1

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

2021

22

23

24

25

26

A bill to be entitled An act relating to Alzheimer's disease; amending s. 120.80, F.S.; exempting grant programs administered by the Alzheimer's Disease Research Grant Advisory Board from the Administrative Procedure Act; amending s. 252.355, F.S.; requiring the Division of Emergency Management, in coordination with local emergency management agencies, to maintain a registry of persons with special needs; requiring the division to develop and maintain a special needs shelter registration program by a specified date; requiring specified agencies and authorizing specified health care providers to provide registration information to special needs clients or their caregivers and to assist emergency management agencies in registering persons for special needs shelters; amending s. 381.0303, F.S.; providing additional staffing requirements for special needs shelters; requiring special needs shelters to establish designated shelter areas for persons with Alzheimer's disease or related forms of dementia; authorizing the Department of Health, in coordination with the division, to adopt rules relating to standards for the special needs registration program; creating s. 381.82, F.S.; establishing the Ed and Ethel Moore Alzheimer's Disease Research Program within the department;

Page 1 of 16

(15)

requiring the program to provide grants and
fellowships for research relating to Alzheimer's
disease; creating the Alzheimer's Disease Research
Grant Advisory Board; providing for appointment and
terms of members; providing for organization, duties,
and operating procedures of the board; requiring the
department to provide staff to assist the board in
carrying out its duties; requiring the board to
annually submit recommendations for proposals to be
funded; requiring a report to the Governor,
Legislature, and State Surgeon General; providing that
implementation of the program is subject to
appropriation; amending s. 430.502, F.S.; requiring
the Department of Elderly Affairs to develop minimum
performance standards for memory disorder clinics to
receive base-level annual funding; requiring the
department to provide incentive-based funding, subject
to appropriation, for certain memory disorder clinics;
providing an effective date.
Be It Enacted by the Legislature of the State of Florida:
Section 1. Subsection (15) of section 120.80, Florida
Statutes, is amended to read:
120.80 Exceptions and special requirements; agencies

Page 2 of 16

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

DEPARTMENT OF HEALTH.-

$\underline{\text{(a)}}$ Notwithstanding s. 120.57(1)(a), formal hearings may
not be conducted by the State Surgeon General, the Secretary of
Health Care Administration, or a board or member of a board
within the Department of Health or the Agency for Health Care
Administration for matters relating to the regulation of
professions, as defined by chapter 456. Notwithstanding s.
120.57(1)(a), hearings conducted within the Department of Health
in execution of the Special Supplemental Nutrition Program for
Women, Infants, and Children; Child Care Food Program;
Children's Medical Services Program; the Brain and Spinal Cord
Injury Program; and the exemption from disqualification reviews
for certified nurse assistants program need not be conducted by
an administrative law judge assigned by the division. The
Department of Health may contract with the Department of
Children and Family Services for a hearing officer in these
matters

- (b) This chapter does not apply to grant programs administered by the Alzheimer's Disease Research Grant Advisory Board pursuant to s. 381.82.
- Section 2. Section 252.355, Florida Statutes, is amended to read:
- 252.355 Registry of persons with special needs; notice; registration program.—
- (1) In order to meet the special needs of persons who would need assistance during evacuations and sheltering because of physical, mental, cognitive impairment, or sensory

Page 3 of 16

disabilities, the division, 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.

- (2) In order to ensure that all persons with special needs may register, the division shall develop and maintain a special needs shelter registration program. The registration program must be developed by January 1, 2015, and fully implemented by March 1, 2015.
- (a) The registration program shall include, at a minimum, a uniform electronic registration form and a database for uploading and storing submitted registration forms that may be accessed by the appropriate local emergency management agency. The link to the registration form shall be easily accessible on each local emergency management agency's website. Upon receipt of a paper registration form, the local emergency management agency shall enter the person's registration information into the database.
- (b) To assist the local emergency management agency in identifying such persons with special needs, home health agencies, hospices, nurse registries, home medical equipment providers, the Department of Children and Families Family Services, the Department of Health, the Agency for Health Care Administration, the Department of Education, the Agency for

Page 4 of 16

2014 CS/CS/HB 709

105	Persons with Disabilities, <u>the</u> 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	<u>licensed under chapter 465 may, annually</u> 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 must be easily accessible
114	on the division's website. All appropriate agencies and
115	community-based service providers, including aging and
116	disability resource centers, memory disorder clinics, home
117	health care providers, hospices, nurse registries, and home
118	medical equipment providers, shall, and any physician licensed
119	under chapter 458 or chapter 459 may, assist emergency
120	management agencies by annually registering persons with special
121	needs for special needs shelters, collecting registration
122	information for persons with special needs as part of the
123	program intake process, and establishing programs to educate
124	clients about the registration process and disaster preparedness
125	safety procedures. A client of a state-funded or federally
126	funded service program who has a physical, mental, or cognitive
127	impairment or sensory disability and who needs assistance in
128	evacuating, or when in a shelter, must register as a person with
129	special needs. The registry shall be updated annually. The
130	registration program shall give persons with special needs the

Page 5 of 16

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

option of preauthorizing emergency response personnel to enter their homes during search and rescue operations if necessary to ensure assure their safety and welfare following disasters.

