The Florida Senate

BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

Prepared By: The Professional Staff of the Committee on Appropriations

BILL:	CS/CS/SB 872
INTRODUCER:	Appropriations Committee; Health Policy Committee; and Senators Richter and Soto
SUBJECT:	Alzheimer's Disease
DATE:	April 24, 2014 REVISED:

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Peterson	Stovall	HP	**Fav/CS**
2.	McVaney	McVaney	GO	**Favorable**
3.	Brown	Kynoch	AP	**Fav/CS**

Please see Section IX. for Additional Information:

COMMITTEE SUBSTITUTE - Substantial Changes

I. Summary:

CS/CS/SB 872 makes a number of changes related to Alzheimer's disease that implement recommendations of the Purple Ribbon Task Force that was created by the Legislature in 2012.

The bill requires the Division of Emergency Management (DEM), in coordination with local emergency management agencies, to maintain a registry of persons with special needs using an electronic registration form and database. The bill requires memory disorder clinics and aging and disability resource centers, and authorizes licensed physicians and pharmacies, to provide information and assistance to individuals with special needs and their caregivers regarding special needs shelter registration.

The bill requires county health departments to staff special needs shelters with a person who is familiar with the needs of persons with Alzheimer's disease and requires that all special needs shelters establish sheltering areas for persons with Alzheimer's disease or related dementia.

The bill creates the Ed and Ethel Moore Alzheimer's Disease Research Program (Moore program) to fund research for the prevention and cure of Alzheimer's disease. The bill requires the Department of Elder Affairs to develop performance standards for memory disorder clinics and to condition contract funding on compliance with the standards.

The Department of Health would experience a negative fiscal impact of approximately $140,000 in recurring general revenue to implement the Moore program; however, the bill provides that implementation of the Moore program is subject to legislative appropriation. See Section V.

II. Present Situation:

Alzheimer's Disease

Alzheimer's disease is a progressive, degenerative disorder that attacks the brain's nerve cells and results in loss of memory, loss of cognitive and language skills, and behavioral changes.[1] Alzheimer's disease was named after Dr. Alois Alzheimer, a German physician who, in the early 1900's, cared for a 51-year-old woman suffering from severe dementia. Upon the woman's death, Dr. Alzheimer conducted a brain autopsy and found bundles of neurofibers and plaques in her brain which are distinguishing characteristics of what we call Alzheimer's disease today.[2]

More than five million Americans currently live with Alzheimer's disease, and that number is projected to rise to 16 million by 2050.[3] As the life expectancy for Americans has continued to rise, so has the number of new cases of Alzheimer's disease. For instance, in 2000 there were an estimated 411,000 new cases of Alzheimer's disease in the United States, and in 2010 that number was estimated to be 454,000 – a 10 percent increase.[4] The number is expected to rise to 959,000 new cases of Alzheimer's disease by 2050, a 130 percent increase from 2000.[5] Specifically in Florida, approximately 360,000 people age 65 or older had Alzheimer's disease in 2000, and in 2010 that number had risen to 450,000.[6]

As the number of people with Alzheimer's disease increases, so does the cost of caring for these individuals. In 2013, the aggregate cost for health care, long-term care, and hospice for persons with Alzheimer's and other dementia was estimated to be $203 billion. That number is projected to be $1.2 trillion by 2050.[7] A major contributing factor to the cost of care for persons with Alzheimer's disease is the fact that these individuals have more hospital stays, skilled nursing home stays, and home health care visits than older persons who do not have Alzheimer's disease. Research shows that 29 percent of individuals with Alzheimer's disease who have Medicare also have Medicaid coverage, which pays for nursing home care and other long-term care services.[8] The total Medicaid spending for people with Alzheimer's disease and other dementia in 2013 is projected to be $37 billion.[9]

