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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; requiring specified agencies and authorizing  
12 specified health care providers to provide  
13 registration information to special needs clients or  
14 their caregivers and to assist emergency management  
15 agencies in registering persons for special needs  
16 shelters; amending s. 381.0303, F.S.; providing  
17 additional staffing requirements for special needs  
18 shelters; requiring special needs shelters to  
19 establish designated shelter areas for persons with  
20 Alzheimer's disease or related forms of dementia;  
21 authorizing the Department of Health, in coordination  
22 with the division, to adopt rules relating to  
23 standards for the special needs registration program;  
24 creating s. 381.82, F.S.; establishing the Ed and  
25 Ethel Moore Alzheimer's Disease Research Program  
26 within the department; requiring the program to

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CODING: Words ~~stricken~~ are deletions; words underlined are additions.

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

45  
46 Be It Enacted by the Legislature of the State of Florida:

47  
48 Section 1. Subsection (15) of section 120.80, Florida  
49 Statutes, is amended to read:

50 120.80 Exceptions and special requirements; agencies.—

51 (15) DEPARTMENT OF HEALTH.—

52 (a) Notwithstanding s. 120.57(1)(a), formal hearings may

53 not be conducted by the State Surgeon General, the Secretary of  
 54 Health Care Administration, or a board or member of a board  
 55 within the Department of Health or the Agency for Health Care  
 56 Administration for matters relating to the regulation of  
 57 professions, as defined by chapter 456. Notwithstanding s.  
 58 120.57(1)(a), hearings conducted within the Department of Health  
 59 in execution of the Special Supplemental Nutrition Program for  
 60 Women, Infants, and Children; Child Care Food Program;  
 61 Children's Medical Services Program; the Brain and Spinal Cord  
 62 Injury Program; and the exemption from disqualification reviews  
 63 for certified nurse assistants program need not be conducted by  
 64 an administrative law judge assigned by the division. The  
 65 Department of Health may contract with the Department of  
 66 Children and Family Services for a hearing officer in these  
 67 matters.

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

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

73 252.355 Registry of persons with special needs; notice;  
 74 registration program.—

75 (1) In order to meet the special needs of persons who  
 76 would need assistance during evacuations and sheltering because  
 77 of physical, mental, cognitive impairment, or sensory  
 78 disabilities, the division, in coordination with each local

79 emergency management agency in the state, shall maintain a  
80 registry of persons with special needs located within the  
81 jurisdiction of the local agency. The registration shall  
82 identify those persons in need of assistance and plan for  
83 resource allocation to meet those identified needs.

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

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

96 (b) To assist ~~the local emergency management agency~~ in  
97 identifying ~~such~~ persons with special needs, home health  
98 agencies, hospices, nurse registries, home medical equipment  
99 providers, the Department of Children and ~~Families~~ Family  
100 Services, ~~the~~ Department of Health, ~~the~~ Agency for Health Care  
101 Administration, ~~the~~ Department of Education, ~~the~~ Agency for  
102 Persons with Disabilities, ~~the~~ ~~and~~ Department of Elderly  
103 Affairs, and memory disorder clinics shall, and any physician  
104 licensed under chapter 458 or chapter 459 and any pharmacy

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105 licensed under chapter 465 may, annually ~~shall~~ provide  
106 registration information to all of their special needs clients  
107 or their caregivers ~~and to all persons with special needs who~~  
108 ~~receive services.~~ The division shall develop a brochure that  
109 provides information regarding special needs shelter  
110 registration procedures. The brochure must be easily accessible  
111 on the division's website. All appropriate agencies and  
112 community-based service providers, including memory disorder  
113 clinics, home health care providers, hospices, nurse registries,  
114 and home medical equipment providers shall, and any physician  
115 licensed under chapter 458 or chapter 459 may, assist emergency  
116 management agencies by annually registering persons with special  
117 needs for special needs shelters, collecting registration  
118 information for persons with special needs as part of the  
119 program intake process, and establishing programs to educate  
120 clients about the registration process and disaster preparedness  
121 safety procedures. A client of a state-funded or federally  
122 funded service program who has a physical, mental, or cognitive  
123 impairment or sensory disability and who needs assistance in  
124 evacuating, or when in a shelter, must register as a person with  
125 special needs. ~~The registry shall be updated annually.~~ The  
126 registration program shall give persons with special needs the  
127 option of preauthorizing emergency response personnel to enter  
128 their homes during search and rescue operations if necessary to  
129 ensure ~~assure~~ their safety and welfare following disasters.

