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.)

Prepared By: Health and Human Services Appropriations Committee

BILL: CS/CS/SB 428

SPONSOR: Health and Human Services Appropriations Committee, Health Care Committee and Senator Rich

SUBJECT: Developmental Disabilities

DATE: April 26, 2005 REVISED: ____ ____ ____ ____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Collins	Whiddon	CF	**Fav/1 amendment**
2.	Garner	Wilson	HE	**Fav/CS**
3.	Dull	Peters	HA	**Fav/CS**
4.				
5.				
6.				

I. Summary:

The bill directs the Agency for Health Care Administration (AHCA) and the Agency for Persons with Disabilities (APD) to develop a model Medicaid home and community-based waiver program to serve children diagnosed with Familial Dysautonomia, which is also known as Riley-Day Syndrome. The Agency for Health Care Administration 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 AHCA to adopt the rules necessary to administer this waiver program. The bill provides appropriations for implementation.

This bill amends s. 409.912, F.S.

II. Present Situation:

Familial Dysautonomia (FD), which is also known as the Riley-Day Syndrome, is a genetic disease that is present from birth. The disease results in incomplete development of the nervous system, causing a decreased number of nerve cells. The affected nerve cells are those that control certain sensations and autonomic functions. The sensory nerve cells that 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). The rate of incidence of the disease within the Ashkenazi Jewish population is one in 3,600, based on an estimated carrier frequency of one in 32. 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 (19), and California (15). New York is the only state that includes FD as a chronic developmental disability.

Familial Dysautonomia manifests itself as a chronic lung disease, closely related to cystic fibrosis. AHCA currently administers a Cystic Fibrosis Waiver for adults.

Coverage for Familial Dysautonomia

Persons with FD are not currently served by the Agency for Persons with Disabilities (APD). According to the APD, Familial Dysautonomia has not been approved by the federal Centers for Medicaid and Medicare Services (CMS) 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 health care services from the Children’s Medical Services program through the Department of Health until age 21 if they meet certain financial eligibility requirements.

Medicaid Home and Community-Based Waivers

Home and community-based service delivery programs have become a growing part of states’ Medicaid programs, serving as an alternative to care in institutional settings such as nursing homes. To provide these services, states obtain waivers from certain federal statutory requirements for Medicaid. States often operate multiple waiver programs serving different population groups, such as the elderly, persons with mental retardation or developmental disabilities, persons with physical disabilities, and children with special health care needs.

States may apply to CMS for section 1915(c) waivers to provide home and community-based services as an alternative to institutional care in a hospital, nursing home, or intermediate care facility for the developmentally disabled. If approved, the waivers allow states to limit the availability of services geographically, to target services to specific populations or medical/disease conditions, or to limit the number of persons served; actions not allowed under Medicaid state plan services. Under a 1915(c) waiver, states determine the types of services they wish to offer and any provider who is interested and meets application requirements can provide services. Waivers may offer a variety of skilled services to only a few individuals with a particular condition, such as persons with traumatic brain injury, or they may offer only a few unskilled services to a large number of people, such as the aged or disabled.

A benefit of the implementation of a federal waiver program is the federal Medicaid reimbursement of 58.89 percent 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.

III. Effect of Proposed Changes:

Section 1. Amends s. 409.912, F.S., creating subsection (50). This subsection directs AHCA to work with APD to develop a model Medicaid home and community-based waiver program that is designed to serve children with Familial Dysautonomia/Riley-Day Syndrome. The Agency for Health Care Administration 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 AHCA to adopt rules to administer the waiver program.

Section 2. Appropriates $171,840 from the General Revenue Fund and $246,160 from the Medical Care Trust Fund to the Agency for Health Care Administration.

Section 3. Establishes July 1, 2005 as the effective date of this legislation.

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 Article VII, Section 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 Article III, Subsection 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 Disabilities Program unless the condition is combined with a covered developmental disability. The bill could provide some assistance to these children and their families.

C. Government Sector Impact:

Currently there are multiple medical studies available on Familial Dysautonomia, however, there are no studies or data available regarding the cost of treatment for individuals with this disease. The Familial Dysautonomia foundation of New York was contacted for information regarding the cost of treating an individual with FD. The foundation indicated that there are large variances in the cost of treatment, due to the varying levels of symptoms experienced by each individual, but the could not provide information regarding actual average costs. However, the foundation did indicate that treatment regimens are closely related to individuals with Cystic Fybrosis. The Florida Medicaid program currently operates a waiver program for individuals with Cystic Fybrosis. The Medicaid program indicates that the average annual cost per individual in the waiver is approximately $22,000. Due to the lack of specific data related to FD, this analysis assumes that the average cost of an individual with FD will be closely related to that of an individual in the current Cystic Fybrosis waiver.

According to the Familial Dysautonomia foundation in New York, there are 19 individuals, ages 3 months to 52, with the disease and currently residing in Florida. There is no data available to justify if all individuals will qualify for Medicaid, however, it is possible that the model waiver developed through this bill could possibly cover the majority of the individuals. Therefore, this analysis assumes that all 19 individuals will qualify for the waiver.

Summary of Fiscal Impact

FY 2005-06			FY 2006-07		
Number of Individuals	**Average Annual Cost PMPY**	**Total**	**Number of Individuals**	**Average Annual Cost PMPY ***	**Total**
19	$22,000	$418,000	19	$23,760	$451,440
Recurring General Revenue		$171,840			$185,587
Trust Fund		$246,160			$265,853

** Assumes an 8% increase due to medical inflation*

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Summary of Amendments:

None.
