5)~~ Pursuant to s. 287.057, the department ~~of Elderly~~
366 ~~Affairs~~ shall contract for the provision of respite care. All
367 funds appropriated for the provision of respite care shall be
368 distributed annually by the department to each funded county
369 according to an allocation formula. In developing the formula,
370 the department shall consider the number and proportion of the
371 county population of individuals who are 75 years of age and
372 older. Each respite care program shall be used as a resource for
373 research and statistical data by the memory disorder clinics
374 established in this part. In consultation with the memory
375 disorder clinics, the department shall specify the information



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376 | to be provided by the respite care programs for research
377 | purposes.

378 | (11)~~(8)~~ The department shall implement the waiver program
379 | specified in subsection (10) ~~(7)~~. The agency and the department
380 | shall ensure that providers who have a history of successfully
381 | serving persons with Alzheimer's disease are selected. The
382 | department and the agency shall develop specialized standards
383 | for providers and services tailored to persons in the early,
384 | middle, and late stages of Alzheimer's disease and designate a
385 | level of care determination process and standard that is most
386 | appropriate to this population. The department and the agency
387 | shall include in the waiver services designed to assist the
388 | caregiver in continuing to provide in-home care. The department
389 | shall implement this waiver program subject to a specific
390 | appropriation or as provided in the General Appropriations Act.

391 | (12)~~(9)~~ Authority to continue the waiver program specified
392 | in subsection (10) ~~(7)~~ shall be automatically eliminated at the
393 | close of the 2010 Regular Session of the Legislature unless
394 | further legislative action is taken to continue it before ~~prior~~
395 | ~~to~~ such time.

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