

SENATE STAFF ANALYSIS AND ECONOMIC IMPACT STATEMENT

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

BILL: SB 150

SPONSOR: Senator Wasserman Schultz

SUBJECT: Developmental Disabilities

DATE: March 2, 2003

REVISED: _____

| | ANALYST | STAFF DIRECTOR | REFERENCE | ACTION |
|----|----------------|----------------|------------|-------------------------|
| 1. | <u>Collins</u> | <u>Whiddon</u> | <u>CF</u> | <u>Fav/2 amendments</u> |
| 2. | <u>Liem</u> | <u>Wilson</u> | <u>HC</u> | <u>Favorable</u> |
| 3. | _____ | _____ | <u>JU</u> | _____ |
| 4. | _____ | _____ | <u>AHS</u> | _____ |
| 5. | _____ | _____ | <u>AP</u> | _____ |
| 6. | _____ | _____ | _____ | _____ |

I. Summary:

Senate Bill 150 adds “familial dysautonomia” to the list of disorders included in the definition of “developmental disability” in ch. 393, F.S.

This bill amends ss. 393.063, 92.53, 400.464, 419.001, 914.16, 914.17, and 918.16, F.S.

II. Present Situation:

Familial dysautonomia (FD) is a genetic disease that is present from birth which results in incomplete development of the nervous system causing a decreased number of nerve cells. The affected nerve cells are those which control certain sensations and autonomic functions. The sensory nerve cells which are most severely affected are those responsible for pain, heat perception, and taste. The autonomic nerve cells control bodily functions such as sweating, swallowing, regulation of blood pressure and body temperature, and the ability to cry tears. Secondary problems associated with the disease may include feeding problems, vomiting, poor growth, spinal curvature and lung problems.

Familial dysautonomia is a recessive genetic disease, meaning that both parents carry the gene despite a lack of outward signs. The recessive gene causing FD occurs with a remarkably high carrier frequency in individuals of Eastern European Jewish ancestry (Ashkenazi Jewish extraction). It is estimated that one in 30 persons with Eastern European Jewish ancestry is a carrier of the FD gene. Affected individuals usually are of normal intelligence. Familial dysautonomia patients can be expected to function independently, if treatment is begun early and major disabilities are avoided.

Familial dysautonomia does not express itself in a consistent manner and the costs for treatment vary depending upon the severity and types of symptoms experienced by the individual. Symptoms vary by age as well. Some of the more commonly needed treatments are as follows:

- Artificial tears;
- Special feeding techniques;
- Special therapies (feeding, occupational, physical, speech);
- Special drug management of autonomic manifestations;
- Respiratory care;
- Protecting the child from injury (coping with decreased taste, temperature and pain perception);
- Treatment of orthopedic problems (tibial torsion and spinal curvature); and
- Compensating for labile blood pressures.

The FD Foundation in New York reports that based on the FD world-wide registry, there are currently 331 surviving persons with FD, and 178 of those persons reside in the United States. Seventy percent of these persons reside in New York (68), New Jersey (24), Florida (17), and California (15). New York is the only state that includes FD as a chronic developmental disability. However, similar legislation has been introduced in California as well.

Section 393.063(12), F.S., defines “developmental disability” as a disorder or syndrome that is attributable to retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely. The Department of Children and Family Services’ Developmental Disabilities program estimates that their client population currently served in the community for these disorders is as follows: retardation, 28,704 (79 percent); cerebral palsy, 3,826 (11 percent); autism, 2,538 (7 percent); children at risk for developmental disabilities, 447 (1 percent); spina bifida, 980 (3 percent); and Prader-Willi syndrome, 52 (.1 percent).

Persons with FD are not currently served by the Developmental Disabilities program of the department. According to the department, FD has not been approved by the Centers for Medicare and Medicaid Services as a developmental disability for which Medicaid services may be reimbursed under the Developmental Services Home and Community-Based Services (DS/HCBS) waiver program. However, children suffering from this disorder may currently receive health care services from the Children’s Medical Services program of the Department of Health until age 21, if they meet certain financial eligibility requirements.

III. Effect of Proposed Changes:

This legislation adds familial dysautonomia to the list of developmental disabilities in ch. 393, F.S., making persons with that condition eligible for publicly funded services.

The bill amends ss. 92.53, 400.464, 419.001, 914.16, 914.17, and 918.16, F.S., to reflect the renumbering of definitions in s. 393.063, F.S., because of the addition of a definition for “familial dysautonomia”.

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:**

None.

B. Private Sector Impact:

Families with children who suffer with FD currently receive no financial assistance from the publicly funded Developmental Disabilities program unless the condition is combined with a covered developmental disability. The bill could provide some assistance to these persons and their families, assuming resources are available.

C. Government Sector Impact:

The fiscal impact of this bill is unknown as there is no historical cost data associated with serving persons with FD. If there are sufficient resources, and persons with FD are determined to be eligible for Developmental Disabilities services, these services would likely have to be funded exclusively through general revenue until federal approval for inclusion in the Home and Community Based Services (HCBS) waiver could be obtained.

The average monthly cost of serving a person under the Developmental Disabilities waiver program currently exceeds \$1,500 per person per month.

VI. Technical Deficiencies:

None.

VII. Related Issues:

The department would have to expand its capability to serve persons with FD. While some existing providers render services to persons with similar challenges, more resources and provider education would be required to appropriately serve persons with FD.

The Department of Children and Families projects a \$13,669,937 shortfall in general revenue funding for the Home and Community Based Services Waiver for FY 02-03, and at the end of December 2002, the client waiting list for services exceeded 10,000.

Amending state eligibility law will put Florida at odds with current federal eligibility requirements, preventing the state from funding any services to persons with FD using federal dollars.

The changes proposed by this bill could be interpreted to set the precedent for the addition of other similar groups to become eligible for services under this program and result in additional strain on the service system.

VIII. Amendments:

#1 by Children and Families:

Removes details regarding the prevalence of Familial Dysautonomia.

#2 by Children and Families:

Deletes the word “mental” in the bill to be consistent with the term “retardation” as it is defined in the statute. (WITH TITLE AMENDMENT)

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