

SENATE STAFF ANALYSIS AND ECONOMIC IMPACT STATEMENT

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

Date: March 18, 1998 Revised: 4/6/98 \_\_\_\_\_

Subject: Neurodegenerative Disorders

	<u>Analyst</u>	<u>Staff Director</u>	<u>Reference</u>	<u>Action</u>
1.	Crosby	Whiddon	CF	Fav/1 amendment
2.	_____	_____	WM	_____
3.	_____	_____	_____	_____
4.	_____	_____	_____	_____
5.	_____	_____	_____	_____

I. Summary:

This bill addresses issues dealing with neurodegenerative disorders including Alzheimer’s disease and Parkinson’s disease. Specifically, this bill:

- Limits membership to the Alzheimer’s Disease Advisory Committee to two consecutive years;
- Creates the Parkinson’s Disease Advisory Committee to advise the Department of Health and make recommendations to the Legislature regarding Parkinson’s disease and similar neurodegenerative disorders and sets guidelines for performing its duties;
- Requires the committee to submit a preliminary report by December 1, 1999 and a final report by June 30, 2001;
- Specifies research and information to be included in the committee reports;
- Dissolves the Parkinson’s Disease Advisory Committee on July 1, 2001;
- Specifies requirements for the membership of the Parkinson’s Disease Advisory Committee;
- Creates and sets requirements for Parkinson’s disease memory disorder clinics and day care and respite care programs;
- Provides an effective date of July 1, 1998.

This bill substantially amends sections 430.501 and 430.502, Florida Statutes, and creates a new section of law.

## **II. Present Situation:**

### **Parkinson's Disease**

Parkinson's disease is a common progressive neurological disorder that results from degeneration of nerve cells in a region of the brain that controls movement. This degeneration creates a shortage of the brain signaling chemical known as dopamine, causing impaired movement. Drugs are often prescribed by doctors to help reduce the symptoms, and surgery is sometimes necessary in severe cases. There is no cure for Parkinson's disease. The Florida Department of Health (DOH) estimates that Parkinson's disease costs society nearly \$6 billion every year.

Usually the first symptom of Parkinson's disease is tremor of a limb, which often begins on one side of the body. Other common symptoms include slow movement, an inability to move, rigid limbs, a shuffling gait, and stooped posture. People with Parkinson's disease often show reduced facial expression, personality changes, dementia, sleep disturbances, speech impairments, or sexual difficulties.

In the United States, between 1 and 1.5 million people are believed to suffer from Parkinson's disease, and about 50,000 new cases are reported every year. Because the symptoms often appear later in life, the number of cases is expected to grow as the average age of the population increases over the next several decades. Forty percent of Americans with Parkinson's disease are under the age of 60.

There are many theories about the cause of Parkinson's disease. Until recently the prevailing theory was that one or more environmental factors cause the disease. However, some researchers report cases of families with inherited Parkinson's disease.

In a recent collaborative study headed by the National Human Genome Research Institute (NHGRI) and the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health, strong evidence was discovered of a gene on chromosome 4 that can lead to Parkinson's disease in some families. In June 1997, NHGRI research described how the gene was discovered and how a specific defect on the gene causes Parkinson's disease in some families. This gene may be responsible for a significant portion of a type of Parkinson's that appears in individuals before the age of 60. It is expected that information about this gene will help scientists gain further information about the causes of Parkinson's disease and perhaps aid in gaining information on other common and devastating brain disorders such as Alzheimer's disease.

The National Parkinson's Foundation, located in Miami, Florida, provides approximately \$500,000 annually in funds for Parkinson's disease research to the University of Miami and

approximately \$100,000 annually to the University of Florida. There are over 100 local unfunded support groups for patients with Parkinson's disease and their caregivers.

### **Alzheimer's Disease Initiative**

The Department of Elderly Affairs currently coordinates the Alzheimer's Disease Initiative, which is authorized by ss. 430.501-430.504, F.S. The program's purpose is to seek innovative methods to meet the multi-stage, ever-changing needs of patients suffering from Alzheimer's disease and related memory disorders and their caregivers.

The Alzheimer's Disease Initiative is a coordinated, comprehensive plan of care and is made up of five program components: Memory Disorder Clinics, discussed in greater detail below; Model Alzheimer's Day Care programs, which provide specialized day care services designed for clients with a diminished level of functioning; Respite Care Programs, which provide a period of relief for caregivers from a few hours a day to a longer period of time; Alzheimer's Disease Research Brain Bank, which provides autopsies for Alzheimer's clients' brain tissues and matches clinical data with the pathological findings; and the Alzheimer's Disease Advisory Committee, a ten-member body that advises the department on Alzheimer's related issues.