130 (c)(2) The division shall be the designated lead agency

131 responsible for community education and outreach to the public,  
132 including special needs clients, regarding registration and  
133 special needs shelters and general information regarding shelter  
134 stays.

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

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

143 2. Two separate annual notifications between January 1 and  
144 May 31.

145  
146 ~~(b)~~ The notification may be made by any available means,  
147 including, but not limited to, written, electronic, or verbal  
148 notification, and may be made concurrently with any other  
149 notification to residential customers required by law or rule.

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

153 (4)~~(5)~~ All records, data, information, correspondence, and  
154 communications relating to the registration of persons with  
155 special needs as provided in subsection (1) are confidential and  
156 exempt from ~~the provisions of~~ s. 119.07(1), except that such

157 information shall be available to other emergency response  
158 agencies, as determined by the local emergency management  
159 director. Local law enforcement agencies shall be given complete  
160 shelter roster information upon request.

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

173 Section 3. Subsections (3) through (7) of section  
174 381.0303, Florida Statutes, are renumbered as subsections (4)  
175 through (8), respectively, paragraph (b) of subsection (2) and  
176 present subsection (6) are amended, and a new subsection (3) is  
177 added to that section, to read:

178 381.0303 Special needs shelters.—

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

182 (b) County health departments shall, in conjunction with

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

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

201 (7)(6) RULES.—The department, in coordination with the  
202 Division of Emergency Management, has the authority to adopt  
203 rules necessary to implement this section. Rules shall include:

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



209 (b) The process for special needs shelter health care  
 210 practitioners and facility reimbursement for services provided  
 211 in a disaster.

212 (c) Guidelines for special needs shelter staffing levels  
 213 to provide services.

214 (d) The definition of and standards for special needs  
 215 shelter supplies and equipment, including durable medical  
 216 equipment.

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

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

225 (g) The requirement of the county health departments to  
 226 seek the participation of hospitals, nursing homes, assisted  
 227 living facilities, home health agencies, hospice providers,  
 228 nurse registries, home medical equipment providers, dialysis  
 229 centers, and other health and medical emergency preparedness  
 230 stakeholders in pre-event planning activities.

231 Section 4. Section 381.82, Florida Statutes, is created to  
 232 read:

233 381.82 Ed and Ethel Moore Alzheimer's Disease Research  
 234 Program.—

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

240       (a) Improve the health of Floridians by researching better  
241 prevention and diagnoses of and treatments and cures for  
242 Alzheimer's disease.

243       (b) Expand the foundation of knowledge relating to the  
244 prevention, diagnosis, treatment, and cure of Alzheimer's  
245 disease.

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

248       (2) (a) Funds appropriated for the Ed and Ethel Moore  
249 Alzheimer's Disease Research Program shall be used exclusively  
250 for the award of grants and fellowships through a competitive,  
251 peer-reviewed process for research relating to the prevention,  
252 diagnosis, treatment, and cure of Alzheimer's disease and for  
253 expenses incurred in the administration of this section.

254 Priority shall be granted to research designed to prevent or  
255 cure Alzheimer's disease.

256       (b) Applications for Alzheimer's disease research funding  
257 under the program may be submitted from any university or  
258 established research institute in the state. All qualified  
259 investigators in the state, regardless of institution  
260 affiliation, shall have equal access and opportunity to compete

261 for research funding. The following types of applications may be  
262 considered for funding:

