

## HOUSE OF REPRESENTATIVES STAFF ANALYSIS

**BILL #:** HB 883 Memory Disorder Clinics  
**SPONSOR(S):** Miller, M. and others  
**TIED BILLS:** IDEN./SIM. **BILLS:** SB 1050

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR or BUDGET/POLICY CHIEF
1) Health Quality Subcommittee	9 Y, 0 N	Royal	McElroy
2) Health Care Appropriations Subcommittee	13 Y, 0 N	Clark	Pridgeon
3) Health & Human Services Committee	17 Y, 0 N	Royal	Calamas

### SUMMARY ANALYSIS

Section 430.502 establishes 15 Memory Disorder Clinics (MDCs) in the State of Florida that provide comprehensive assessments, diagnostic services, and treatment to individuals who exhibit symptoms of Alzheimer's disease and related memory disorders. MDCs also develop training programs and materials, and conduct training for caregivers, respite service providers, and health care professionals in the care of persons with Alzheimer's disease and related memory disorders. In addition, MDCs conduct service-related research projects. MDCs receive performance based funding from the General Revenue.

HB 883 establishes a 16<sup>th</sup> MDC at Florida Hospital in Orange County. Florida Hospital in Orange County established a self-funded memory disorder program in 2012. The bill does not provide an appropriation of funds to the MDC at the Florida Hospital.

The bill does not have a fiscal impact on state or local governments.

The bill provides an effective date of July 1, 2017.

## FULL ANALYSIS

### I. SUBSTANTIVE ANALYSIS

#### A. EFFECT OF PROPOSED CHANGES:

##### Background

##### Alzheimer's Disease

Alzheimer's disease is a form of dementia, a general term for memory loss. It is a progressive brain disorder that damages and eventually destroys brain cells, leading to memory loss and changes in the functions of the brain.<sup>1</sup> Alzheimer's disease accounts for 60 to 80 percent of dementia cases.<sup>2</sup> Alzheimer's disease is a progressive disease in which dementia symptoms worsen gradually over time. In the early stages of Alzheimer's disease, memory loss is mild, but in late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment.<sup>3</sup> Currently, there is no cure for Alzheimer's disease, but treatments that can temporarily slow the worsening of symptoms do exist.<sup>4</sup>

There are an estimated 5.5 million people in the United States with Alzheimer's disease, including 5.3 million people aged 65 and older and 200,000 individuals under age 65 who have younger-onset Alzheimer's disease.<sup>5</sup> 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.<sup>6</sup> By 2050, the number of people aged 65 and older with Alzheimer's disease is expected to nearly triple to a projected 13.8 million people.<sup>7</sup>

Since 2000, deaths attributed to Alzheimer's disease have increased 89 percent nationally, while deaths attributed to heart disease, the number one cause of death, decreased by 14 percent.<sup>8</sup> 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.<sup>9</sup>

An estimated 520,000 Floridians have Alzheimer's disease.<sup>10</sup> The projected number of Floridians with Alzheimer's disease in 2025 is 720,000.<sup>11</sup> Alzheimer's disease is the 6<sup>th</sup> leading cause of death in Florida. According to the Alzheimer's Association, the Medicaid cost of caring for people with Alzheimer's disease in Florida is 2.279 billion dollars.<sup>12</sup>

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<sup>1</sup> Alzheimer's Association. *What We Know Today About Alzheimer's Disease and Dementia*. Available at: [http://www.alz.org/research/science/alzheimers\\_research.asp](http://www.alz.org/research/science/alzheimers_research.asp) (last visited March 17, 2017).

<sup>2</sup> Id.

<sup>3</sup> Alzheimer's Association. *What is Alzheimer's?*. Available at: [http://www.alz.org/alzheimers\\_disease\\_what\\_is\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp) (last visited March 17, 2017).

<sup>4</sup> Id.

<sup>5</sup> Alzheimer's Association. *2017 Alzheimer's Disease Fact and Figures*. Available at [http://www.alz.org/alzheimers\\_disease\\_facts\\_and\\_figures.asp](http://www.alz.org/alzheimers_disease_facts_and_figures.asp) (last visited March 17, 2017).

<sup>6</sup> Id.

<sup>7</sup> Id.

<sup>8</sup> Id.

<sup>9</sup> Id.