- $\underline{\text{(c)}}$ The division shall be the designated lead agency responsible for community education and outreach to the public, including special needs clients, regarding registration and special needs shelters and general information regarding shelter stays.
- (d) (4) (a) On or before May 31 of each year, each electric utility in the state shall annually notify residential customers in its service area of the availability of the registration program available through their local emergency management agency by:
- 1. 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
- 2. Two separate annual notifications between January 1 and May 31.
- (b) The notification may be made by any available means, including, but not limited to, written, electronic, or verbal notification, and may be made concurrently with any other 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.

Page 6 of 16

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

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

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

381.0303 Special needs shelters.-

Page 7 of 16

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

- (b) County health departments shall, in conjunction with the local emergency management agencies, have the lead responsibility for coordination of the recruitment of health care practitioners to staff local special needs shelters. County health departments shall assign their employees to work in special needs shelters when those employees are needed to protect the health and safety of persons with special needs. County governments shall assist the department with nonmedical staffing and the operation of special needs shelters. The local health department and emergency management agency shall coordinate these efforts to ensure appropriate staffing in special needs shelters, including a staff member who is familiar with the needs of persons with Alzheimer's disease.
- (3) SPECIAL CARE FOR PERSONS WITH ALZHEIMER'S DISEASE OR RELATED FORMS OF DEMENTIA.—All special needs shelters must establish designated shelter areas for persons with Alzheimer's disease or related forms of dementia to enable those persons to maintain their normal habits and routines to the greatest extent possible.
- (7) (6) RULES.—The department, in coordination with the Division of Emergency Management, has the authority to adopt rules necessary to implement this section. Rules shall include:
 - (a) The definition of a "person with special needs,"

Page 8 of 16

including eligibility criteria for individuals with physical, mental, cognitive impairment, or sensory disabilities and the services a person with special needs can expect to receive in a 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 levels to 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.

Page 9 of 16

235 Section 4. Section 381.82, Florida Statutes, is created to 236 read: 237 381.82 Ed and Ethel Moore Alzheimer's Disease Research 238 Program.-239 (1) The Ed and Ethel Moore Alzheimer's Disease Research 240 Program is created within the Department of Health. The purpose 241 of the program is to fund research leading to prevention of or a 242 cure for Alzheimer's disease. The long-term goals of the program 243 are to: Improve the health of Floridians by researching better 244 (a) 245 prevention and diagnoses of and treatments and cures for 246 Alzheimer's disease. 247 (b) Expand the foundation of knowledge relating to the 248 prevention, diagnosis, treatment, and cure of Alzheimer's 249 disease. 250 Stimulate economic activity in the state in areas 251 related to Alzheimer's disease research. 252 (2) (a) Funds appropriated for the Ed and Ethel Moore 253 Alzheimer's Disease Research Program shall be used exclusively 254 for the award of grants and fellowships through a competitive, 255 peer-reviewed process for research relating to the prevention, 256 diagnosis, treatment, and cure of Alzheimer's disease and for 257 expenses incurred in the administration of this section. 258 Priority shall be granted to research designed to prevent or 259 cure Alzheimer's disease. 260 (b) Applications for Alzheimer's disease research funding

Page 10 of 16

under the program may be submitted from any university or established research institute in the state. All qualified investigators in the state, regardless of institution affiliation, shall have equal access and opportunity to compete for research funding. The following types of applications may be considered for funding:

- 1. Investigator-initiated research grants.
- 2. Institutional research grants.

