

BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

Prepared By: The Professional Staff of the Committee on Children, Families, and Elder Affairs

BILL: CS/SB 242

INTRODUCER: Senator Baxley

SUBJECT: Developmental Disabilities

DATE: January 17, 2017 REVISED: _____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Delia	Hendon	CF	Fav/CS
2.	_____	_____	BI	_____
3.	_____	_____	AP	_____
4.	_____	_____	RC	_____

Please see Section IX. for Additional Information:
 COMMITTEE SUBSTITUTE - Substantial Changes

I. Summary:

CS/SB 242 expands the definition of “developmental disability” in statute to include any disorder or syndrome attributable to Duchenne Muscular Dystrophy (DMD).

DMD is the most commonly diagnosed type of muscular dystrophy, and is considered to be among the most common fatal genetic diseases discovered in childhood. DMD often occurs in people without a known family history of the condition. Symptoms progress at a faster rate than other forms of muscular dystrophy; DMD patients lose muscular tissue and function rapidly as they age, and most patients are unable to walk by age 12. There is no known cure for DMD, and the average life expectancy of a DMD patient is 26, although some patients live into their 30s.

The bill will potentially give DMD patients access to various services, such as residential habilitation, behavioral services, adult day training, employment services, physical therapy, and other services provided by the Agency for Persons with Disabilities (APD) by making DMD patients eligible for the Medicaid iBudget waiver.

The bill has an effective date of July 1, 2018, and the fiscal impact is indeterminate.

II. Present Situation:

Duchenne Muscular Dystrophy

DMD is a genetic disease that primarily affects males and is considered the most common fatal inherent disorder that is diagnosed in childhood.¹ A progressive form of muscular dystrophy, DMD is caused by an alteration (mutation) in the DMD gene.² The DMD gene codes for a protein called dystrophin, which is crucial for muscles to work properly. Without dystrophin, muscle fibers degenerate and are gradually replaced by fat and connective tissue until voluntary movement becomes impossible.³

While many women are asymptomatic carriers, some may also have health effects.⁴ DMD often occurs in people whose families have no known family history of the disease.⁵ Although symptoms may start earlier, the average age at the time of diagnosis is four to six years of age, when families may already have, or are planning, more children. For this reason, parents are often unaware that they may be at high risk of having another child who could inherit this genetic disorder.⁶

Each year, between 400 and 600 boys in the United States are born with DMD or Becker muscular dystrophy (BMD), a related genetic disorder.⁷ This means DMD occurs in about 1 in every 3,500 male births in the U.S.⁸ According to APD, there are an estimated 286 individuals with DMD in Florida based upon a census of 2,859,433 males between the ages of 5 and 30.⁹

The most common symptoms of DMD are delayed motor skills, such as not sitting, standing, or walking, as well as speech delay.¹⁰ Symptoms typically appear before age 6, though symptoms can sometimes begin to be seen as early as infancy.¹¹ Muscle weakness tends to appear in early childhood, and worsens progressively, usually resulting in wheelchair dependence by adolescence.¹²

Both DMD and BMD are associated with a heart condition called cardiomyopathy, in which cardiac muscle is weakened by a lack of dystrophin, preventing the heart from pumping blood

¹ Parent Project Muscular Dystrophy; <http://www.parentprojectmd.org> (last visited January 10, 2018).

² National Human Genome Research Institute; <https://www.genome.gov/19518854/learning-about-duchenne-muscular-dystrophy/> (last visited January 10, 2018).

³ *Id.*

⁴ *Id.*

⁵ *Id.*

⁶ *Id.*

⁷ Genetic Home Reference; Duchenne and Becker Muscular Dystrophy; <https://ghr.nlm.nih.gov/condition/duchenne-and-becker-muscular-dystrophy#statistics> (last visited January 10, 2018).

⁸ *Id.*

⁹ Agency for Persons with Disabilities, Agency Bill Analysis for 2018 Senate Bill 242, available at <http://abar.laspbs.state.fl.us/ABAR/Document.aspx?id=20951&yr=2018> (last visited January 16, 2018).

¹⁰ *Supra*, note 7.