<sup>10</sup> Alzheimer's Association. *Florida Factsheet*. Available at: [http://www.alz.org/documents\\_custom/facts\\_2017/statesheet\\_florida.pdf?type=interior\\_map&facts=undefined&facts=facts](http://www.alz.org/documents_custom/facts_2017/statesheet_florida.pdf?type=interior_map&facts=undefined&facts=facts) (last visited March 17, 2017).

<sup>11</sup> Id.

<sup>12</sup> Id.

## Alzheimer's Disease Research<sup>13</sup>

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.<sup>14</sup> Research investments at the state and federal levels in institutions such as Scripps, Torrey Pines, and Sanford-Burnham have added to our general research capabilities, but very few scientists at these institutions focus on ADRD.<sup>15</sup> Fifteen state funded Memory Disorder Clinics (MDC) provide ADRD research, and the majority of academic institutions in Florida have active ADRD research programs.<sup>16</sup>

The National Institute on Aging, within the National Institute of Health (NIH), funds 29 Alzheimer's Disease Research Centers (ADRCs) at major medical institutions across the United States.<sup>17</sup> NIH ADRCs serve a similar role to nationally designated cancer centers. They create infrastructure that supports clinical care for patients with ADRD.<sup>18</sup>

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.<sup>19</sup>

Currently, the Mayo Clinic Alzheimer's Disease Research Center and the University of Florida Alzheimer's Disease Center are the only NIH ADRCs in Florida.<sup>20</sup> NIH ADRCs receive \$1.5 million in federal funding, annually, for five years.<sup>21</sup> The Mayo Clinic ADRC focuses their research on patient-oriented research and basic science research.<sup>22</sup> Scientists at the Mayo Clinic ADRC were among the first in the United States to identify novel genetic mutations in some families with frontotemporal dementia<sup>23</sup> and the three most common dominantly inherited gene mutations that cause frontotemporal dementia were discovered at the Mayo Clinic ADRC.<sup>24</sup>

## Alzheimer's Disease Initiative

The Alzheimer's Disease Initiative (ADI)<sup>25</sup> was created within the Department of Elder Affairs (DOEA) to provide a continuum of services to meet the changing needs of individuals with Alzheimer's disease

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<sup>13</sup> Department of Elder Affairs, Purple Ribbon Task Force, *2013 Final Report and Recommendation*, available at [http://elderaffairs.state.fl.us/doea/purple\\_ribbon.php](http://elderaffairs.state.fl.us/doea/purple_ribbon.php) (last visited March 17, 2017).

<sup>14</sup> Id.

<sup>15</sup> Id.

<sup>16</sup> Id.

<sup>17</sup> 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).

<sup>18</sup> *Supra*, note 13.

<sup>19</sup> 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 17, 2017).

<sup>20</sup> *Supra*, note 17.

<sup>21</sup> *Supra*, note 13.

<sup>22</sup> The Mayo Clinic Alzheimer's Disease Research Center. Focus Areas. Available at: <http://www.mayo.edu/research/centers-programs/alzheimers-disease-research-center/research-activities/focus-areas> (last visited March 17, 2017).

<sup>23</sup> The Mayo Clinic defines Frontotemporal dementia as: (frontotemporal lobar degeneration) is an umbrella term for a diverse group of uncommon disorders that primarily affect the frontal and temporal lobes of the brain — the areas generally associated with personality, behavior and language. In frontotemporal dementia, portions of these lobes atrophy or shrink. Signs and symptoms vary, depending upon the portion of the brain affected. Some people with frontotemporal dementia undergo dramatic changes in their personality and become socially inappropriate, impulsive or emotionally indifferent, while others lose the ability to use language. Frontotemporal dementia is often misdiagnosed as a psychiatric problem or as Alzheimer's disease. But frontotemporal dementia tends to occur at a younger age than does Alzheimer's disease, generally between the ages of 40 and 75. Available at: <http://www.mayoclinic.org/diseases-conditions/frontotemporal-dementia/basics/definition/con-20023876> (last visited March 17, 2017).

<sup>24</sup> *Supra*, note 22.

