

By the Committee on 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.
3 120.80, F.S.; exempting grant programs administered by
4 the Alzheimer's Disease Research Grant Advisory Board
5 from the Administrative Procedure Act; amending s.
6 252.355, F.S.; requiring the Division of Emergency
7 Management, in coordination with local emergency
8 management agencies, to maintain a registry of persons
9 with special needs; requiring the division to develop
10 and maintain a special needs shelter registration
11 program by a specified date; requiring specified
12 agencies and authorizing specified health care
13 providers to provide registration information to
14 special needs clients or their caregivers and to
15 assist emergency management agencies in registering
16 persons for special needs shelters; amending s.
17 381.0303, F.S.; providing additional staffing
18 requirements for special needs shelters; requiring
19 special needs shelters to establish designated shelter
20 areas for persons with Alzheimer's disease or related
21 forms of dementia; authorizing the Department of
22 Health, in coordination with the division, to adopt
23 rules relating to standards for the special needs
24 registration program; creating s. 381.82, F.S.;
25 establishing the Ed and Ethel Moore Alzheimer's
26 Disease Research Program within the department;
27 requiring the program to provide grants and
28 fellowships for research relating to Alzheimer's
29 disease; creating the Alzheimer's Disease Research

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30 Grant Advisory Board; providing for appointment and
31 terms of members; providing for organization, duties,
32 and operating procedures of the board; requiring the
33 department to provide staff to assist the board in
34 carrying out its duties; requiring the board to
35 annually submit recommendations for proposals to be
36 funded; requiring a report to the Governor,
37 Legislature, and State Surgeon General; providing that
38 implementation of the program is subject to
39 appropriation; amending s. 430.502, F.S.; requiring
40 the Department of Elderly Affairs to develop minimum
41 performance standards for memory disorder clinics to
42 receive base-level annual funding; requiring the
43 department to provide incentive-based funding, subject
44 to appropriation, for certain memory disorder clinics;
45 providing an effective date.

46
47 Be It Enacted by the Legislature of the State of Florida:

48
49 Section 1. Subsection (15) of section 120.80, Florida
50 Statutes, is amended to read:

51 120.80 Exceptions and special requirements; agencies.—

52 (15) DEPARTMENT OF HEALTH.—

53 (a) Notwithstanding s. 120.57(1)(a), formal hearings may
54 not be conducted by the State Surgeon General, the Secretary of
55 Health Care Administration, or a board or member of a board
56 within the Department of Health or the Agency for Health Care
57 Administration for matters relating to the regulation of
58 professions, as defined by chapter 456. Notwithstanding s.

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59 120.57(1)(a), hearings conducted within the Department of Health
60 in execution of the Special Supplemental Nutrition Program for
61 Women, Infants, and Children; Child Care Food Program;
62 Children's Medical Services Program; the Brain and Spinal Cord
63 Injury Program; and the exemption from disqualification reviews
64 for certified nurse assistants program need not be conducted by
65 an administrative law judge assigned by the division. The
66 Department of Health may contract with the Department of
67 Children and Families ~~Family Services~~ for a hearing officer in
68 these matters.

69 (b) This chapter does not apply to grant programs
70 administered by the Alzheimer's Disease Research Grant Advisory
71 Board pursuant to s. 381.82.

72 Section 2. Section 252.355, Florida Statutes, is amended to
73 read:

74 252.355 Registry of persons with special needs; notice;
75 registration program.-

76 (1) In order to meet the special needs of persons who would
77 need assistance during evacuations and sheltering because of
78 physical, mental, cognitive impairment, or sensory disabilities,
79 the division, in coordination with each local emergency
80 management agency in the state, shall maintain a registry of
81 persons with special needs located within the jurisdiction of
82 the local agency. The registration shall identify those persons
83 in need of assistance and plan for resource allocation to meet
84 those identified needs.

85 (2) In order to ensure that all persons with special needs
86 may register, the division shall develop and maintain a special
87 needs shelter registration program. The registration program

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88 must be developed by January 1, 2015, and fully implemented by
89 March 1, 2015.

90 (a) The registration program shall include, at a minimum, a
91 uniform electronic registration form and a database for
92 uploading and storing submitted registration forms which may be
93 accessed by the appropriate local emergency management agency.
94 The link to the registration form shall be easily accessible on
95 each local emergency management agency's website. Upon receipt
96 of a paper registration form, the local emergency management
97 agency shall enter the person's registration information into
98 the database.

