

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. HOUSE PRINCIPLES ANALYSIS:

Provide limited government: The bill has the effect of creating Medicaid eligibility for a new group of persons.

Promote personal responsibility: The bill creates an opportunity for families to obtain Medicaid eligibility for their children by disregarding the family's income and considering the child as a "family of one" for determining income and assets.

Empower families: The bill creates Medicaid eligibility for a new group of persons, increasing dependence of families upon government support or assistance.

B. EFFECT OF PROPOSED CHANGES:

Background

Familial dysautonomia (FD), or 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 emotional tears. Secondary problems associated with the disease may include feeding problems, vomiting, poor growth, spinal curvature, and lung problems.

Familial dysautonomia patients can be expected to function independently if treatment is begun early and major disabilities are avoided. Affected individuals usually are of normal intelligence.

FD 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. FD 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.¹

The Dysautonomia Foundation, Inc. in New York reports that based on the FD world-wide registry, as of January 2004 there are over 340 persons worldwide living with FD. One third of them live in the metropolitan New York City area, one third reside in Israel, and the remaining third live elsewhere in the United States and worldwide.² It has been reported that 17 persons with FD are residents of Florida.

¹ See, e.g., *Jewish Genetic Diseases A Mazornet Guide* at http://www.mazornet.com/genetics/familial_dysautonomia.asp; Chicago Center for Jewish Genetic Disorders at <http://www.jewishgeneticscenter.org/what/ashkenazi/familial2.asp>.

² Dysautonomia Foundation, Inc. at <http://www.familialdysautonomia.org/history.htm>

The Department of Health, Children's Medical Services, currently provides services to children diagnosed with FD whose families meet certain income limitations. Under the federal requirements of OBRA 89 that Medicaid programs meet children's medical needs, CMS is able to provide care coordination for a range of needed services and therapies. However, CMS does not have funding to provide families of FD children with respite or behavioral services.

Persons with FD are not currently served by the Agency for Persons with Disabilities (APD).³

Medicaid Home and Community-based Waivers

In 1981, Congress authorized the waiver of certain federal requirements to enable a state to provide home and community services (other than room and board) to individuals who would otherwise require institutional care reimbursed by Medicaid. The waiver programs are called "1915(c) waivers." Under 1915(c) waiver authority, states can provide services not usually covered by the Medicaid program, as long as these services are **required** to keep a person from being institutionalized.

The Model waiver (originally known as a Katie Beckett waiver) is a provision in the Tax Equity and Fiscal Responsibility Act (TEFRA, 134) that was added to the Medicaid program in 1982. TEFRA 134 gives states the option to cover non-institutionalized children with disabilities. Before TEFRA 134 was enacted, if a child with disabilities lived at home, the parents' income and resources were automatically counted (deemed) as available for medical expenses. However, if the same child was institutionalized for 30 days or more, only the child's own income and resources were counted in determining financial eligibility.

TEFRA 134 amended the Medicaid law to give states the option to waive or disregard the deeming of parental income and resources for children under 18 years old who were living at home but who would otherwise be eligible for Medicaid-funded institutional care. Not counting parental income enables these children to receive Medicaid services at home or in other community settings. CMS reports that many states use this option. States must determine that:

- (1) the child requires the level of care provided in an institution;
- (2) it is appropriate to provide care outside the facility; and
- (3) the cost of care at home is no more than the cost of institutional care. In states that use this option, parents may choose either institutional or community care for their Medicaid eligible children.

Effect of Changes

AHCA is directed to develop a model home and community-based waiver. If approved, Medicaid coverage would be available to children diagnosed with familial dysautonomia. It is likely that AHCA would serve children who are financially eligible by disregarding their parent's income and assets. Eligibility for the Medicaid waiver also provides access to all other Medicaid services.

C. SECTION DIRECTORY:

³ The Agency for Persons with Disabilities was formerly the Development Disabilities Program of the Department of Children and Families.

Section 1: Amends s. 409.912, F.S.; adds subsection (50) requiring AHCA to develop a model waiver program to serve children with Familial Dysautonomia.

Section 2: Provides an effective date of July 1, 2005.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

No revenue is generated by this bill.

2. Expenditures:

The fiscal impact of this bill is unknown as there is no historical cost data associated with serving persons with FD in either the Medicaid program or the Developmental Services program.

If the federal Center for Medicare and Medicaid Services approves the Model waiver authorized in the bill, children with FD who qualified for the waiver would be eligible not only for the waiver services but also for the entire package of Medicaid services.

For reference, the average monthly cost of serving a person under the Developmental Disabilities waiver program currently exceeds \$1,500 per person per month. According to a report by the Auditor General, some participants have plans of care that exceed \$100,000 per year.⁴ However, that monthly cost is only for waiver services. In addition to the \$1,500 monthly for waiver services, recipients also receive the full array of other Medicaid services.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

The bill provides that AHCA may implement the federally approved waiver subject to the availability of funds and any limitations provided in the General Appropriations Act.

Establishing Medicaid eligibility for the child under this waiver authority will also make the child eligible for all Medicaid services. However, Medicaid would coordinate benefits with any other

⁴ State of Florida Auditor General Report No. 13470, *Operational Audit of the Florida Department of Children and Family Services' Administration of the Developmental Services Home and Community-Based Waiver*, May 24, 1999, pg. 18-19.

third party payer as long as that payer was available. Very sick or disabled children frequently exhaust the lifetime cap on the family's health insurance benefits.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

The mandates provision is not implicated by this bill.

2. Other:

None.

B. RULE-MAKING AUTHORITY:

AHCA is granted rulemaking authority to implement the provisions of the act.

C. DRAFTING ISSUES OR OTHER COMMENTS:

None.

IV. AMENDMENTS/COMMITTEE SUBSTITUTE CHANGES

At its January 26, 2005, meeting, the Committee on Elder and Long Term Care adopted one amendment to the bill which deleted references to "Department of Children and Family Services." AHCA has responsibility for the existing model waiver program; neither DCF nor APD would administer the waiver if it receives federal approval.

This analysis is drafted to the Committee Substitute.