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: Children and Families Committee

BILL: SB 428

SPONSOR: Senator Rich

SUBJECT: Developmental Disabilities

DATE: December 22, 2004 REVISED: 01/26/05

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

Please see last section for Summary of Amendments

☒ Technical amendments were recommended
☐ Amendments were recommended
☐ Significant amendments were recommended

I. Summary:

Senate Bill 428 directs the Agency for Health Care Administration (AHCA) and the Department of Children and Families (DCF or the department) 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.

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 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). 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 (17), 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 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 mentally retarded. 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 to the implementation of a federal waiver program is the Medicaid reimbursement of 58.93 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:

This bill amends s. 409.912, F.S., creating subsection (45). This subsection directs AHCA to work with DCF 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. The effective date of this legislation is July 1, 2005.

The Agency for Persons with Disabilities has responsibility for programmatic oversight of waiver programs for persons with developmental disabilities. The APD is the entity that should be directed to work with AHCA to develop a model community-based waiver program to serve persons with 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 children and their families, assuming resources are available.

C. Government Sector Impact:

A new waiver program will require 41% of its funding to be provided by General Revenue in order to obtain the additional federal funds to support the program

Implementing a new waiver increases staff workload for the Developmental Disabilities Program. Since funding levels are unknown and the program is not yet developed, it is impossible to estimate the fiscal impact at this time.

Agency for Health Care Administration

According to the AHCA, the fiscal impact of this bill is unknown. Approximately 17 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. It is also unknown if any of these individuals would be eligible for Medicaid.

The development and implementation of a new waiver program will result in an increased workload for AHCA staff.

VI. Technical Deficiencies:

The Agency for Persons with Developmental Disabilities, instead of the Department of Children and Families, should be directed to work with the Agency for Health Care Administration to develop the model waiver program.

The 2004 Legislature passed legislation establishing The Agency for Persons with Disabilities (APD). This legislation provided for the removal of the Developmental Disabilities Program from the Department of Children and Family Services and transferred this program to APD, for the purpose of providing services to persons with developmental disabilities (ch. 2004-267, L.O.F.).

VII. Related Issues:

None.

VIII. Summary of Amendments:

Barcode 535670 by Committee on Children and Families:
This bill directs the Agency for Health Care Administration (AHCA) to work with the Department of Children and Family Services to develop a model community-based waiver program to serve persons with Familial Dysautonomia. However, the Agency for Persons with Disabilities now has responsibility for programmatic oversight of waiver programs for persons with developmental disabilities and is the entity that should be directed to work with AHCA.

This amendment directs the Agency for Persons with Disabilities rather than the Department of Children and Family Services to work with AHCA to develop the model waiver program.