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[1] Alzheimer's Foundation of America, *About Alzheimer's, Definition of Alzheimer's,* http://www.alzfdn.org/AboutAlzheimers/definition.html (last visited Feb. 25, 2014).
[2] Michael Plontz, *A Brief History of Alzheimer's Disease*, TODAY'S CAREGIVER, http://www.caregiver.com/channels/alz/articles/a_brief_history.htm (last visited Feb. 25, 2014).
[3] Alzheimer's Association., *Fact Sheet: 2013 Alzheimer's Disease Facts and Figures* (March 2013), *available at* http://www.alz.org/documents_custom/2013_facts_figures_fact_sheet.pdf (last visited Feb. 25, 2014).
[4] Alzheimer's Association., *2013 Alzheimer's Disease Facts and Figures*, 9 ALZHEIMER'S & DEMENTIA (Issue 2) at 20, *available at* http://www.alz.org/downloads/facts_figures_2013.pdf (last visited Feb. 25, 2014).
[5] *Id*.
[6] *Id*. at 21.
[7] *Id*. at 49.
[8] *Id*. at 39.
[9] *Id*. at 49.

In addition to the cost of health care, there is a significant cost associated with unpaid caregivers. An unpaid caregiver is primarily a family member but can also be other relatives or friends. These caregivers often provide assistance with daily activities, such as shopping for groceries, preparing meals, bathing, dressing, grooming, assisting with mobility, helping the person take medications, making arrangements for medical care, and performing other household chores. In 2012, 15.4 million unpaid caregivers provided an estimated 17.5 billion hours of unpaid care, valued at $216.4 billion.[10] In 2010, there were 1,015,000 million caregivers in Florida who provided an estimated value of unpaid care reaching nearly $14.3 million.[11]

Florida Purple Ribbon Task Force

In 2012, the Legislature established the Purple Ribbon Task Force (task force) within the Department of Elder Affairs (DOEA) to submit a report to the governor, the president of the Senate, and the Speaker of the House of Representatives on a comprehensive set of issues related to Alzheimer's disease and related forms of dementia. Specifically, the task force was required to: [12]

- Submit an interim study on state trends on persons with Alzheimer's disease and their needs;
- Assess the current and future impact of Alzheimer's disease and related forms of dementia on the state;
- Examine the existing industries, services, and resources addressing the needs of persons with Alzheimer's disease or a related form of dementia and their family caregivers;
- Examine the needs of persons of all cultural backgrounds having Alzheimer's disease or a related form of dementia and how their lives are affected by the disease from younger-onset, through mid-stage, to late-stage;
- Develop a strategy to mobilize a state response to Alzheimer's disease; and
- Hold public meetings and employ technological means to gather feedback on the recommendations submitted by persons having Alzheimer's disease or a related form of dementia and their family caregivers and by the general public.

Other issues required to be addressed by the task force included:

- The role of the state in providing community-based care, long-term care, family caregiver support, and assistance to persons who are in the early stages of Alzheimer's disease, who have younger-onset Alzheimer's disease, or who have a related form of dementia;
- The development of state policy with respect to persons having Alzheimer's disease or a related form of dementia;
- Surveillance of persons having Alzheimer's disease or a related form of dementia for the purpose of accurately estimating the number of such persons in the state;
- Existing services, resources, and capacity; including:
  - The type, cost, and availability of dementia services in the state;
  - Policy requirements and effectiveness for dementia-specific training for professionals providing care;
  - Quality care measures employed by providers of care;

[10] This number was established by using an average of 21.9 hours of care a week with a value of $12.33 per hour. (*Id.* at 30).
[11] *Id*. at 32.
[12] Ch. 2012-172, Laws of Fla.

- The capability of public safety workers and law enforcement officers to respond to persons having Alzheimer's disease or a related form of dementia;
- The availability of home and community-based services and respite care for persons having Alzheimer's disease or a related form of dementia and education and support services to assist their families and caregivers;
- An inventory of long-term care facilities and community-based services serving persons having Alzheimer's disease or a related form of dementia;
- The adequacy and appropriateness of geriatric-psychiatric units for persons having behavior disorders associated with Alzheimer's disease or other dementia;
- Residential assisted living options for persons having Alzheimer's disease or a related form of dementia;
- The level of preparedness of service providers before, during, and after a catastrophic emergency involving a person having Alzheimer's disease or a related form of dementia; and
- Needed state policies or responses.