99 (b) To assist ~~the local emergency management agency~~ in
100 identifying ~~such~~ persons with special needs, home health
101 agencies, hospices, nurse registries, home medical equipment
102 providers, the Department of Children and Families Family
103 Services, ~~the~~ Department of Health, ~~the~~ Agency for Health Care
104 Administration, ~~the~~ Department of Education, ~~the~~ Agency for
105 Persons with Disabilities, ~~the~~ ~~and~~ Department of Elderly
106 Affairs, and memory disorder clinics shall, and any physician
107 licensed under chapter 458 or chapter 459 and any pharmacy
108 licensed under chapter 465 may, annually ~~shall~~ provide
109 registration information to all of their special needs clients
110 or their caregivers and ~~to all persons with special needs who~~
111 ~~receive services.~~ The division shall develop a brochure that
112 provides information regarding special needs shelter
113 registration procedures. The brochure shall be published on the
114 division's website. All appropriate agencies and community-based
115 service providers, including memory disorder clinics, home
116 health care providers, hospices, nurse registries, and home

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117 medical equipment providers shall, and any physician licensed
118 under chapter 458 or chapter 459 may, assist emergency
119 management agencies by annually registering persons with special
120 needs for special needs shelters, collecting registration
121 information for persons with special needs as part of the
122 program intake process, and establishing programs to educate
123 clients about the registration process and disaster preparedness
124 safety procedures. A client of a state-funded or federally
125 funded service program who has a physical, mental, or cognitive
126 impairment or sensory disability and who needs assistance in
127 evacuating or while in a shelter must register as a person with
128 special needs. The registry shall be updated annually. The
129 registration program shall give persons with special needs the
130 option of preauthorizing emergency response personnel to enter
131 their homes during search and rescue operations if necessary to
132 ensure ~~assure~~ their safety and welfare following disasters.

133 (c)(2) The division shall be the designated lead agency
134 responsible for community education and outreach to the public,
135 including special needs clients, regarding registration and
136 special needs shelters and general information regarding shelter
137 stays.

138 (d)(4)(a) On or before May 31 of each year, each electric
139 utility in the state shall annually notify residential customers
140 in its service area of the availability of the registration
141 program available through their local emergency management
142 agency by:

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

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146 2. Two separate annual notifications between January 1 and
147 May 31.

148
149 ~~(b)~~ The notification may be made by any available means,
150 including, but not limited to, written, electronic, or verbal
151 notification, and may be made concurrently with any other
152 notification to residential customers required by law or rule.

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

156 (4)~~(5)~~ All records, data, information, correspondence, and
157 communications relating to the registration of persons with
158 special needs as provided in subsection (1) are confidential and
159 exempt from ~~the provisions of~~ s. 119.07(1), except that such
160 information shall be available to other emergency response
161 agencies, as determined by the local emergency management
162 director. Local law enforcement agencies shall be given complete
163 shelter roster information upon request.

164 ~~(6) All appropriate agencies and community-based service~~
165 ~~providers, including home health care providers, hospices, nurse~~
166 ~~registries, and home medical equipment providers, shall assist~~
167 ~~emergency management agencies by collecting registration~~
168 ~~information for persons with special needs as part of program~~
169 ~~intake processes, establishing programs to increase the~~
170 ~~awareness of the registration process, and educating clients~~
171 ~~about the procedures that may be necessary for their safety~~
172 ~~during disasters. Clients of state or federally funded service~~
173 ~~programs with physical, mental, cognitive impairment, or sensory~~
174 ~~disabilities who need assistance in evacuating, or when in~~

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175 ~~shelters, must register as persons with special needs.~~

176 Section 3. Present subsections (3) through (7) of section
177 381.0303, Florida Statutes, are redesignated as subsections (4)
178 through (8), respectively, paragraph (b) of subsection (2) and
179 present subsection (6) are amended, and a new subsection (3) is
180 added to that section, to read:

181 381.0303 Special needs shelters.—

182 (2) SPECIAL NEEDS SHELTER PLAN; STAFFING; STATE AGENCY
183 ASSISTANCE.—If funds have been appropriated to support disaster
184 coordinator positions in county health departments:

185 (b) County health departments ~~shall~~, in conjunction with
186 the local emergency management agencies, have the lead
187 responsibility for coordination of the recruitment of health
188 care practitioners to staff local special needs shelters. County
189 health departments shall assign their employees to work in
190 special needs shelters when those employees are needed to
191 protect the health and safety of persons with special needs.
192 County governments shall assist the department with nonmedical
193 staffing and the operation of special needs shelters. The local
194 health department and emergency management agency shall
195 coordinate these efforts to ensure appropriate staffing in
196 special needs shelters, including a staff member who is familiar
197 with the needs of persons with Alzheimer's disease.

