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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;
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27 requiring the program to provide grants and 28 fellowships for research relating to Alzheimer's 29 disease; creating the Alzheimer's Disease Research 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 annually submit recommendations for proposals to be 35 36 funded; requiring a report to the Governor, 37 Legislature, and State Surgeon General; providing that 38 implementation of the program is subject to appropriation; amending s. 430.502, F.S.; requiring 39 the Department of Elderly Affairs to develop minimum 40 41 performance standards for memory disorder clinics to 42 receive base-level annual funding; requiring the 43 department to provide incentive-based funding, subject to appropriation, for certain memory disorder clinics; 44 45 providing an effective date. 46 47 Be It Enacted by the Legislature of the State of Florida: 48 49 Subsection (15) of section 120.80, Florida Section 1.

50 Statutes, is amended to read:

51 120.80 Exceptions and special requirements; agencies.52 (15) DEPARTMENT OF HEALTH.-

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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.
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 Family Services for a hearing officer in these
68	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
73	to read:
74	252.355 Registry of persons with special needs; notice <u>;</u>
75	registration program
76	(1) In order to meet the special needs of persons who
77	would need assistance during evacuations and sheltering because
78	of physical, mental, cognitive impairment, or sensory
•	Page 3 of 16

disabilities, <u>the division</u>, in coordination with each local emergency management agency in the state, shall maintain a registry of persons with special needs located within the jurisdiction of the local agency. The registration shall identify those persons in need of assistance and plan for resource allocation to meet 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 88 must be developed by January 1, 2015, and fully implemented by 89 March 1, 2015.

The registration program shall include, at a minimum, 90 (a) a uniform electronic registration form and a database for 91 92 uploading and storing submitted registration forms that may be 93 accessed by the appropriate local emergency management agency. The link to the registration form shall be easily accessible on 94 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 <u>Families Family</u> 103 Services, the Department of Health, the Agency for Health Care 104 Administration, the Department of Education, the Agency for 105 Page 4 of 16

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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 registration procedures. The brochure must be easily accessible 113 on the division's website. All appropriate agencies and 114 115 community-based service providers, including memory disorder clinics, home health care providers, hospices, nurse registries, 116 117 and home medical equipment providers shall, and any physician 118 licensed under chapter 458 or chapter 459 may, assist emergency 119 management agencies by annually registering persons with special needs for special needs shelters, collecting registration 120 121 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 when 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 Page 5 of 16

131 their homes during search and rescue operations if necessary to 132 ensure assure their safety and welfare following disasters.

133 <u>(c) (2)</u> 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 <u>(d) (4) (a)</u> 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:

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

146 2. Two separate annual notifications between January 1 and147 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.

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

156 (4) (5) All records, data, information, correspondence, and Page 6 of 16

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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.

(6) All appropriate agencies and community-based service 164 165 providers, including home health care providers, hospices, nurse 166 registries, and home medical equipment providers, shall assist 167 emergency management agencies by collecting registration information for persons with special needs as part of program 168 169 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 175 shelters, must register as persons with special needs. 176 Subsections (3) through (7) of section Section 3.

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

- 181
- 182

381.0303 Special needs shelters.-

(2)SPECIAL NEEDS SHELTER PLAN; STAFFING; STATE AGENCY Page 7 of 16

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183 ASSISTANCE.-If funds have been appropriated to support disaster 184 coordinator positions in county health departments:

185 County health departments shall, in conjunction with (b) 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 staffing and the operation of special needs shelters. The local 193 health department and emergency management agency shall 194 195 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 SPECIAL CARE FOR PERSONS WITH ALZHEIMER'S DISEASE OR (3)

199 <u>RELATED FORMS OF DEMENTIA.-All special needs shelters must</u> 200 <u>establish designated shelter areas for persons with Alzheimer's</u> 201 <u>disease or related forms of dementia to enable those persons to</u> 202 <u>maintain their normal habits and routines to the greatest extent</u> 203 possible.

204 <u>(7) (6)</u> RULES.-The department, in coordination with the 205 <u>Division of Emergency Management</u>, 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, Page 8 of 16

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.

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

(c) Guidelines for special needs shelter staffing levelsto provide services.