As its final responsibility, the task force was required to submit final, date-specific recommendations in the form of an Alzheimer's disease state plan to the governor and Legislature by August 1, 2013.

The task force has issued its final report and recommendations.[13] Pertinent to this bill are the following recommendations:

- To allocate $10 million annually to support Alzheimer's disease research through a peer-reviewed grant program;[14]
- To develop a well-coordinated and dementia-capable emergency management system, including reforms to the special needs shelter and registry function;[15] and
- To fund memory disorder clinics according to performance standards and benchmark goals related to base level and incentive funding.[16]

Alzheimer's Research Funding

The U.S. budget bill passed by Congress and signed into law by President Barack Obama on January 17, 2014, contains increased funding for Alzheimer's disease initiatives. The new federal funding includes a $100 million increase for the National Institute on Aging (NIA)[17] for Alzheimer's research, which will be added to what the National Institutes of Health (NIH) estimates will be $484 million in Alzheimer's research funding across NIH in the 2013 federal fiscal year.[18]

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[13] Florida Department of Elder Affairs, *Purple Ribbon Task Force Final Report and Recommendations* (2013), *available at* http://elderaffairs.state.fl.us/doea/purple_ribbon/PRTF_final_report.pdf (last visited Feb. 26, 2014).
[14] *Id*. at 30.
[15] *Id*. at 64 – 66.
[16] *Id*. at 72 – 73.
[17] NIA is one of the 27 institutes and centers of the National Institutes of Health. NIA is the primary federal agency supporting and conducting Alzheimer's research.
[18] Alzheimer's Association, *Record $122 million increase for Alzheimer's disease signed into law by President Obama*, http://www.alz.org/news_and_events_law_by_obama.asp (last visited Feb. 26, 2014).

The NIA funds Alzheimer's Disease Centers (ADC) at major medical institutions with the goal of improving diagnosis and care and ultimately finding a way to cure and possibly prevent Alzheimer's disease. Although each center has its own unique area of emphasis, a common goal of the ADCs is to enhance research on Alzheimer's disease by providing a network for sharing new ideas and research results. Collaborative studies draw upon the expertise of scientists from many different disciplines. Currently, there are 29 NIA-funded centers, including one at the Mayo Clinic in Jacksonville.[19]

In 2002, the Legislature created the Florida Alzheimer's Center and Research Institute (institute) at the University of South Florida (USF).[20] The institute was governed by a not-for-profit corporation, acting as an instrumentality of the state, under the direction of its 16-member Board of Directors. Its mission related to research, education, treatment, prevention, and early detection of Alzheimer's disease.[21] In 2004, the Legislature renamed the institute the Johnnie B. Byrd, Sr. Alzheimer's Center and Research Institute (Byrd Institute) and funded it with a $15 million distribution from alcoholic beverage tax collections for the purposes of conducting research, developing and operating integrated data projects, and providing assistance to memory disorder clinics.[22] The 2006 Legislature replaced the automatic distribution with a recurring appropriation from general revenue and clarified that researchers from any university or established research institution were eligible for funding from the Byrd Institute.[23] The recurring appropriation was reduced to $13.5 million in 2007[24] and eliminated in 2008.[25] In 2009, the statute authorizing the Byrd Institute was substantially revised to establish the Institute as an entity within and operated by the USF and provided that its budget included any money specifically appropriated in the General Appropriations Act, or otherwise provided to it from private, local, state, or federal sources, or income generated by activities at the Byrd Institute.[26]

Section 430.501, F.S., creates the Alzheimer's Disease Advisory Committee, whose members are appointed by the governor, to advise the DOEA in the performance of its duties. The committee also has responsibility for awarding research grants to qualified entities from any funds made available to the DOEA through gifts, grants, or other sources.

