

HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: HB 709 Alzheimer's Disease
SPONSOR(S): Hudson and others
TIED BILLS: HB 711 **IDEN./SIM. BILLS:** SB 872

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR or BUDGET/POLICY CHIEF
1) Health Quality Subcommittee		Guzzo	O'Callaghan
2) Appropriations Committee			
3) Health & Human Services Committee			

SUMMARY ANALYSIS

In 2012, the Legislature created the Purple Ribbon Task Force (task force) within the Department of Elder Affairs (DOEA) to develop a comprehensive state plan to address the needs of individuals with Alzheimer's disease and their caregivers. The task force submitted its final report and recommendations for an Alzheimer's disease state strategy to the Governor and the Legislature on August 1, 2013.

House Bill 709 implements several of the recommendations identified by the task force.

Special needs shelters (SNSs) provide shelter and services to persons with special needs, including individuals with Alzheimer's disease, who have no other option for sheltering in an emergency situation. Each local emergency management agency in the state is required to maintain a registry of persons with special needs. Currently, local emergency management agencies are required to register individuals with special needs with SNSs, but they are not required to provide SNS registration online.

The bill requires the Division of Emergency Management (DEM) to develop and maintain a SNS registration program, which must include a uniform registration form and a database for uploading and storing registration forms. The bill also requires SNSs to have a staff member who is familiar with the needs of persons with Alzheimer's disease and to establish a designated area in the shelter for individuals with Alzheimer's disease to enable them to maintain their normal habits and routines.

The bill creates the Ed and Ethel Moore Alzheimer's Disease Research Program within the Department of Health to fund research leading to prevention of, or a cure for, Alzheimer's disease. The bill creates the Alzheimer's Disease Research Grant Advisory Board to consist of 13 members, including a required number of licensed professionals in specific fields generally associated with the provision of care for the elderly and individuals with Alzheimer's disease. The board is tasked with recommending to the State Surgeon General which research proposals should be funded.

DOEA is responsible for oversight and management of Memory Disorder Clinics (MDCs) in Florida. MDCs provide comprehensive assessments, diagnostic services, and treatment to individuals who exhibit symptoms of Alzheimer's disease. There are 15 MDCs in Florida, 13 of which are funded by the state. Currently, these MDCs receive equal funding and are not required to meet any performance measures.

The bill requires DOEA to develop a performance-based funding mechanism to allocate funds based on minimum performance standards, and reward those MDCs who exceed the minimum performance standards with funding above the base level.

The bill has a significant negative fiscal impact on DEM relating to the creation of the SNS registration database.

The bill provides an effective date of July 1, 2014.

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. EFFECT OF PROPOSED CHANGES:

Current Situation

Alzheimer's Disease Statistics

United States

There are an estimated 5.4 million people in the United States with Alzheimer's disease, including 5.2 million people aged 65 and older and 200,000 individuals under age 65 who have younger-onset Alzheimer's disease.¹

By 2030, the segment of the United States population aged 65 years and older is expected to double, and the estimated 71 million older Americans will make up approximately 20 percent of the total population.² By 2050, the number of people aged 65 and older with Alzheimer's disease is expected to triple to a projected 16 million people.³

Between 2000 and 2008, deaths attributed to Alzheimer's disease increased 66 percent nationally, while deaths attributed to heart disease, the number one cause of death, decreased by 13 percent. Alzheimer's disease is the sixth leading cause of death in the United States and the fifth leading cause of death age 65 and older.⁴

Florida

In 2000, there were an estimated 360,000 Floridians with Alzheimer's disease. The estimated number in 2010 was 450,000, and the estimated number for 2025 is 590,000.⁵

Alzheimer's Disease Research⁶

There are several not-for-profit institutions and associations in Florida who have invested capital to support "Alzheimer's disease and related forms of dementia" (ADRD) research. Research investments at the state and federal levels in institutions such as Scripps, Torrey Pines, and Burnham have added to our general research capabilities, but very few scientists at these institutions focus on ADRD. The 13 state funded MDCs provide valuable ADRD research, and the majority of academic institutions in Florida have active ADRD research programs.