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

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204 (7)~~(6)~~ RULES.—The department, in coordination with the
205 Division of Emergency Management, may ~~has the authority to~~ adopt
206 rules ~~necessary~~ to implement this section. Rules shall include:

207 (a) The definition of a "person with special needs,"
208 including eligibility criteria for individuals with physical,
209 mental, cognitive impairment, or sensory disabilities and the
210 services a person with special needs can expect to receive in a
211 special needs shelter.

212 (b) The process for special needs shelter health care
213 practitioners and facility reimbursement for services provided
214 in a disaster.

215 (c) Guidelines for special needs shelter staffing levels to
216 provide services.

217 (d) The definition of and standards for special needs
218 shelter supplies and equipment, including durable medical
219 equipment.

220 (e) Standards for the special needs shelter registration
221 program process, including all necessary forms and guidelines
222 for addressing the needs of unregistered persons in need of a
223 special needs shelter.

224 (f) Standards for addressing the needs of families where
225 only one dependent is eligible for admission to a special needs
226 shelter and the needs of adults with special needs who are
227 caregivers for individuals without special needs.

228 (g) The requirement of the county health departments to
229 seek the participation of hospitals, nursing homes, assisted
230 living facilities, home health agencies, hospice providers,
231 nurse registries, home medical equipment providers, dialysis
232 centers, and other health and medical emergency preparedness

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233 stakeholders in pre-event planning activities.

234 Section 4. Section 381.82, Florida Statutes, is created to
235 read:

236 381.82 Ed and Ethel Moore Alzheimer's Disease Research
237 Program.—

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

243 (a) Enhance the health of Floridians by researching
244 improved prevention, diagnosis, treatment, and cure of
245 Alzheimer's disease.

246 (b) Expand the foundation of knowledge relating to the
247 prevention, diagnosis, treatment, and cure of Alzheimer's
248 disease.

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

251 (2) (a) Funds appropriated for the Ed and Ethel Moore
252 Alzheimer's Disease Research Program shall be used exclusively
253 for the award of grants and fellowships through a competitive,
254 peer-reviewed process for research relating to the prevention,
255 diagnosis, treatment, and cure of Alzheimer's disease and for
256 expenses incurred in the administration of this section.
257 Priority shall be granted to research designed to prevent or
258 cure Alzheimer's disease.

259 (b) Applications for Alzheimer's disease research funding
260 under the program may be submitted from any university or
261 established research institute in the state. All qualified

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262 investigators in the state, regardless of institution
263 affiliation, shall have equal access and opportunity to compete
264 for research funding. The following types of applications may be
265 considered for funding:

- 266 1. Investigator-initiated research grants.
- 267 2. Institutional research grants.
- 268 3. Predoctoral and postdoctoral research fellowships.
- 269 4. Collaborative research grants, including those that
270 advance the finding of cures through basic or applied research.

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

273 (a) The board shall consist of 11 members appointed by the
274 State Surgeon General. The board shall be composed of two
275 gerontologists, two geriatric psychiatrists, two geriatricians,
276 two neuroscientists, and three neurologists. Initial
277 appointments to the board shall be made by October 1, 2014. The
278 board members shall serve 4-year terms, except that, to provide
279 for staggered terms, six of the initial appointees shall serve
280 2-year terms and six shall serve 4-year terms. All subsequent
281 appointments shall be for 4-year terms. The chair of the board
282 shall be elected from the membership of the board and shall
283 serve as chair for 2 years. An appointed member may not serve
284 more than two consecutive terms. Appointed members must have
285 experience in Alzheimer's disease or related biomedical
286 research. The board shall adopt internal organizational
287 procedures as necessary for its organization. The board shall
288 establish and follow guidelines for ethical conduct and adhere
289 to a policy established to avoid conflicts of interest. A member
290 of the board may not participate in any discussion or decision

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291 of the board or a panel with respect to a research proposal by
292 any firm, entity, or agency with which the member is associated
293 as a member of the governing body or as an employee or with
294 which the member has entered into a contractual arrangement.