Special Needs Shelters

The Comprehensive Emergency Management Plan (CEMP) is the master operations document for the state in responding to all catastrophic disasters and all emergencies, whether major or minor.[27] The CEMP, which is developed and maintained by the Division of Emergency Management (DEM), in coordination with local governments and agencies and organizations with emergency management responsibilities, defines the responsibilities of all levels of

[19] U.S. Department of Health & Human Services, National Institute on Aging, *Alzheimer's Disease Research Centers*, http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers#florida (last visited Feb. 26, 2014).
[20] Ch. 2002-387, s. 191, Laws of Fla.; ch. 2002-389, s. 2, Laws of Fla.
[21] *Id.*
[22] Ch. 2004-2, ss. 3 & 5, Laws of Fla.
[23] Ch. 2006-182, s.12, Laws of Fla.
[24] Ch. 2007-332, Laws of Fla.
[25] Ch. 2008-113, Laws of Fla. The Institute received $1.25 million in FY 2013–2014 funding via an allocation to the USF Medical Center in the Department of Education's budget.
[26] Ch. 2009-60, s. 5, Laws of Fla.
[27] Section 252.35(2)(a), F.S.

government and private, volunteer, and non-governmental organizations that make up the State Emergency Response Team. In general, the CEMP assumes that all emergencies and disasters are local, but local governments may require state assistance.[28]

The CEMP includes a shelter component which provides policy guidance for sheltering people with special needs.[29] Specifically, it states:[30]

> All shelters must meet physical and programmatic accessibility requirements as defined by the Americans with Disabilities Act and Florida Accessibility Codes. Special Needs Shelters provide a higher level of attendant care than general population shelters. Any facility designated as a shelter must meet minimum safety requirements. To ensure consistency with state and national standards, guidelines and best practices, the Division has adopted the American Red Cross (ARC) 4496 Standards for Hurricane Evacuation Shelter Selection.[31]

Each local emergency management agency is required to maintain a registry of persons with special needs.[32] The information is used to identify people with special needs, people who may need assistance with transportation to the shelters, and to ensure that any area affected by an emergency or disaster has adequate special needs shelter capacity, staffing, equipment, and supplies.[33]

The DEM has lead responsibility for community outreach and education about registration and shelter stays.[34] However, community-based service providers, including home health agencies, hospices, nurse registries, and home medical equipment providers, and state agencies likely to serve individuals with special needs, including the Department of Children and Families, the Department of Health (DOH), the Agency for Health Care Administration, the Department of Education, the Agency for Persons with Disabilities, and the DOEA, are directed to provide registration information to all of their special needs clients and to collect registration information during the client intake process.[35]

The law further requires agencies that contract with providers for the care of people with disabilities or who are otherwise dependent on others for care, to include emergency and disaster

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[28] Florida Division of Emergency Management, *The State of Florida Comprehensive Emergency Management Plan*, 11, (Feb. 2012), *available at* http://floridadisaster.org/documents/CEMP/2012/2012%20State%20CEMP%20Basic%20Plan%20-%20Final.pdf (last visited Feb. 26, 2014). "Initial response is by local jurisdictions working with county emergency management agencies. It is only after local emergency response resources are exhausted, or local resources do not exist to address a given emergency or disaster that state emergency response resources and assistance may be requested by local authorities." (*Id.* at 19).

[29] A "person with special needs" means someone, who during periods of evacuation or emergency, requires sheltering assistance, due to physical impairment, mental impairment, cognitive impairment, or sensory disabilities. (Rule 64-3.010(1), F.A.C.)

[30] Florida Division of Emergency Management, *supra* note 28 at 35.

[31] *Available at* http://www.floridadisaster.org/Response/engineers/documents/newarc4496.pdf (last visited Feb. 26, 2014).

[32] Section 252.355(1), F.S.

[33] Florida Department of Health, *Senate Bill 872 Legislative Bill Analysis* (Feb. 5, 2014) (on file with the Senate Health Policy Committee).

[34] Section 252.355(2), F.S.