<sup>25</sup> Section 430.503, F.S.

and their families.<sup>26</sup> In conjunction with a ten-member advisory committee appointed by the Governor<sup>27</sup>, the initiative includes the following four programs administered by DOEA.<sup>28</sup>

### *Respite Services*

ADI respite care programs exist in all 67 Florida counties and provide in-home, facility-based, emergency and extended care (up to 30 days) respite for caregivers who serve individuals with memory disorders.<sup>29</sup> Additional services include caregiver training and support, education, counseling, specialized medical equipment, services and supplies, and case management.<sup>30</sup>

Funds for respite care programs are contracted according to an allocation formula based on the number and proportion of the county population of individuals who are 75 years of age and older.<sup>31</sup>

### *Model Day Care*

Model day care programs<sup>32</sup> have been established in conjunction with Memory Disorder Clinics to test therapeutic models of care and provide day care services.<sup>33</sup> Model day care programs provide a safe environment where Alzheimer's patients gather for the day and socialize with each other, as well as receive therapeutic treatments designed to maintain or improve their cognitive functioning.<sup>34</sup> Model day care programs also provide training for health care and social service personnel that care for persons having Alzheimer's disease and related memory disorders.<sup>35</sup> Currently, model day care programs have been established in Gainesville, Tampa, and Miami.<sup>36</sup>

### *Brain Bank<sup>37</sup>*

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*

The State of Florida has designated by statute 15 MDCs<sup>38</sup> that provide comprehensive assessments, diagnostic services, and treatment to individuals who exhibit symptoms of Alzheimer's disease and related memory disorders.<sup>39</sup>

- West Florida Hospital Memory Disorder Clinic (Pensacola)
- Tallahassee Memorial Healthcare Memory Disorder Clinic (Tallahassee)
- Mayo Clinic Jacksonville Memory Disorder Clinic (Jacksonville)
- University of Florida Memory Disorder Clinic (Gainesville)

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<sup>26</sup> Chapter 95-418, L.O.F., *see also* ss. 430.501-430.504, F.S.

<sup>27</sup> Section 430.501, F.S., Alzheimer's Disease Advisory Committee.

<sup>28</sup> Florida Department of Elder Affairs. *Alzheimer's Disease Initiative*. Available at: <http://elderaffairs.state.fl.us/english/alz.php> (last visited March 17, 2017).

<sup>29</sup> *Id.*

<sup>30</sup> *Supra*, note 13.

<sup>31</sup> Section 430.502(5), F.S.

<sup>32</sup> Section 430.502(7), F.S.

<sup>33</sup> *Supra*, note 28.

<sup>34</sup> *Id.*

<sup>35</sup> *Id.*

<sup>36</sup> *Id.*

<sup>37</sup> The Florida Brain Bank. Available at: <http://elderaffairs.state.fl.us/doea/BrainBank/index.php> (last visited March 18, 2017).

<sup>38</sup> Section 430.502(1), F.S.

<sup>39</sup> *Supra*, note 28

- Orlando Health Center for Aging and Memory Disorder (Orlando)
- East Central Florida Memory Disorder Clinic (Melbourne)
- Madonna Ptak Center for Memory Disorders at Morton Plant Mease (Clearwater)
- University of South Florida Memory Disorder Clinic (Tampa)
- St. Mary's Medical Center Memory Disorder Clinic (West Palm Beach)
- Florida Atlantic University, Louis & Anne Green Memory and Wellness Center (Boca Raton)
- Sarasota Memorial Hospital Memory Disorder Clinic (Sarasota)
- Lee Memorial Health System, Lee Memory Care (Fort Myers)
- Broward Health North Memory Disorder Clinic (Deerfield Beach)
- The Wien Center for Alzheimer's Disease and Memory Disorders, Mt. Sinai Medical Center (Miami Beach)
- University of Miami Memory Disorders Center, Center of Aging Mental Health (Miami)

MDCs also develop training programs and materials, and conduct training for caregivers, respite service providers, and health care professionals in the care of persons with Alzheimer's disease and related memory disorders.<sup>40</sup> In addition, MDCs conduct service-related research projects through model day care programs and respite care programs.<sup>41</sup> MDCs are established at medical schools, teaching hospitals, and public and private not-for-profit hospitals throughout the state in accordance with section s. 430.502, F.S.

