

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 0194
 SPONSOR: Sen. Wasserman-Shultz
 SUBJECT: Developmental Disabilities/AHCA Development of a Waiver
 DATE: November 4, 2003 REVISED: _____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Collins	Whiddon	CF	Favorable
2.	_____	_____	HC	_____
3.	_____	_____	AHS	_____
4.	_____	_____	AP	_____
5.	_____	_____	_____	_____
6.	_____	_____	_____	_____

I. Summary:

Senate Bill 194 directs the Agency for Healthcare Administration (AHCA or the agency) and the Department of Children and Families (DCF or the department) to develop a model home and community-based waiver to serve children diagnosed with Familial Dysautonomia which is also known as Riley-Day Syndrome. The agency is further directed to seek a federal waiver and, upon approval, implement the program subject to the availability of funds and any limitations provided in the General Appropriations Act. The bill authorizes the agency to adopt rules necessary to administer this waiver program

This bill amends section 409.912 of the Florida Statutes.

II. Present Situation:

Familial dysautonomia (FD) which is also known as the Riley Day Syndrome 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 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.

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)
- 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.

Persons with FD are not currently served by the Developmental Disabilities program of the Department of Children and Families (DCF or the department). According to the department, FD has not been approved by the Centers for Medicaid and Medicare Services as a developmental disability for which medical 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 healthcare services from Children's Medical Services, Department of Health, until age 21 if they meet certain financial eligibility requirements.

III. Effect of Proposed Changes:

This bill amends s. 409.912, F.S., creating subsection (45). This subsection directs AHCA to work with DCF to develop a model home and community based waiver program that is designed to serve children with familial dysautonomia/Riley-Day Syndrome. The agency is also directed to apply for federal approval of a model waiver program and, if approved, implement the waiver program subject to the availability of funding and any limitations provided in the General Appropriations Act. Authorization is provided to the agency to adopt rules to administer the waiver program. If approved, the effective date of this legislation is July 1, 2004.

A benefit to the implementation of a federal waiver program is the Medicaid reimbursement of 58.93% for each state dollar spent. Federal waiver programs require the commitment of some state funding but reduce the amount of state funding necessary to support approved programs.

There are some difficulties associated with the implementation of waiver programs. Federal waiver programs are typically “entitlement” programs. For example, if a person is eligible for services, they must have access to all services to which they are “entitled” based upon their program eligibility. It is also frequently difficult for states to “cap” the levels of services provided or the number of persons served as federal program requirements take precedence. Meeting the federal program requirements can result in increased state spending, and cost containment initiatives are frequently difficult to implement successfully.

Additionally, it is likely that the agency and the department would serve children who are financially eligible by disregarding their parent’s income and assets. Eligibility requirements for the Medicaid waiver are stringent and aligned with the eligibility requirements for other state plans. Therefore, as persons become eligible for a waiver program, they are also provided access to all other Medicaid services.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

D. Other Constitutional Issues:

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. Currently, up to seventeen individuals live in Florida that could become eligible for services depending upon their age. The potential cost for providing the needed services is unknown as there is no historical cost data available. Forty-one percent of any costs incurred by implementing the waiver program would have to be paid from general revenue funding.

The development and implementation of a new waiver program will result in an increased workload for staff from the agency and the department.

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Amendments:

None.

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