[35] Section 252.355(1) & (6), F.S.

planning conditions in their service contracts. Among other provisions, the contracts must include a requirement for the provider to have a procedure to help its clients register for special needs sheltering.[36]

The DOH, through county public health units, is tasked with lead responsibility, in coordination with the local emergency management agency, to recruit and staff special needs shelters with appropriate health care personnel, pursuant to a staffing plan developed at the local level.[37] Designation and operation of the shelter, however, remains the responsibility of the local emergency management agency, [38] although subject to operational standards established by rule of the DOH.[39]

Admission to a special needs shelter is subject to an assessment of the person's eligibility. A person is eligible if he or she:[40]

- Has special needs;
- Has care needs that exceed basic first aid that is available at the general emergency shelters; and
- Has impairments that are medically stable and do not exceed the capacity, staffing, and equipment of the shelter.

A shelter may accept someone whose needs exceed the eligibility criteria. Decisions related to shelter capacity, both available skills and equipment, are made by the local emergency management agency and the county public health department.[41]

Alzheimer's Disease Initiative

In 1985, the Florida Legislature created the Alzheimer's Disease Initiative (ADI) to provide a continuum of services to individuals with Alzheimer's disease and their families.[42] The ADI has four objectives: (1) to provide supportive services; (2) to establish memory disorder clinics; (3) to provide model day care programs to test new care alternatives; and (4) to establish a research database and brain bank to support research.[43] There are 15 memory disorder clinics throughout the state, 13 of which are state-funded.[44] The purpose of these clinics is to conduct research related to diagnostic technique, therapeutic interventions, and supportive services for persons with Alzheimer's disease and to develop caregiver-training materials.[45] According to the ADI, the memory disorder clinics are required to:

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[36] Section 252.356(3), F.S.
[37] Section 381.0303(1) & (2), F.S.
[38] Section 381.0303(2)(d), F.S.
[39] Section 381.0303(6), F.S., requires the DOH to adopt rules for the following: the definition of "person with special needs;" shelter services; practitioner and facility reimbursement; staffing levels; supplies and equipment; registration procedures; family and caretaker needs; and pre-event planning.
[40] Rule 64-3.020, F.A.C.
[41] *Id*.
[42] *See* ss. 430.501 – 430.504, F.S.
[43] Florida Department of Elder Affairs, *Summary of Programs & Services, Alzheimer's Disease Initiative* (Jan. 2013) at 91, *available at* http://elderaffairs.state.fl.us/doea/pubs/pubs/sops2013/2013%20SOPS%20Section%20D.pdf (last visited Feb. 25, 2014).
[44] *Id*.
[45] Section 430.502(2), F.S.

- Provide services to persons suspected of having Alzheimer's disease or other related dementia;
- Provide four hours of in-service training during the contract year to all ADI respite and model day care service providers and develop and disseminate training models to service providers and the DOEA;
- Develop training materials and educational opportunities for caregivers and provide specialized training for caregivers and caregiver organizations;
- Conduct service-related applied research;
- Establish a minimum of one annual contact with each respite care and model day care service provider to discuss, plan, develop, and conduct service-related research projects; and
- Plan for the public dissemination of research findings through professional papers and to the general public.[46]

Individuals diagnosed with or suspected of having Alzheimer's disease are eligible for memory disorder clinic services. In Fiscal Year 2012-2013, Florida's memory disorder clinics received nearly $3 million in state funds and served an estimated 6,722 clients.[47]

Model day care programs have been established in conjunction with memory disorder clinics to test therapeutic models and provide day care services. These programs provide a safe environment where Alzheimer's patients can socialize with each other and receive therapeutic interventions designed to maintain or improve their cognitive functioning. Model day care programs also provide training for health care and social service personnel in the care of individuals with Alzheimer's disease or related memory disorders. There are currently four model day care programs in the state.[48]