- 3. Predoctoral and postdoctoral research fellowships.
- 4. Collaborative research grants, including those that advance the finding of cures through basic or applied research.
- (3) There is created within the Department of Health the Alzheimer's Disease Research Grant Advisory Board.
- (a) The board shall consist of 11 members appointed by the State Surgeon General. The board shall be composed of two gerontologists, two geriatric psychiatrists, two geriatricians, two neuroscientists, and three neurologists. Initial appointments to the board shall be made by October 1, 2014. The board members shall serve 4-year terms, except that, to provide for staggered terms, five of the initial appointees shall serve 2-year terms and six shall serve 4-year terms. All subsequent appointments shall be for 4-year terms. The chair of the board shall be elected from the membership of the board and shall serve as chair for 2 years. An appointed member may not serve more than two consecutive terms. Appointed members must have experience in Alzheimer's disease or related biomedical

Page 11 of 16

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

- (b) The department shall provide such staff, information, and other assistance as is reasonably necessary to assist the board in carrying out its responsibilities. Members of the board shall serve without compensation and may not receive reimbursement for per diem or travel expenses.
- (c) The board shall advise the State Surgeon General as to the scope of the research program and shall submit its recommendations for proposals to be funded to the State Surgeon General by December 15 of each year. Grants and fellowships shall be awarded by the State Surgeon General, after consultation with the board, on the basis of scientific merit. Other responsibilities of the board may include, but are not limited to, providing advice on program priorities and emphases; assisting in the development of appropriate linkages to nonacademic entities, such as voluntary organizations, health care delivery institutions, industry, government agencies, and

Page 12 of 16

313	public officials; and developing and providing oversight
314	regarding mechanisms for the dissemination of research results.
315	(4) The board shall submit a fiscal-year progress report
316	on the programs under its purview annually to the Governor, the
317	President of the Senate, the Speaker of the House of
318	Representatives, and the State Surgeon General by February 15.
319	The report must include:
320	(a) A list of research projects supported by grants or
321	fellowships awarded under the program.
322	(b) A list of recipients of program grants or fellowships.
323	(c) A list of publications in peer-reviewed journals
324	involving research supported by grants or fellowships awarded
325	under the program.
326	(d) The state ranking and total amount of Alzheimer's
327	disease research funding currently flowing into the state from
328	the National Institutes of Health.
329	(e) New grants for Alzheimer's disease research which were
330	funded based on research supported by grants or fellowships
331	awarded under the program.
332	(f) Progress toward programmatic goals, particularly in
333	the prevention, diagnosis, treatment, and cure of Alzheimer's
334	disease.
335	(g) Recommendations to further the mission of the program.
336	(5) Implementation of the Ed and Ethel Moore Alzheimer's
337	Disease Research Program is subject to legislative
338	appropriation.

Page 13 of 16

339 Section 5. Subsections (3) through (9) of section 430.502, 340 Florida Statutes, are renumbered as subsections (6) through 341 (12), respectively, new subsections (3), (4), and (5) are added 342 to that section, and present subsections (4), (5), (8), and (9) 343 of that section are amended, to read: 344 430.502 Alzheimer's disease; memory disorder clinics and 345 day care and respite care programs. -346 The department shall develop minimum performance 347 standards for memory disorder clinics and include those standards in each memory disorder clinic contract as a condition 348 for receiving base-level funding. The performance standards must 349 address, at a minimum, quality of care, comprehensiveness of 350 351 services, and access to services. 352 The department shall develop performance goals that (4) 353 exceed the minimum performance standards developed under 354 subsection (3), which goals must be achieved in order for a 355 memory disorder clinic to be eligible for incentive funding 356 above the base level, subject to legislative appropriation. 357 Incentive funding shall be based on criteria including, but not 358 limited to: Significant increase in the volume of clinical 359 (a) 360 services. 361 Significant increase in public outreach to low-income 362 and minority populations. 363 (c) Significant increase in acceptance of Medicaid and

Page 14 of 16

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

commercial insurance policies.

(d) Significant institutional financial commitments.

- (5) The department shall measure and score each memory disorder clinic based on minimum performance standards and incentive performance goals.
- (7) (4) Pursuant to the provisions of s. 287.057, the department of Elderly Affairs may contract for the provision of specialized model day care programs in conjunction with the memory disorder clinics. The purpose of each model day care program must be to provide service delivery to persons suffering from Alzheimer's disease or a related memory disorder and training for health care and social service personnel in the care of persons having Alzheimer's disease or related memory disorders.
- (8)(5) Pursuant to s. 287.057, the department of Elderly Affairs shall contract for the provision of respite care. All funds appropriated for the provision of respite care shall be distributed annually by the department to each funded county according to an allocation formula. In developing the formula, the department shall consider the number and proportion of the county population of individuals who are 75 years of age and older. Each respite care program shall be used as a resource for research and statistical data by the memory disorder clinics established in this part. In consultation with the memory disorder clinics, the department shall specify the information to be provided by the respite care programs for research purposes.

Page 15 of 16

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

(12) (9) Authority to continue the waiver program specified in subsection (10) (7) shall be automatically eliminated at the close of the 2010 Regular Session of the Legislature unless further legislative action is taken to continue it <u>before</u> prior to such time.

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

Page 16 of 16