The National Institute on Aging, within the National Institute of Health (NIH), funds Alzheimer's Disease Research Centers (ADRCs) at major medical institutions across the United States.⁷ NIH ADRCs serve a similar role to nationally designated cancer centers. They create infrastructure that supports clinical care for patients with ADRD.

¹ Alzheimer's Association, 2013 Alzheimer's Disease Fact and Figures, available at http://www.alz.org/alzheimers_disease_facts_and_figures.asp (last visited February 26, 2014).

² *Id.*

³ *Id.*

⁴ *Id.*

⁵ *Id.*

⁶ Department of Elder Affairs, Purple Ribbon Task Force, *2013 Final Report and Recommendation*, available at http://elderaffairs.state.fl.us/doea/purple_ribbon.php (last visited February 26, 2014).

⁷ National Institute on Aging, Alzheimer's Disease Research Centers, see <http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers> (last visited February 28, 2014).

In order to be eligible for funding and recognition as an ADRC, institutions are required to have an established ongoing base of high-quality Alzheimer's disease research or research in other neurodegenerative diseases, or in aging of the nervous system.⁸

Currently, there are no active NIH ADRCs in Florida. Other states have multiple ADRCs, including California, which has six active NIH ADRCs and a similar population of individuals with ADRC compared to Florida. NIH ADRCs receive \$1.5 million annually for five years.

Alzheimer's Disease – State Plans

In 2009, the Alzheimer's Study Group (ASG), an eleven member blue ribbon panel, released a report outlining recommendations to deal with Alzheimer's disease-related issues and policy. In response to the ASG report, Congress passed the National Alzheimer's Project Act (NAPA). NAPA requires the federal Department of Health and Human Services to create a national strategic plan to coordinate Alzheimer's disease efforts across the federal government.⁹ Currently, 35 states have developed state plans to deal with the Alzheimer's disease epidemic.

Purple Ribbon Task Force

In 2012, the Legislature adopted HB 473, which created the Purple Ribbon Task Force (task force) within the Department of Elder Affairs (DOEA) to develop a comprehensive state plan to address the needs of individuals with Alzheimer's disease and their caregivers.

The task force conducted an inventory of resources available to assist and support individuals with ADRC, and their caregivers and families. DOEA conducted five surveys developed in collaboration with the task force. The surveys addressed the experiences of five groups of stakeholders, including:

- Persons with ADRC;
- Family caregivers of persons with ADRC;
- Concerned family members and friends of persons with ADRC;
- Health care providers and paid caregivers of persons with ADRC; and
- Policy, legal, education, and other professionals.

A total of 840 people responded to the surveys. The inventory of resources and the surveys together highlighted needs of persons with ADRC and their caregivers, the impact of ADRC, and the existing services and resources, and also provided an identification of gaps and limitations.¹⁰

The task force submitted its final report and recommendations for an Alzheimer's disease state strategy to the Governor and the Legislature on August 1, 2013.

Alzheimer's Disease Initiative

The Alzheimer's Disease Initiative (ADI) was created in law to provide a continuum of services to meet the changing needs of individuals with Alzheimer's disease and their families.¹¹ DOEA coordinates and develops policy to carry out the statutory requirements for the ADI. In conjunction with a ten-member advisory committee appointed by the Governor, the program includes the following four components:¹²

- Respite and supportive services;
- Model day care programs to test new care alternatives;

⁸ National Institute of Health Funding Opportunities, *NIH Guide for Grants and Contract, Alzheimer's Disease Research Centers, Eligibility Information*, available at <http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-13-019.html> (last visited March 3, 2014).

⁹ Alzheimer's Association, *Issue Kit: State Government Alzheimer's Disease Plans*

¹⁰ Department of Elder Affairs, *Purple Ribbon Task Force, 2013 Final Report and Recommendation*, available at http://elderaffairs.state.fl.us/doea/purple_ribbon.php (last visited February 26, 2014).