The ADI also includes respite care services, which includes in-home, facility-based, emergency and extended care respite for caregivers who serve individuals with memory disorders.[49] In addition to respite care services, caregivers and consumers may receive supportive services essential to maintaining individuals with Alzheimer's disease or related dementia in their own homes. The supportive services may include caregiver training and support groups, counseling, consumable medical supplies, and nutritional supplements. Services are authorized by a case manager based on a comprehensive assessment. Alzheimer's Respite Care programs are established in all of Florida's 67 counties.[50]

Statutory Creation of Advisory Bodies, Commissions, or Boards

The statutory creation of any collegial body to serve as an adjunct to an executive agency is subject to certain provisions in s. 20.052, F.S. Such a body may only be created when it is found to be necessary and beneficial to the furtherance of a public purpose, and it must be terminated by the Legislature when it no longer fulfills such a purpose. The Legislature and the public must

[46] Florida Department of Elder Affairs, *supra* note 43 at 90-91.
[47] *Id*. at 96.
[48] *Id*. at 92.
[49] *Id*. at 91.
[50] *Id*.

be kept informed of the numbers, purposes, memberships, activities, and expenses of any collegial or advisory bodies.

Private citizen members of any advisory body (with exceptions for members of commissions or boards of trustees) may be appointed only by the governor, the head of the executive agency to which the advisory body is adjunct, the executive director of the agency, or a cabinet officer. Private citizen members of a commission or a board of trustees may be appointed only by the governor, must be confirmed by the Senate, and are subject to the dual-office-holding prohibition of section 5(a) of Article II of the State Constitution.

Members of agency advisory bodies serve four-year staggered terms and are ineligible for any compensation other than travel expenses, unless expressly provided otherwise in the State Constitution. Unless an exemption is specified by law, all meetings are public, and records of minutes and votes must be maintained.

III. Effect of Proposed Changes:

Section 1 requires the Division of Emergency Management (DEM) to develop a special needs shelter registration program by January 1, 2015, and to fully implement the program by March 1, 2015. The bill shifts responsibility for maintaining a special needs registry from the local emergency management agencies to the DEM, working in coordination with the local agencies. In effect, the bill centralizes the registry at the state level, although still providing access for local emergency management agencies. The bill directs the DEM to develop a uniform electronic registration form and database that may be used by local agencies to upload registration information they receive. The DEM is directed to develop and post on its website a brochure describing the registration procedures.

The bill adds memory disorder clinics and aging and disability resource centers to the existing list of providers and agencies that are required to: give registration information to their special needs clients; and assist emergency management by collecting registration information for persons with special needs during their program intake procedures and establishing education programs for their clients about the registration process and disaster preparedness. These duties are expanded under the bill to require the providers and agencies to also provide registration information to client caregivers and to register their special needs clients annually. The bill specifies that physicians and pharmacies may, but are not required to, perform all of these same duties.

Section 2 requires county health departments to ensure that special needs shelters are staffed with a person who is familiar with the needs of persons with Alzheimer's disease. In addition, the bill requires that all special needs shelters designate areas within the shelter for persons with Alzheimer's disease or related dementia in order to maximize their normal routines to the greatest extent possible. The bill specifies that the DOH must work in conjunction with the DEM to adopt rules related to the special needs shelters and includes forms within the scope of the DOH's rulemaking authority.

Section 3 creates the Ed and Ethel Moore Alzheimer's Disease Research Program (Moore program) within the DOH to fund research leading to prevention of or a cure for Alzheimer's disease. Long-term goals of the Moore program are to:

- Enhance the health of Floridians by researching improved prevention, diagnosis, treatment, and cure of Alzheimer's disease;
- Expand the foundation of knowledge relating to the prevention, diagnosis, treatment, and cure of Alzheimer's disease; and
- Stimulate activity in the state related to Alzheimer's disease research.

The program is modeled after the James and Esther King Biomedical Research Program that is established in s. 215.5602, F.S.

The bill specifies that:

- Moore program funds may be used only for grants and fellowships awarded through a competitive process and expenses related to program administration. Grants will be awarded by the state surgeon general on the basis of scientific merit.
- Funding applications may be submitted from any university or established research institute[51] in the state. Qualified investigators, regardless of institution, will have equal access to competitive funding.
- Implementation of the program is contingent upon a legislative appropriation.