¹¹ *Id.*

¹² *Id.*

efficiently.¹³ Heart failure due to Duchenne cardiomyopathy typically begins in adolescence, progressively worsens, and results in death.¹⁴ Few individuals with DMD live beyond their 30s.¹⁵

Because DMD is an X-linked condition, and a characteristic of X-linked inheritance is that fathers cannot pass X-linked traits to their sons, only mothers can pass on the mutated DMD gene.¹⁶ Approximately two-thirds of males with DMD have inherited the disease from their mothers; the other one-third developed mutations in the womb that were not inherited.¹⁷

Agency for Persons with Disabilities

APD provides services to persons in Florida with developmental disabilities. A developmental disability is defined as a disorder or syndrome that is attributable to intellectual disability, cerebral palsy, autism, spina bifida, Down syndrome, Phelan-McDermid syndrome or Prader-Willi syndrome, that manifests before the age of 18 and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely.¹⁸

Individuals who meet Medicaid eligibility requirements, including individuals with developmental disabilities¹⁹, may choose to receive services in the community through the state's Medicaid HCBS waiver for individuals with developmental disabilities administered by APD or in an Intermediate Care Facility for the Developmentally Disabled.

The Medicaid Home and Community-Based Services (HCBS) waiver, known as iBudget Florida, offers 27 supports and services delivered by contracted service providers to assist individuals to live in their community.²⁰ Such services are not covered under the regular Medicaid program. Examples of waiver services enabling children and adults to live in their own home, a family home, or in a licensed residential setting are residential habilitation, behavioral services, adult day training, employment services, and physical therapy.²¹

DMD is not currently included in the statutory definition of “developmental disabilities,” and is therefore not currently considered a qualifying disability for purposes of HCBS waiver eligibility.²²

¹³ Kazuhiko Segawa, Hirofumi Komaki, Madoka Mori-Yoshimura, Yasushi Oya, Koichi Kimura, Hisateru Tachimori, Naohiro Kato, Masayuki Sasaki, and Yuji Takahashi, *Cardiac Conduction Disturbances and Aging in Patients with Duchenne Muscular Dystrophy*, MEDICINE (BALTIMORE), (Oct. 2017), available at, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5662415/> (last visited January 10, 2018).

¹⁴ *Id.*

¹⁵ *Id.*

¹⁶ *Supra*, note 7.

¹⁷ *Id.*

¹⁸ Section 393.063(12), F.S.

¹⁹ S. 393.0662(1), F.S., provides eligibility criteria for the iBudget waiver.

²⁰ Agency for Persons with Disabilities, Quarterly Report on Agency Services to Floridians with Developmental Disabilities and Their Costs: Third Quarter Fiscal Year 2016-17, May 2017.

²¹ *Id.*

²² *Supra*, note 18.

III. Effect of Proposed Changes:

Section 1 states this act shall be known as “Gabe’s Act.”

Section 2 amends s. 393.063, F.S., by modifying the definition of “developmental disability” to include a disorder or syndrome attributable to DMD. The bill would likely make individuals diagnosed with DMD eligible for some APD services, such as those available through the iBudget waiver.

Section 3 provides an effective date of July 1, 2018.

IV. Constitutional Issues:**A. Municipality/County Mandates Restrictions:**

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

V. Fiscal Impact Statement:**A. Tax/Fee Issues:**

None.

B. Private Sector Impact:

The bill may have an indeterminate impact on private sector insurance companies who currently cover some services for DMD patients because APD may provide these individuals access to some of the same or similar services covered by private insurance carriers.

C. Government Sector Impact:

Some DMD patients may be currently served under Medicaid, the Medically Needy Program, or Children’s Medical Services (CMS). To the extent these individuals are not being served, the bill may create a fiscal impact on APD by increasing the number of individuals eligible to receive services through the iBudget waiver, as well as other services available through the agency. These costs are indeterminate.

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Statutes Affected:

This bill substantially amends section 393.063 of the Florida Statutes.

IX. Additional Information:

- A. Committee Substitute – Statement of Substantial Changes:
(Summarizing differences between the Committee Substitute and the prior version of the bill.)

CS by Children, Families, and Elder Affairs on January 16, 2018:**The Committee Substitute:**

- Removes Section 1, containing the short title of the bill.

- B. Amendments:

None.