¹¹ Chapter 95-418, L.O.F., see also ss. 430.501-430.504, F.S.

¹² Florida Department of Elder Affairs, see <http://elderaffairs.state.fl.us/english/alz.php> (last visited February 26, 2014).

- A research database and brain bank to support research; and
- Memory disorder clinics to provide diagnosis, research, treatment, and referral.

Section 430.501, F.S., authorizes DOEA to adopt rules necessary to carry out the duties of the advisory committee. Each Area Agency on Aging (AAA), under contract with DOEA, is responsible for the planning and administration of respite and model day care services funded under the ADI and must contract with local service providers for the provision of these services.¹³

The ADI is funded by General Revenue and Tobacco Settlement funds. DOEA allocates General Revenue funding appropriated by the Legislature to each of the 11 AAAs, which in turn fund providers of model day care and respite care programs in designated counties. Provider agencies are responsible for the collection of fees for ADI services. To help pay for services received pursuant to the ADI, a functionally impaired elderly person is assessed a fee based on an overall ability to pay in accordance with Rule 58C-1.007, F.A.C.

Respite Services

Alzheimer's Respite Care programs are established in all of Florida's 67 counties. ADI respite includes in-home, facility-based, emergency and extended care (up to 30 days) respite for caregivers who serve individuals with memory disorders. Funds are contracted according to an allocation formula, which is based on the number and proportion of the county population of individuals who are 75 years of age and older.¹⁴ The AAAs contract with more than 60 providers for the provision of respite care, caregiver training and support, education, counseling, specialized medical equipment, services and supplies, and case management.¹⁵ Services are authorized by a case manager based on a comprehensive assessment.

Model Day Care

Specialized model day care programs provide services to persons suffering from ADRD and training for health care and social service personnel caring for persons having ADRD. Currently, model day care services are funded in three planning and service areas (PSAs 3 - Gainesville, 6 - Tampa, and 11 - Miami-Dade). Examples of activities implemented at model day care centers may include:¹⁶

- Exercise programs;
- Active and passive range of motion exercises;
- Daily walks;
- Music Therapy; and
- Therapeutic Art.

Brain Bank

The Florida Alzheimer's disease Brain Bank is a service and research oriented network of statewide regional sites. The intent of the Brain Bank program is to collect and study the brains of deceased patients who had been clinically diagnosed with dementia. Mt. Sinai Medical Center contracts annually with the state of Florida to operate the primary Brain Bank. Coordinators at regional brain bank sites in Orlando, Tampa and Pensacola help recruit participants and act as liaisons between the Brain Bank and participants' families.

Memory Disorder Clinics

Memory Disorder Clinics (MDCs) provide diagnostic and referral services, conduct basic and service-related multidisciplinary research, and develop training materials and educational opportunities for lay

¹³ Rule 58D-1.005, F.A.C.

¹⁴ Section 430.502(5), F.S.

¹⁵ *Supra* note 10.

¹⁶ *Id.*

and professional caregivers of individuals with Alzheimer's disease. Currently, there are 13 state funded MDCs in Florida.¹⁷ MDCs are established at medical schools, teaching hospitals, and public and private not-for-profit hospitals throughout the state in accordance with s. 430.502, F.S.

Currently MDCs receive equal funding regardless of performance. Each of the 13 MDCs received \$222,801 during fiscal year 2013-2014.

Pursuant to an annual contract agreement with DOEA, MDCs are required to provide and conduct certain services, training, and research.¹⁸ Specifically, the contract requires MDCs to:¹⁹

- Evaluate at least 80 new unduplicated patients with symptoms of memory loss or other cognitive impairment;
- Follow-up with at least 40 patients or reevaluate patients to document rate of progression of the disease, its symptoms and its reaction to treatment;
- Identify and evaluate the needs of patients, including underserved minority populations, undergoing medical evaluation and their caregivers to provide appropriate referrals for services;
- Address driving issues with all patients, such as whether the patient is driving and if the patient or caregiver have concerns about driving;
- Follow-up on all Silver Alerts in the service area;
- Refer all appropriate patients to the State of Florida Brain Bank for enrollment;
- Identify and disseminate information on community resources for assistance with Alzheimer's disease, including information on Silver Alert;
- Determine satisfaction with the services provided; and
- Monitor the performance of subcontractors.