In addition, the bill creates the 11-member Alzheimer's Disease Research Grant Advisory Board (board) within the DOH, as follows:

- The board consists of two gerontologists, two geriatric psychiatrists, two geriatricians, two neuroscientists, and three neurologists appointed by the state surgeon general to four-year terms, except that five of the initial appointees shall serve two-year terms. Initial appointments must be made by October 1, 2014. Appointees must have experience in Alzheimer's disease or related biomedical research. The board chair is elected by the members to serve as chair for two years. No board member may serve on the board more than two consecutive terms.
- The board must adopt internal organization procedures, as necessary, for its organization and establish and follow guidelines for ethical conduct to avoid conflicts of interest. A member may not participate in any discussion or decision related to a research proposal by any entity with which the member has a relationship, whether as governing board member, employee, or contracted party.
- Members of the board serve without compensation.
- The DOH must provide staff to the board.
- The board's role is to:
    - Advise the state surgeon general on the scope of the program and proposals to be funded;

[51] Currently, the DOH defines an "established research institute" as an organization that is any Florida nonprofit or foreign nonprofit covered under ch. 617, F.S., with a physical location in Florida, whose stated purpose and powers are scientific, biomedical or biotechnological research and/or development and is legally registered with the Florida Department of State, Division of Corporations. This includes federal government and non-profit medical and surgical hospitals including Veteran's Administration hospitals. Florida Department of Health, *James and Esther King Biomedical Research Program, Announcement of Funding Opportunity and Call for Applications* (2013-2014), *available at* http://www.research.fsu.edu/newsletters/2013/July/documents/2013-2014%20SUMMER%20CALL%20King%20Program.pdf (last visited Feb. 25, 2014).

  - Advise on program priorities and emphases;
  - Assist in the development of appropriate linkages to nonacademic entities; and
  - Develop and provide oversight of mechanisms for disseminating research results.
- The board must submit a fiscal year progress report to the governor, the president of the Senate, the speaker of the House of Representatives, and the state surgeon general by February 15 annually that includes:
  - A list of funded projects;
  - A list of funded researchers;
  - A list of publications in peer-reviewed journals involving research supported by grants or fellowships awarded under the Moore program;
  - The state ranking and total amount of Alzheimer's disease research funding received from the National Institutes of Health;
  - New grants for Alzheimer's disease research which were based on research funded by the Moore program;
  - Progress toward the goals of the Moore program; and,
  - Recommendations to further the mission of the Moore program.
- The activities of the board are exempt from ch. 120, F.S., the Administrative Procedure Act.
- The DOH is given rulemaking authority to implement the Moore program.

Section 4 changes the name of the memory disorder clinic operating in Brevard County from "The Memory Disorder Clinic, Inc." to "a memory disorder clinic operated by Health First."

The bill directs the DOEA to develop performance standards for memory disorder clinics; to include the standards as a condition of each clinic's funding contract; and to measure and score each clinic based on the standards.

Base-level funding standards must address, at a minimum, quality of care, comprehensiveness of services, and access to services.

Standards for incentive funding beyond base-level funding, subject to legislative appropriation, include:
- A significant increase in the volume of clinical services;
- A significant increase in public outreach to low-income and minority populations;
- A significant increase in the acceptance of Medicaid and commercial insurance policies; and
- Significant institutional financial commitments.

Section 5 provides an effective date of July 1, 2014.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

V. Fiscal Impact Statement:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

The research program created by CS/CS/SB 872, if funded, will have a positive fiscal impact on any private institutions or researchers who are awarded grants or fellowships under the program.

It is not clear, however, whether incentive funding for the memory disorder clinics, as contemplated by the bill, would be the result of a supplemental appropriation for the program or a redistribution of the existing appropriations.