MDCs receive performance based funding from the General Revenue Fund.<sup>42</sup> To receive base level funding, MDCs must meet minimum performance measures established by DOEA. Incentive funding, subject to legislative approval, is available for MDCs that meet additional performance measures established by DOEA.<sup>43</sup> Performance measures are established by DOEA in its annual contracts with the MDCs.<sup>44</sup>

Each MDC receives \$222,801 in base level funding.<sup>45</sup> Pursuant to the 2016-2017 contract, MDCs may receive up to \$50,000 in incentive funding if the MDC meets any of the incentive performance measures.<sup>46</sup> The \$50,000 incentive funding is allocated based on how many incentive performance measures the MDCs meet and is divided amongst all 15 MDCs.<sup>47</sup> For example, if all 15 MDCs achieved 10 of the incentive performance measures, the \$50,000 would be divided by 10 and then by 15, resulting in each MDC receiving approximately \$333.00 in incentive funding.

Section 430.502(1), F.S. expressly prohibits decreasing funding for MDCs funded as of June 30, 1995,<sup>48</sup> solely to accommodate subsequent MDC additions.<sup>49</sup>

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<sup>40</sup> Id.

<sup>41</sup> Supra, note 13.

<sup>42</sup> Section 430.502(3) and (4), F.S.; Department of Elder Affairs. *2017 Legislative Bill Analysis HB 883, March 9, 2017*. On file with Health Quality Subcommittee.

<sup>43</sup> Id.

<sup>44</sup> Section 430.502(3) and (4), F.S.; Department of Elder Affairs. *Standard Contract-Alzheimer's Disease Initiative-Memory Disorder Clinic*, June 2016-July 2017. On file with the Health Quality Subcommittee.

<sup>45</sup> Department of Elder Affairs. *2017 Legislative Bill Analysis HB 883, March 9, 2017*. On file with Health Quality Subcommittee.

<sup>46</sup> Supra, note 44.

<sup>47</sup> Supra, note 45.

<sup>48</sup> Prior to 1995, MDCs were established at each of the three medical schools in the state, major private nonprofit research-oriented teaching hospital and in a public hospital that is operated by an independent special hospital taxing district that governs multiple hospitals and is located in a county with a population greater than 800,000 persons. See s. 37, ch. 95-418 L.O.F.

<sup>49</sup> Section 430.502 (1), F.S.

The minimum performance measures for base level funding for Fiscal Year 2016-2017 are as follows.<sup>50</sup>

<b>Quarterly Base Level Funding Measures</b>	<b>Quarterly Minimum</b>
Unduplicated patients with symptoms of memory loss or other cognitive impairment that received diagnostic evaluation.	81
New persons with symptoms of memory loss or other cognitive impairment that received a diagnostic evaluation	25
Evaluations, reevaluations, and follow-ups	30
Referrals made	230
Percentage of patients with driving issues addressed	100%
Percentage of Silver Alerts received by MDC for which protocol forms were submitted to DOEA	100%
Percentage of patients informed of Brain Bank	100%
Percentage of patients that received information about community resources, including Silver Alert	100%
Training/education presentations, programs, events or support groups	6
<b>Yearly Base Level Funding Measures</b>	<b>Yearly Minimum</b>
Staff liaisons to Area Agencies on Aging/Aging and Disability Resource Centers	1
Specialized training programs provided for caregivers, caregiver groups/organizations and service providers	1
Hours of in-service training to ADI model day care and respite care providers	4
Service-related research projects	1
Percentage of subcontractors monitored	100%

To receive base level funding, MDCs must also operate Monday-Friday from 8 a.m.-5 p.m.

Fiscal Year 2016-2017 performance measures for incentive funding are as follows.<sup>51</sup>

<b>Yearly Incentive Funding Measures</b>	<b>Yearly Minimum</b>
Unduplicated patients with symptoms of memory loss or other cognitive impairment that received diagnostic evaluation.	486
New persons with symptoms of memory loss or other cognitive impairment that received a diagnostic evaluation	150
Evaluations, reevaluations, and follow-ups	180
Referrals made	1378
Medicaid patients that received diagnostic evaluation	12
Patients with commercial insurance policy that received diagnostic evaluation	125
In-person outreach to medical professionals to increase access to services	20
Education events conducted with community entities to increase awareness	4
Training/education presentations, programs, events or support groups	50
Outreach events in low-income or minority areas	4
Caregiver training events, programs or sessions with pre- and post-assessment	4
Caregiver trainings that included discussion of disaster preparedness	100%
Specialized training for law enforcement and/or first responders	1
Articles published in DOEA newsletter	1
Percentage of clients that would recommend MDC to others	85%
Service-related research projects	2
Research partners	4
Grants or contracts that provided additional funding	1
Total amount of institutional financial commitments received	\$46,201
Newsletters, brochures, handouts by MDC; or MDC Coordinator Quarterly Meetings or ADI Advisory Committee meeting hosted by MDC; or Trainings provided in another language; or Leadership roles relating to dementia taken by MDC Coordinator/Administrator/Director	1