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

300 (c) The board shall advise the State Surgeon General as to
301 the scope of the research program and shall submit its
302 recommendations for proposals to be funded to the State Surgeon
303 General by December 15 of each year. Grants and fellowships
304 shall be awarded by the State Surgeon General, after
305 consultation with the board, on the basis of scientific merit.
306 Other responsibilities of the board may include, but are not
307 limited to, providing advice on program priorities and emphases;
308 assisting in the development of appropriate linkages to
309 nonacademic entities, such as voluntary organizations, health
310 care delivery institutions, industry, government agencies, and
311 public officials; and developing and providing oversight
312 regarding mechanisms for the dissemination of research results.

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

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

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

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

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

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

330 (f) Progress toward programmatic goals, particularly in the
331 prevention, diagnosis, treatment, and cure of Alzheimer's
332 disease.

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

334 (5) Implementation of the Ed and Ethel Moore Alzheimer's
335 Disease Research Program is subject to legislative
336 appropriation.

337 Section 5. Present subsections (3) through (9) of section
338 430.502, Florida Statutes, are redesignated as subsections (6)
339 through (12), respectively, new subsections (3), (4), and (5)
340 are added to that section, and present subsections (4), (5),
341 (8), and (9) of that section are amended, to read:

342 430.502 Alzheimer's disease; memory disorder clinics and
343 day care and respite care programs.—

344 (3) The department shall develop minimum performance
345 standards for memory disorder clinics and include those
346 standards in each memory disorder clinic contract as a condition
347 for receiving base-level funding. The performance standards must
348 address, at a minimum, quality of care, comprehensiveness of

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349 services, and access to services.

350 (4) The department shall develop performance goals that
351 exceed the minimum performance standards developed under
352 subsection (3) which must be achieved in order for a memory
353 disorder clinic to be eligible for incentive funding above the
354 base level, subject to legislative appropriation. Incentive
355 funding shall be based on criteria including, but not limited
356 to:

357 (a) A significant increase in the volume of clinical
358 services.

359 (b) A significant increase in public outreach to low-income
360 and minority populations.

361 (c) A significant increase in the acceptance of Medicaid
362 and commercial insurance policies.

363 (d) Significant institutional financial commitments.

364 (5) The department shall measure and score each memory
365 disorder clinic based on minimum performance standards and
366 incentive performance goals.

367 (7)~~(4)~~ Pursuant to ~~the provisions of~~ s. 287.057, the
368 department ~~of Elderly Affairs~~ may contract for the provision of
369 specialized model day care programs in conjunction with the
370 memory disorder clinics. The purpose of each model day care
371 program must be to provide service delivery to persons suffering
372 from Alzheimer's disease or a related memory disorder and
373 training for health care and social service personnel in the
374 care of persons having Alzheimer's disease or a related memory
375 disorder disorders.

376 (8)~~(5)~~ Pursuant to s. 287.057, the department ~~of Elderly~~
377 ~~Affairs~~ shall contract for the provision of respite care. All

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378 funds appropriated for the provision of respite care shall be
379 distributed annually by the department to each funded county
380 according to an allocation formula. In developing the formula,
381 the department shall consider the number and proportion of the
382 county population of individuals who are 75 years of age and
383 older. Each respite care program shall be used as a resource for
384 research and statistical data by the memory disorder clinics
385 established in this part. In consultation with the memory
386 disorder clinics, the department shall specify the information
387 to be provided by the respite care programs for research
388 purposes.

389 (11)~~(8)~~ The department shall implement the waiver program
390 specified in subsection (10) ~~(7)~~. The agency and the department
391 shall ensure the selection of ~~that~~ providers who have a history
392 of successfully serving persons with Alzheimer's disease ~~are~~
393 ~~selected~~. The department and the agency shall develop
394 specialized standards for providers and services tailored to
395 persons in the early, middle, and late stages of Alzheimer's
396 disease and designate a level of care determination process and
397 standard that is most appropriate to this population. The
398 department and the agency shall include in the waiver services
399 designed to assist the caregiver in continuing to provide in-
400 home care. The department shall implement this waiver program
401 subject to a specific appropriation or as provided in the
402 General Appropriations Act.

403 (12)~~(9)~~ Authority to continue the waiver program specified
404 in subsection (10) ~~(7)~~ shall be automatically eliminated at the
405 close of the 2010 Regular Session of the Legislature unless
406 further legislative action is taken to continue it before ~~prior~~

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407 ~~to~~ such time.

408 Section 6. This act shall take effect July 1, 2014.