MDCs are required to provide at least 4 hours of in-service training annually to model day care and respite care providers in the designated service areas, and they must annually contact each model day care and respite care provider in the designated service areas to plan and develop service-related research projects. Further, MDCs must develop and disseminate training modules to respite and model day care providers and DOEA.²⁰

According to the final report of the task force, the MDCs at the University of Florida and Mayo Clinic Jacksonville play a crucial role in the training of behavioral neurology fellows who are subspecialists able to care expertly for dementia patients. To date, the University of Florida has trained 81 fellows, and Mayo Clinic Jacksonville has trained 9 fellows.

The annual contract also requires MDCs to identify major research projects to be undertaken, which must include an innovative service-related research project designed, conducted, and evaluated in association with model day care, respite, and Brain Bank projects. MDCs are required to describe the scope, research methodology, and timeframe of the project.²¹

Included in the contract, is the MDC annual plan, which describes how the MDC will accomplish the services, training, and research initiatives to be undertaken during the contract period.

MDCs are required to submit quarterly reports to DOEA with details on the services and training provided, and the research conducted. The quarterly report must include specific information on the services provided, including the total number of:²²

- Unduplicated persons seen;

¹⁷ Section 430.502(1), F.S.

¹⁸ Department of Elder Affairs, *Standard Contract-Alzheimer's Disease Initiative-Memory Disorder Clinic*, June 2013-July 2014.

¹⁹ *Id.*

²⁰ *Id.*

²¹ *Id.*

²² *Id.*

- New patients;
- Evaluations completed;
- Community screenings conducted;
- Office visits;
- Referrals;
- Persons involved in research; and
- Persons referred to the Brain Bank.

The quarterly report also provides DOEA with demographic information for the individuals served, including age, sex, race, and ethnicity information.

In fiscal year 2011-2012, the MDCs:²³

- Provided 3,942 total training hours to a total of 34,784 trainees, including 14,000 medical health professionals, 3,000 students, and 6,975 volunteers;
- Conducted 10,105 office visits and served 6,723 unduplicated persons;
- Provided telephone counseling, information, and support 12,570 times;
- Conducted 1,573 memory screenings;
- Made 13,678 referrals on the behalf of clients and caregivers for respite care, support groups, long-term care placement, counseling, medical care, and other social services.

The final report of the task force made a recommendation to remove the equal funding mechanism for MDCs. The task force recommends authorizing DOEA to develop minimum standards that must be achieved to be eligible for base level annual funding, and creating an incentive-based funding mechanism to reward MDCs who achieve greater levels of performance.

Special Needs Shelters (SNS)

Part I of chapter 252, F.S., is the “State Emergency Management Act” (Act). Under s. 252.35, F.S., the Division of Emergency Management (DEM) is responsible for maintaining a comprehensive statewide program of emergency management and for coordinating with efforts of the Federal Government, other departments and agencies of state government, county and municipal governments and school boards, and private agencies that have a role in emergency management. Included in the Act, is a provision to set forth policy guidance for public shelters, including sheltering people with special needs.²⁴

Section 252.355, F.S., requires each local emergency management agency to maintain a registry of persons with special needs located within the jurisdiction of the local agency. This section also requires all appropriate agencies and community-based service providers, including, home health care providers, hospices, nurse registries, and home medical equipment providers to assist local emergency management agencies by:

- Collecting registration information for persons with special needs;
- 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.

Section 381.0303, F.S., designates the Department of Health (DOH), through its county health departments, as the lead agency for coordination of the recruitment of health care practitioners to staff special needs shelters in times of emergency or disaster. This section requires DOH to reimburse, subject to the availability of funds for this purpose, health care practitioners for medical care provided at the request of DOH in special needs shelters.