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

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

270 (a) The board shall consist of 12 members appointed by the  
271 State Surgeon General. The board shall be composed of three  
272 gerontologists, three geriatric psychiatrists, three  
273 geriatricians, and three neurologists. Initial appointments to  
274 the board shall be made by October 1, 2014. The board members  
275 shall serve 4-year terms, except that, to provide for staggered  
276 terms, six of the initial appointees shall serve 2-year terms  
277 and six shall serve 4-year terms. All subsequent appointments  
278 shall be for 4-year terms. The chair of the board shall be  
279 elected from the membership of the board and shall serve as  
280 chair for 2 years. An appointed member may not serve more than  
281 two consecutive terms. Appointed members must have experience in  
282 Alzheimer's disease or related biomedical research. The board  
283 shall adopt internal organizational procedures as necessary for  
284 its efficient organization. The board shall establish and follow  
285 rigorous guidelines for ethical conduct and adhere to a strict  
286 policy with regard to conflicts of interest. A member of the

287 board may not participate in any discussion or decision of the  
288 board or a panel with respect to a research proposal by any  
289 firm, entity, or agency with which the member is associated as a  
290 member of the governing body or as an employee or with which the  
291 member has entered into a contractual arrangement.

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

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

310 (4) The board shall submit a fiscal-year progress report  
311 on the programs under its purview annually to the Governor, the  
312 President of the Senate, the Speaker of the House of

313 Representatives, and the State Surgeon General by February 15.

314 The report must include:

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

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

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

321 (d) The state ranking and total amount of Alzheimer's  
322 disease research funding currently flowing into the state from  
323 the National Institutes of Health.

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

327 (f) Progress toward programmatic goals, particularly in  
328 the prevention, diagnosis, treatment, and cure of Alzheimer's  
329 disease.

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

331 (5) Implementation of the Ed and Ethel Moore Alzheimer's  
332 Disease Research Program is subject to legislative  
333 appropriation.

334 Section 5. Subsections (3) through (9) of section 430.502,  
335 Florida Statutes, are renumbered as subsections (6) through  
336 (12), respectively, new subsections (3), (4), and (5) are added  
337 to that section, and present subsections (4), (5), (8), and (9)  
338 of that section are amended, to read:

339 430.502 Alzheimer's disease; memory disorder clinics and  
 340 day care and respite care programs.—

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

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

354 (a) Significant increase in the volume of clinical  
 355 services.

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

358 (c) Significant increase in acceptance of Medicaid and  
 359 commercial insurance policies.

360 (d) Significant institutional financial commitments.

361 (5) The department shall measure and score each memory  
 362 disorder clinic based on minimum performance standards and  
 363 incentive performance goals.

364 (7)-(4) Pursuant to ~~the provisions of~~ s. 287.057, the

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

373 (8)~~(5)~~ Pursuant to s. 287.057, the department ~~of Elderly~~  
374 ~~Affairs~~ shall contract for the provision of respite care. All  
375 funds appropriated for the provision of respite care shall be  
376 distributed annually by the department to each funded county  
377 according to an allocation formula. In developing the formula,  
378 the department shall consider the number and proportion of the  
379 county population of individuals who are 75 years of age and  
380 older. Each respite care program shall be used as a resource for  
381 research and statistical data by the memory disorder clinics  
382 established in this part. In consultation with the memory  
383 disorder clinics, the department shall specify the information  
384 to be provided by the respite care programs for research  
385 purposes.

386 (11)~~(8)~~ The department shall implement the waiver program  
387 specified in subsection (10) ~~(7)~~. The agency and the department  
388 shall ensure that providers who have a history of successfully  
389 serving persons with Alzheimer's disease are selected. The  
390 department and the agency shall develop specialized standards

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391 for providers and services tailored to persons in the early,  
392 middle, and late stages of Alzheimer's disease and designate a  
393 level of care determination process and standard that is most  
394 appropriate to this population. The department and the agency  
395 shall include in the waiver services designed to assist the  
396 caregiver in continuing to provide in-home care. The department  
397 shall implement this waiver program subject to a specific  
398 appropriation or as provided in the General Appropriations Act.

399 (12)~~(9)~~ Authority to continue the waiver program specified  
400 in subsection (10) ~~(7)~~ shall be automatically eliminated at the  
401 close of the 2010 Regular Session of the Legislature unless  
402 further legislative action is taken to continue it before ~~prior~~  
403 ~~to~~ such time.

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