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 1544

SPONSOR: Senator Wasserman Schultz

SUBJECT: Developmental Disabilities

DATE: February 24, 2002 REVISED: _____ _____ _____ _____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Barnes	Whiddon	CF	Fav/1 Amendment
2.	Liem	Wilson	HC	Favorable
3.			AHS	
4.			AP	
5.				
6.				

I. Summary:

Senate Bill 1544 adds "familial dysautonomia" to the list of disorders included in the definition of "developmental disability" in ch. 393, F.S. The bill defines the condition as a genetic neurological condition characterized by decreased pain and temperature sensation, absence of overflow tearing, pernicious vomiting, spine curvature, and blood pressure lability.

This bill amends section 393.063, F.S.

II. Present Situation:

Familial dysautonomia (FD) is a genetic disease which is present from birth resulting 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. All children with FD have the same basic problem—incomplete development of nerve cells. Some children also have secondary problems, such as 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 remarkable 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.

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).

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 (department) estimates that their current client population by disorder is as follows: retardation, 30,608 (82.5 percent); cerebral palsy, 3,457 (9.32 percent), autism, 2,045 (5.51 percent); spina bifida, 939 (2.53 percent), and Prader-Willi syndrome, 45 (.12 percent).

Persons with FD are not currently served by the Developmental Disability Program of the department. According to the department, FD has not been approved by the Centers for Medicaid and Medicare Services, (formally HCFA) as a developmental disability for which medical services may be reimbursed under the Developmental Services Home and Community-Based Services (DS/HCBS) waiver program. Seventy-three percent of the persons served by the Developmental Disability program live in the community and are served under the Developmental Services Home and Community-Based Services (DS/HCBS) waiver, which results in the federal government matching state expenditures for services at a 45 percent state, 55 percent federal expenditure ratio.

III. Effect of Proposed Changes:

SB 1544 amends s. 393.063(12), F.S., to specify that "familial dysautonomia" is a developmental disability and defines the term in s. 393.063(21), F.S., to mean a genetic neurological condition characterized by decreased pain and temperature sensation, absence of overflow tearing, pernicious vomiting, spine curvature, and blood pressure lability. The bill specifies that the incidence of the disease within the Ashkenazi Jewish population is one in 3,600, based on an estimated carrier frequency of one in 32.

The effective date of the bill is July 1, 2002.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

The provisions of this bill have no impact on municipalities and the counties under the requirements of Art. VII, s. 18 of the Florida Constitution.

B. Public Records/Open Meetings Issues:

The provisions of this bill have no impact on public records or open meetings issues under the requirements of Art. I, s. 24(a) and (b) of the Florida Constitution.

C. Trust Funds Restrictions:

The provisions of this bill have no impact on the trust fund restrictions under the requirements of Art. III, s. 19(f) of the Florida Constitution.

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 Disability Program unless it is combined with a covered developmental disability. The bill could provide some assistance to these persons and their families.

C. Government Sector Impact:

The fiscal impact of the bill is not known. According to AHCA, the fiscal impact on the Medicaid program will be minimal. DCF reports that the cost to serve this group are uncertain as there is no historical cost data, although average costs in the program currently exceed $1500 per person per month.

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Amendments:

#1 by Children and Families:
Removes language from the bill that is not directly related to the definition of “familial dysautonomia” such as the incidence rate of the disease.