Currently, local emergency management agencies are not required to post SNS registration information online. The DEM’s website does provide links to each county’s local emergency management website.

²³ Department of Elder Affairs, *Memory Disorder Clinic Statewide Report*, 2011-2012.

²⁴ Section 252.35(2)(a), F.S.

However, the registration information is often very difficult to find and many local emergency management agencies do not include any special needs information at all.

A review was performed of all 67 counties in Florida to assess the availability of special needs information provided on their websites.²⁵ The results indicated the websites of 17 counties did not include a SNS page, a SNS registration form, or SNS information.²⁶

Effect of Proposed Changes

Alzheimer's Disease Research

As recommended by the task force, the bill creates the Ed and Ethel Moore Alzheimer's Disease Research Program (program), and authorizes the program to be administered by DOH. The purpose of the program is to fund research leading to prevention of, or a cure for, Alzheimer's disease.

The bill provides that applications for research funding under the program may be submitted by any university or established research institute in the state, and all qualified investigators in the state must have equal access and opportunity to compete for research funding. The bill authorizes certain types of applications to be considered for funding, including:

- Investigatory-initiated research grants;
- Institutional research grants;
- Pre-doctoral and post-doctoral research fellowships; and
- Collaborative research grants, including those that advance the finding of cures through basic or applied research.

The bill creates the Alzheimer's Disease Research Grant Advisory Board (board). The board must consist of 12 members appointed by the State Surgeon General. The board members must include three gerontologists, three geriatric psychiatrists, three geriatricians, and three neurologists. In addition, the bill:

- Requires staggered 4-year terms for board members;
- Requires the board to elect a chairperson from the membership of the board to serve a term of two years;
- Requires the board to establish operating procedures and follow rigorous guidelines for ethical conduct and adhere to a strict policy with regard to conflict of interest;
- Requires DOH to provide staff to assist the board in carrying out its duties, and prohibits members of the board from receiving compensation, or reimbursement for per diem or travel;
- Requires the board to advise the State Surgeon General as to the scope of the research program;
- Requires the board to submit their recommendations to the State Surgeon General by December 15 of each year; and
- Requires the board to submit a fiscal-year progress report to the Governor, President of the Senate, and Speaker of the House by a specified date.

The bill provides that implementation of the program is subject to legislative appropriation.

Memory Disorder Clinics

Currently, each of the 13 statutorily designated memory disorder clinics receives equal funding in the amount of \$222,801. As recommended by the task force, the bill allows for the creation of a performance-based funding mechanism to allocate funds based on minimum performance standards and benchmark goals.

²⁵ Review based on data report generated by Florida CHARTS.

²⁶ The Counties include Bay, Calhoun, Escambia, Gilchrist, Gulf, Highlands, Jackson, Jefferson, Lafayette, Leon, Liberty, Madison, Okaloosa, Okeechobee, Putnam, Suwanee, and Wakulla.

Specifically, the bill:

- Requires DOEA to develop minimum performance standards that memory disorder clinics must achieve in order to receive base level annual funding;
- Requires DOEA to develop performance goals that exceed the minimum performance standards, which must be achieved in order for a memory disorder clinic to be eligible for incentive funding, which is above base level funding, and subject to appropriations;
- Provides guidance relating to criteria to be considered by DOEA in creating the minimum performance standards and performance goals; and
- Requires DOEA to measure and score memory disorder clinics based on the minimum performance standards and incentive performance goals.

DOEA has already created a performance check list to score MDCs in accordance with the provisions of the bill.²⁷

Special Needs Shelters

The bill amends s. 252.355, F.S., to require DEM to develop and maintain a SNS registration program. The registration program must include a uniform electronic registration form and a database for uploading and storing the registration forms. The link to the registration form must be easily accessible on each local emergency management agency's website. The registration information must be accessible to the local emergency management agency responsible for providing shelter for that individual.