C. Government Sector Impact:

The Division of Emergency Management (DEM) estimates the nonrecurring cost to develop, test, and implement the electronic registry at $400,000, and the recurring cost to maintain and house the system also at $400,000. The DEM has identified federal grant funding that will cover these costs.[52]

Local governments may incur costs related to facilities they now designate as special needs shelters due to the requirement to provide dedicated space at each for persons with Alzheimer's disease. Not all facilities may be able to accommodate the dedicated space requirement. The DOH suggests that the requirement may be addressed in those shelters that cannot provide dedicated secure shelter space that would prevent wandering and elopement, by providing increased security. The DOH estimates the cost at $480 per 24-hour period for each point of egress.[53]

The bill requires a minimum of one staff person at each special needs shelter who is familiar with the needs of patients with Alzheimer's disease. The DOH indicates that appropriate staffing would mean at least one nurse per facility and possibly a nurse's aide for any person who presents without a caregiver. Those county health departments whose special needs shelter personnel lack the expertise in Alzheimer's disease may need to contract for services through a nurse staffing company. The DOH estimates the cost per shelter for a 24-hour period at $1,560 for nurse coverage and an additional $432 for a nurse's aide to assist with any unaccompanied patients. Currently, there are 127 special

[52] Florida Department of Law Enforcement, *Senate Bill 872 Legislative Bill Analysis* (Feb. 26, 2014) (on file with the Senate Health Policy Committee).
[53] Florida Department of Health, *supra* note 33.

needs shelters statewide.[54] It is not possible to estimate how many shelters would be activated or for how long in any given year.

The Ed and Ethel Moore Alzheimer's Disease Research Program (Moore program) created under the bill, if funded, will have a positive fiscal impact on any public institutions or researchers employed at public institutions who are awarded grants or fellowships under the program.

The DOH anticipates recurring costs related to contract management, peer review, and support of the board under the Moore program. Total projected expenses are $129,503 in Fiscal Year 2014-2015 and $142,448 in Fiscal Year 2015-2016. Costs include two full-time equivalent positions and related expenses; peer review honoraria; and board support expenses.[55]

The bill provides that implementation of the Moore program is subject to legislative appropriation. The Senate has not included Moore program funding in its proposed budget bill[56] for Fiscal Year 2014-2015. The House of Representative included in its proposed budget bill[57] for Fiscal Year 2014-2015 an appropriation of $3 million from the General Revenue Fund for the Moore program, contingent on HB 709 or similar legislation becoming law.[58]

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Statutes Affected:

This bill substantially amends the following sections of the Florida Statutes: 252.355, 381.0303, and 430.502.

This bill creates section 381.82 of the Florida Statutes.

[54] *Id.*
[55] *Id.*
[56] *See* SB 2500.
[57] *See* HB 5001 as introduced, Specific Appropriation 474.
[58] CS/CS/HB 709 has been on second reading in the House of Representatives since April 1, 2014.

IX. Additional Information:

A. Committee Substitute – Statement of Substantial Changes:
(Summarizing differences between the Committee Substitute and the prior version of the bill.)

CS/CS by Appropriations on April 22, 2014:
The CS:

- Moves the exemption from ch. 120, F.S., applicable to the Alzheimer's Disease Research Advisory Board, from ch. 120, F.S., to the section of law creating the Moore program and authorizes the DOH to adopt rules to implement the program;
- Removes specific authority for the DOH to use funds appropriated to the Moore program for peer review activities;
- Adds aging and disability resource centers to the list of providers that must assist in registering special needs clients;
- Makes a technical correction to provide for staggered terms of members of the Alzheimer's Disease Research Grant Advisory Board; and
- Updates the name of the memory disorder clinic in Brevard County.

CS by Health Policy on March 19, 2014:
The CS:

- Requires the Division of Emergency Management to have developed the special needs shelter registration program by January 1, 2015, with full implementation by March 1, 2015; and
- Reduces the Alzheimer's Disease Research Grant Advisory Board by one member, from 12 to 11, and revises the composition of the board by adding two neuroscientists and reducing the number of gerontologists, geriatric psychiatrists, and geriatricians each by one, from three to two.

B. Amendments:

None.