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

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

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

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

234 Section 4. Section 381.82, Florida Statutes, is created to Page 9 of 16

235	read:
236	381.82 Ed and Ethel Moore Alzheimer's Disease Research
237	Program.—
238	(1) The Ed and Ethel Moore Alzheimer's Disease Research
239	Program is created within the Department of Health. The purpose
240	of the program is to fund research leading to prevention of or a
241	cure for Alzheimer's disease. The long-term goals of the program
242	are to:
243	(a) Improve the health of Floridians by researching better
244	prevention and diagnoses of and treatments and cures for
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
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261	established research institute in the state. All qualified
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 within the Department of Health the
272	Alzheimer's Disease Research Grant Advisory Board.
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, five 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
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287	procedures as necessary for its efficient organization. The
288	board shall establish and follow rigorous guidelines for ethical
289	conduct and adhere to a strict policy with regard to conflicts
290	of interest. A member of the board may not participate in any
291	discussion or decision of the board or a panel with respect to a
292	research proposal by any firm, entity, or agency with which the
293	member is associated as a member of the governing body or as an
294	employee or with which the member has entered into a contractual
295	arrangement.
296	(b) The department shall provide such staff, information,
297	and other assistance as is reasonably necessary to assist the
298	board in carrying out its responsibilities. Members of the board
299	shall serve without compensation and may not receive
300	reimbursement for per diem or travel expenses.
301	(c) The board shall advise the State Surgeon General as to
302	the scope of the research program and shall submit its
303	recommendations for proposals to be funded to the State Surgeon
304	General by December 15 of each year. Grants and fellowships
305	shall be awarded by the State Surgeon General, after
306	consultation with the board, on the basis of scientific merit.
307	Other responsibilities of the board may include, but are not
308	limited to, providing advice on program priorities and emphases;
309	assisting in the development of appropriate linkages to
310	nonacademic entities, such as voluntary organizations, health
311	care delivery institutions, industry, government agencies, and
312	public officials; and developing and providing oversight
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313	regarding mechanisms for the dissemination of research results.
314	(4) The board shall submit a fiscal-year progress report
315	on the programs under its purview annually to the Governor, the
316	President of the Senate, the Speaker of the House of
317	Representatives, and the State Surgeon General by February 15.
318	The report must include:
319	(a) A list of research projects supported by grants or
320	fellowships awarded under the program.
321	(b) A list of recipients of program grants or fellowships.
322	(c) A list of publications in peer-reviewed journals
323	involving research supported by grants or fellowships awarded
324	under the program.
325	(d) The state ranking and total amount of Alzheimer's
326	disease research funding currently flowing into the state from
327	the National Institutes of Health.
328	(e) New grants for Alzheimer's disease research which were
329	funded based on research supported by grants or fellowships
330	awarded under the program.
331	(f) Progress toward programmatic goals, particularly in
332	the prevention, diagnosis, treatment, and cure of Alzheimer's
333	disease.
334	(g) Recommendations to further the mission of the program.
335	(5) Implementation of the Ed and Ethel Moore Alzheimer's
336	Disease Research Program is subject to legislative
337	appropriation.
338	Section 5. Subsections (3) through (9) of section 430.502,
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339 Florida Statutes, are renumbered as subsections (6) through (12), respectively, new subsections (3), (4), and (5) are added 340 341 to that section, and present subsections (4), (5), (8), and (9)342 of that section are amended, to read: 343 430.502 Alzheimer's disease; memory disorder clinics and 344 day care and respite care programs.-345 The department shall develop minimum performance (3) 346 standards for memory disorder clinics and include those 347 standards in each memory disorder clinic contract as a condition for receiving base-level funding. The performance standards must 348 address, at a minimum, quality of care, comprehensiveness of 349 350 services, and access to services. 351 The department shall develop performance goals that (4) 352 exceed the minimum performance standards developed under 353 subsection (3), which goals must be achieved in order for a 354 memory disorder clinic to be eligible for incentive funding 355 above the base level, subject to legislative appropriation. 356 Incentive funding shall be based on criteria including, but not 357 limited to: 358 (a) Significant increase in the volume of clinical 359 services. 360 (b) Significant increase in public outreach to low-income 361 and minority populations. 362 (c) Significant increase in acceptance of Medicaid and 363 commercial insurance policies. 364 (d) Significant institutional financial commitments. Page 14 of 16

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365 (5) The department shall measure and score each memory 366 disorder clinic based on minimum performance standards and 367 incentive performance goals.

368 (7) (4) Pursuant to the provisions of s. 287.057, the 369 department of Elderly Affairs may contract for the provision of 370 specialized model day care programs in conjunction with the 371 memory disorder clinics. The purpose of each model day care 372 program must be to provide service delivery to persons suffering 373 from Alzheimer's disease or a related memory disorder and 374 training for health care and social service personnel in the 375 care of persons having Alzheimer's disease or related memory 376 disorders.

377 (8) (5) Pursuant to s. 287.057, the department of Elderly 378 Affairs shall contract for the provision of respite care. All 379 funds appropriated for the provision of respite care shall be 380 distributed annually by the department to each funded county 381 according to an allocation formula. In developing the formula, 382 the department shall consider the number and proportion of the 383 county population of individuals who are 75 years of age and 384 older. Each respite care program shall be used as a resource for 385 research and statistical data by the memory disorder clinics 386 established in this part. In consultation with the memory 387 disorder clinics, the department shall specify the information 388 to be provided by the respite care programs for research 389 purposes.

390

(11) (8) The department shall implement the waiver program Page 15 of 16

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391 specified in subsection (10) (7). The agency and the department 392 shall ensure that providers who have a history of successfully 393 serving persons with Alzheimer's disease are selected. The 394 department and the agency shall develop specialized standards 395 for providers and services tailored to persons in the early, 396 middle, and late stages of Alzheimer's disease and designate a 397 level of care determination process and standard that is most 398 appropriate to this population. The department and the agency 399 shall include in the waiver services designed to assist the 400 caregiver in continuing to provide in-home care. The department shall implement this waiver program subject to a specific 401 402 appropriation or as provided in the 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 <u>before</u> prior 407 to such time.

408

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

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