Currently, certain agencies and entities are required to provide registration information to all of their clients. These agencies and entities include:

- Home health agencies;
- Hospices;
- Nurse registries;
- Home medical equipment providers;
- The Department of Children and Families;
- DOH;
- The Agency for Health Care Administration;
- The Department of Education;
- The Agency for Persons with Disabilities; and
- DOEA.

The bill adds memory disorder clinics to the list of entities and agencies that will provide registration information and assistance to their special needs clients or caregivers. Physicians licensed under chapters 458 or 459, F.S., and any pharmacy licensed under chapter 465, F.S., may provide the registration information assistance. Further, the bill requires DEM to develop a brochure that provides information regarding SNS registration procedures. The brochure must be easily accessible on DEM's website. The informational brochure is intended to assist the specified agencies and entities in providing registration information to their clients.

Currently, all appropriate agencies and community-based service providers, including, home health care providers, hospices, nurse registries, and home medical equipment providers are required to assist emergency management agencies by collecting registration information for persons with special needs as a 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. Since these entities and agencies are currently only required to "assist emergency

²⁷ Department of Elder Affairs, *(Draft) Memory Disorder Clinic Performance Check List*, on file with subcommittee staff.

management agencies by collecting registration information” it is unclear what they are required to do with the registration information upon collection.

The bill requires the appropriate agencies and community-based service providers to assist emergency management agencies by annually registering persons with special needs for special needs shelters. Since these agencies and entities are currently required to collect registration information, this provides guidance by requiring them to submit any registration forms collected at least annually. Submitting the registration forms may be accomplished by means of the newly created registration program and database. The bill adds memory disorder clinics to the list of entities required to submit registration forms and makes it discretionary for physicians licensed under chapters 458 or 459, F.S.

B. SECTION DIRECTORY:

Section 1: Amends s. 120.80, F.S., relating to exceptions and special requirements.

Section 2: Amends s. 252.355, F.S., relating to registry of persons with special needs; notice.

Section 3: Amends s. 381.0303, F.S., relating to special needs shelters.

Section 4: Creates s. 381.82, F.S., relating to the Ed and Ethel Moore Alzheimer’s Disease Research Program.

Section 5: Amends s. 430.502, F.S., relating to Alzheimer’s disease; memory disorder clinics and day care and respite care programs.

Section 6: Provides an effective date of July1, 2014.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

2. Expenditures:

The bill is expected to have a significant negative fiscal impact on DEM for the creation of the SNS Registration Program. However, the exact fiscal impact is presently unknown as the subcommittee is still waiting on information from DEM.

In addition, the bill creates the Ed and Ethel Moore Alzheimer’s Disease Research Program and provides that implementation is subject to legislative appropriation. Presently, the dollar amount to be appropriated is unknown. However, it should be noted that the Governor included funding of \$3 million to DOH for Alzheimer’s disease research in his Fiscal Year 2014-2015 Policy and Budget Recommendations.²⁸

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

²⁸ Governor’s Budget Recommendations, Fiscal Year 2014-15, available at [http://letsgettowork.state.fl.us/web%20forms/Budget/BudgetServiceIssueList.aspx?rid1=187311&rid2=152867&si=64200100&title=COMMUNITYPUBLICHEALTH\(Program\);COMMUNITYHEALTHPROMOTION](http://letsgettowork.state.fl.us/web%20forms/Budget/BudgetServiceIssueList.aspx?rid1=187311&rid2=152867&si=64200100&title=COMMUNITYPUBLICHEALTH(Program);COMMUNITYHEALTHPROMOTION) (last visited March 3, 2014).

None.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

Not applicable. This bill does not appear to affect county or municipal governments.

2. Other:

None.

B. RULE-MAKING AUTHORITY:

No additional rule-making is necessary to implement the provisions of the bill.

C. DRAFTING ISSUES OR OTHER COMMENTS:

None.

IV. AMENDMENTS/ COMMITTEE SUBSTITUTE CHANGES