



## FULL ANALYSIS

### I. SUBSTANTIVE ANALYSIS

#### A. DOES THE BILL:

- |                                      |                              |  |   |
|--------------------------------------|------------------------------|--|---|
| 1. Reduce government?                | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> | N/A <input type="checkbox"/>            |
| 2. Lower taxes?                      | Yes <input type="checkbox"/> | No <input type="checkbox"/>            | N/A <input checked="" type="checkbox"/> |
| 3. Expand individual freedom?        | Yes <input type="checkbox"/> | No <input type="checkbox"/>            | N/A <input type="checkbox"/>            |
| 4. Increase personal responsibility? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> | N/A <input type="checkbox"/>            |
| 5. Empower families?                 | Yes <input type="checkbox"/> | No <input type="checkbox"/>            | N/A <input type="checkbox"/>            |

For any principle that received a “no” above, please explain:

- 1 and 2: The bill adds an additional cohort of persons to those eligible to receive publicly-funded services under chapter 393, F.S., thus expanding government.

#### B. EFFECT OF PROPOSED CHANGES:

The federal definition of a “developmental disability” is:

“the term ‘*developmental disability*’ means a severe, chronic disability of an individual 5 years of age or older that—

- (1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (2) Is manifested before the individual attains age 22;
- (3) Is likely to continue indefinitely;
- (4) Results in substantial functional limitations in three or more of the following areas of major life activity—
  - (i) Self-care;
  - (ii) Receptive and expressive language;
  - (iii) Learning;
  - (iv) Mobility;
  - (v) Self-direction;
  - (vi) Capacity for independent living; and
  - (vii) Economic self-sufficiency;
- (5) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.”

Florida Statutes define a 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.***”

Florida Statutes also provides that persons who have a secondary diagnosis of epilepsy concurrently with retardation, cerebral palsy, or autism are eligible for services under chapter 393, F.S.

Familial dysautonomia (FD) 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 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.

The FD Foundation in New York reports that based on the FD world-wide registry, there are currently 331 persons living with FD. 178 of those persons reside in the United States. Of that 178 persons, seventy percent of them live in New York (68), New Jersey (24), Florida (17), and California (15).

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

Persons with FD are not currently served by the Developmental Disabilities program of the department. According to the department, FD has not been approved by the Centers for Medicare and Medicaid Services as a developmental disability.

This legislation adds familial dysautonomia to the list of developmental disabilities in ch.393, F.S.; this could make persons with that condition eligible for publicly-funded services if they also met the second prong of the statutory definition: ***constitutes a substantial handicap that can reasonably be expected to continue indefinitely.***"

#### C. SECTION DIRECTORY:

Section 1. Amends subsections (12) and (19) of 393.063, F.S., to add the term "familial dysautonomia" to the definition of "Developmental disability" and "Epilepsy."

Sections 2, 3, 4, 5, 6, 7. Amend ss. 92.53, 400.464, 419.001, 914.16, 914.17, and 918.16, F.S., to conform to the changes in s. 393.063, F.S., adding a definition for "familial dysautonomia".

Section 8. Provides an effective date of July 1, 2003.

## II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

### A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

2. Expenditures:

The fiscal impact of this bill is unknown as there is no historical cost data associated with serving persons with FD under chapter 393, F.S.

If persons with FD are determined to be eligible for services under chapter 393, F.S., these services would be funded exclusively through general revenue. The federal Centers for Medicare and Medicaid do not consider FD a developmental disability for purposes of inclusion in Medicaid Home and Community Based Services (HCBS) waivers.

It is not clear how many, if any, persons diagnosed with FD would also meet the other requirements of the definition of developmental disability. Further, to be eligible to participate in the Medicaid waiver for persons with developmental disabilities, a person has to be financially eligible for Medicaid, be diagnosed with a developmental disability, and need the level of care provided in an Intermediate Care Facility for the Developmentally Disabled.

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.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

### III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

Not applicable

2. Other:

B. RULE-MAKING AUTHORITY:

The Department of Children and Family Services currently has rule-making authority for the Developmental Services Program and this bill does not expand or revise it.

C. DRAFTING ISSUES OR OTHER COMMENTS:

**IV. AMENDMENTS/COMMITTEE SUBSTITUTE CHANGES**