The Alzheimer's Disease Initiative provides case management to all Alzheimer's clients who are receiving respite or model day care services. Individuals are eligible for Alzheimer's Disease Initiative services who are diagnosed or suspected of having a memory loss where mental changes appear and gradually interfere with daily living activities. Caregivers of clients may receive training, and clients may be required to contribute an amount toward their services depending upon income.

### **Memory Disorder Clinics**

Currently, s. 430.502, F.S., outlines the establishment and purpose of the memory disorder clinics. There is established a memory disorder clinic at each of the three medical schools in Florida, a major private nonprofit research-oriented teaching hospital, and any of the other affiliated teaching hospitals. Subsequent amendments to law have resulted in an additional five memory disorder clinics, for a current total of nine memory disorder clinics. Research conducted by a memory disorder clinic must be applied research, service-related, and selected in conjunction with the department. An Alzheimer's Disease Advisory Committee must evaluate the need for additional memory disorder clinics with the first report due by December 31, 1995. The Department of Elderly Affairs reports that this evaluation never materialized, and that there are no written recommendations regarding the need for additional memory disorder clinics. Finally, this section provides that the department shall contract for the provision of three specialized model day care programs in conjunction with each memory disorder clinic. Thus far, three model day care programs are established -- one in Dade County, one in Alachua County, and the third in Hillsborough county. The former two programs are affiliated with medical schools while the Hillsborough location is not.

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The department contracts directly with the Memory Disorder Clinics and the Alzheimer's Disease Brain Bank. The department administers case management services and the Respite Care and Model Day Care programs through the 11 area agencies on aging. These area agencies then contract with a variety of local service providers to provide services.

### III. Effect of Proposed Changes:

**Section 1** amends s. 430.501, F.S., regarding the Alzheimer's Disease Advisory Committee, to limit membership to two consecutive terms.

**Section 2** creates the Parkinson's Disease Advisory Committee and establishes requirements and guidelines. The membership composition and appointment process are provided. Preliminary and final reports are required. The committee is dissolved on July 1, 2001.

**Section 3** amends s. 430.502, F.S., relating to Alzheimer's memory disorder clinics to:

- Create and set requirements for Parkinson's disease memory disorder clinics.
- Require that the Alzheimer's Disease Advisory Committee will annually evaluate the need for additional memory disorder clinics and that this evaluation and recommendation must be included in any legislative budget request submitted by the department in funding additional memory disorder clinics.
- Delete the specific number of Alzheimer's disease model day care programs from the statute, thereby authorizing, rather than requiring, the department to contract for the provision of specialized model day care programs in conjunction with memory disorder clinics.
- Require the department to contract for the provision of day care and respite care for persons with Parkinson's disease or similar disorders. The purpose of such programs shall be to provide services to these persons, provide training, and increase public awareness of Parkinson's disease or similar disorders.

**Section 4** provides an effective date of July 1, 1998.

### IV. Constitutional Issues:

#### A. Municipality/County Mandates Restrictions:

None.

#### B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

**V. Economic Impact and Fiscal Note:**

A. Tax/Fee Issues:

This bill allows the department to assess fees, pursuant to s. 430.503, F.S., the Alzheimer’s Disease Initiative. Section 430.503, F.S., is a fee based on an overall ability to pay. The fee schedule is established by the department and is developed in cooperation with the Alzheimer’s Disease Advisory Committee, the area agencies on aging, and service providers. This fee will only be assessed against those who participate.

B. Private Sector Impact:

Again, this bill does allow for a fee, pursuant to s. 430.503, F.S., but this fee will only be assessed against those who participate.

C. Government Sector Impact:

Nonrecurring effects, expected to be assessed in the first year, total **\$5,534**. Additionally, recurring effects are as follows:

<b>Respite and Day Care Programs</b>	<b>1998 -1999</b>	<b>1999-2000</b>	<b>2000-2001</b>
Staff - salaries, benefits, recurring expenses, ½ OPS	\$66,644	\$68,022	\$69,442
Parkinson’s Disease Advisory Committee	2,500	2,500	2,500
Contracted Services	343,010	343,010	343,010
<b>TOTAL</b>	<b>\$412,154</b>	<b>\$413,532</b>	<b>\$414,952</b>

All funds requested are from general revenue.

**VI. Technical Deficiencies:**

None.

**VII. Related Issues:**

None.

**VIII. Amendments:**

#1 by Children, Families & Seniors:

This amendment clarifies that departmental legislative budget requests for additional memory disorder clinics will be limited to the evaluation and recommendation of the Alzheimer's Disease Advisory Committee.

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This Senate staff analysis does not reflect the intent or official position of the bill's sponsor or the Florida Senate.

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