<sup>50</sup> Department of Elder Affairs. *Standard Contract-Alzheimer's Disease Initiative-Memory Disorder Clinic, June 2016-July 2017*. On file with the Health Quality Subcommittee.

<sup>51</sup> Id.

In the Fiscal Year 2015-2016, the MDCs:<sup>52</sup>

- Saw 4,745 new patients.
- Completed 9,810 medical memory evaluations.
- Conducted 1,529 free memory screenings.
- Made 26,739 referrals to medical or community services for patients and families.
- Provided 3,828 hours of training to 33,240 family caregivers, medical professionals, health students, social service workers, and the general public.
- Provided 7,131 family caregivers with educational training on how to care for a loved one at home who has dementia.
- Made 17,769 phone contacts to provide information and referrals to community resources that assist individuals affected by dementia.
- Followed up with family members upon the cancellation of 239 Silver Alerts to provide education, resources, and referrals to assist the recovered person and to help prevent future elopement.

#### Florida Hospital Maturing Minds Clinic<sup>53</sup>

In 2012, Florida Hospital in Orange County established a self-funded memory disorder program, the Florida Hospital Maturing Minds Clinic (FHMMP). FHMMP serves patients with Alzheimer's disease and related disorders in Orange, Seminole and Osceola County. FHMMP provides early screening and diagnosis, management of symptoms, caregiver education and training, and conducts research. FHMMP conducts over 360 new patient memory loss evaluations per year.

#### **Effect of Proposed Changes**

HB 883 amends s. 430.502 by establishing a MDC at the Florida Hospital in Orange County, making it the 16th MDC in Florida and the second located in Orlando. The bill does not provide an appropriation of funds to the MDC at the Florida Hospital.

The bill provides an effective date of July 1, 2017.

#### **B. SECTION DIRECTORY:**

**Section 1:** Amends s. 430.502 relating to Alzheimer's disease; memory disorder clinics and day care and respite care.

**Section 2:** Provides an effective date of July 1, 2017.

## **II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT**

#### **A. FISCAL IMPACT ON STATE GOVERNMENT:**

##### **1. Revenues:**

None.

##### **2. Expenditures:**

None.

<sup>52</sup> Department of Elder Affairs, *Memory Disorder Clinic Statewide Report, 2015-2016*. Available at: [http://elderaffairs.state.fl.us/doea/alz/MDC\\_Year\\_End\\_Summary\\_2015-2016.pdf](http://elderaffairs.state.fl.us/doea/alz/MDC_Year_End_Summary_2015-2016.pdf) (last visited March 18, 2017)

<sup>53</sup> Jean Van Smith, Florida Hospital Government Relations, *Support HB 883/SB 1050, Memory Disorder Clinics*. On file with the Health Quality Subcommittee.

**B. FISCAL IMPACT ON LOCAL GOVERNMENTS:**

1. Revenues:

None.

2. Expenditures:

None.

**C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:**

The MDC at Orlando Health Center for Aging has a six-county service area which contains 62,684 probable persons living with Alzheimer's disease. The Orlando Health Center for Aging MDC may see reduced numbers of clients served if patients begin visiting the new Florida Hospital MDC instead.<sup>54</sup>

**D. FISCAL COMMENTS:**

None.

**III. COMMENTS**

**A. CONSTITUTIONAL ISSUES:**

1. Applicability of Municipality/County Mandates Provision:

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

2. Other:

**B. RULE-MAKING AUTHORITY:**

Not applicable.

**C. DRAFTING ISSUES OR OTHER COMMENTS:**

None.

**IV. AMENDMENTS/ COMMITTEE SUBSTITUTE CHANGES**

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<sup>54</sup> *Supra*, note 45.