

## HOUSE OF REPRESENTATIVES STAFF ANALYSIS

**BILL #:** HB 869 X-linked Myotubular Myopathy

**SPONSOR(S):** Hattersley

**TIED BILLS:** **IDEN./SIM. BILLS:** SB 390

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR or BUDGET/POLICY CHIEF
1) Children, Families & Seniors Subcommittee	12 Y, 0 N	Grabowski	Brazzell
2) Health Care Appropriations Subcommittee	11 Y, 0 N	Mielke	Clark
3) Health & Human Services Committee			

### SUMMARY ANALYSIS

Individuals with specified developmental disabilities who meet Medicaid eligibility requirements may choose to receive services in the community through the state's Medicaid Home and Community-Based Services (HCBS) waiver for individuals with developmental disabilities (known as iBudget Florida), or in an institutional setting known as an Intermediate Care Facility for the Developmentally Disabled (ICF/DD).

Currently, due to demand exceeding available funding, individuals with developmental disabilities who wish to receive iBudget Florida HCBS services administered by the Agency for Persons with Disabilities (APD) are placed on a wait list for services in priority of need, unless they are in a crisis. As of December 2018, 22,034 individuals were waiting for developmental disability waiver services.

The bill adds X-linked myotubular myopathy (XLMTM) to the definition of "developmental disability" included in chapter 393, F.S. This addition allows individuals diagnosed with XLMTM to qualify for APD services, including iBudget program services as long as they met other waiver eligibility criteria. XLMTM is a rare condition that primarily affects muscles used for movement and occurs almost exclusively in males. Individuals with XLMTM have muscle weakness (myopathy) and decreased muscle tone (hypotonia) that are usually evident at birth. Approximately 80% of affected individuals present with severe XLMTM, which is often characterized by profound muscle weakness and respiratory failure. Estimates also indicate that at least 25% of boys with severe XLMTM die in the first year of life, and those who survive rarely live into adulthood.

The bill has no FY 2019-2020 impact on APD. The bill has no fiscal impact on local government. See Fiscal Comments.

The bill provides an effective date of July 1, 2019.

## FULL ANALYSIS

### I. SUBSTANTIVE ANALYSIS

#### A. EFFECT OF PROPOSED CHANGES:

##### **Background**

###### Agency for Person with Disabilities

The Agency for Persons with Disabilities (APD) is responsible for providing services to persons 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.<sup>1</sup> The overarching goal for APD is to prevent or reduce the severity of the developmental disability and implement community-based services that will help individuals with developmental disabilities achieve their greatest potential for independent and productive living in the least restrictive means.<sup>2</sup>

###### iBudget Florida Program

Individuals with specified developmental disabilities who meet Medicaid eligibility requirements may choose to receive services in the community through the state's Medicaid Home and Community-Based Services (HCBS) waiver, known as iBudget Florida, or in an institutional setting known as an Intermediate Care Facility for the Developmentally Disabled (ICF/DD).<sup>3</sup>

APD administers iBudget Florida pursuant to s. 393.0662, F.S. iBudget Florida uses an algorithm, or formula, to set individuals' funding allocations for waiver services. The statute authorizes APD to give individuals additional funding under certain conditions (such as a temporary or permanent change in need, or an extraordinary need that the algorithm does not address).<sup>4</sup> APD phased in the implementation of iBudget Florida, with the final areas transitioned from the previous tiered waiver system on July 1, 2013.<sup>5</sup>

APD serves almost 34,400 individuals through iBudget Florida<sup>6</sup>, contracting with service providers to offer 27 supports and services to assist individuals to live in their community.<sup>7</sup> Examples of waiver services enabling children and adults to live, learn, and work in their communities include residential habilitation, behavioral services, personal supports, adult day training, employment services, and occupational and physical therapy.<sup>8</sup>

###### Eligibility for iBudget Services

The application process for individuals wishing to receive services through the iBudget program are detailed in section 393.065, F.S. APD must review applications for eligibility within 45 days for children under 6 years of age and within 60 days for all other applicants.<sup>9</sup> Individuals who are determined to be

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<sup>1</sup> S. 393.063(9), F.S.

<sup>2</sup> S. 393.062, F.S.

<sup>3</sup> S. 393.0662, F.S.

<sup>4</sup> S. 393.0662(1)(b), F.S.

<sup>5</sup> Agency for Persons with Disabilities, *Quarterly Report on Agency Services to Floridians with Developmental Disabilities and Their Costs: First Quarter Fiscal Year 2017-18*, November 2017, available at <http://apd.myflorida.com/publications/reports/docs/Quarterly%20Report%201st%20Quarter%20FY%202017-18%20FINAL%20v3.pdf> (last accessed February 27, 2019).

<sup>6</sup> Agency for Persons with Disabilities, Agency Overview Presentation to House Children, Families, and Seniors Subcommittee, January 10, 2019. On file with Staff of the Children, Families, and Seniors Subcommittee.

<sup>7</sup> *Supra* note 5.

<sup>8</sup> *Id.*

<sup>9</sup> S. 393.065(1), F.S.

eligible for the waiver program are either given a slot in the program or placed on a wait list. Currently, due to demand exceeding available funding, individuals with developmental disabilities who wish to receive HCBS services from APD are placed on a wait list for services in priority categories of need, unless they are in a crisis.<sup>10</sup>

As of January 2019, 22,039 individuals were on the HCBS wait list, though it is estimated less than 1,400 of those individuals are in true need of services (categories one through five below).<sup>11</sup> A majority of people on the wait list have been on the list for more than five years, though some are children receiving services through the school system and others are individuals who have been offered waiver services previously but refused them and chose to remain on the wait list.<sup>12</sup>

The needs of APD clients are prioritized as prescribed by section 393.065(5), F.S. There are seven categories listed below in decreasing order of priority:

- Category 1 – Clients deemed to be in crisis.
- Category 2 – Children from the child welfare system at the time of:
  - Finalization of an adoption with placement in a family home;
  - Reunification with family members with placement in a family home; or
  - Permanent placement with a relative in a family home.
- Category 3 – Includes, but not limited to, clients:
  - Whose caregiver has a documented condition that is expected to render the caregiver unable to provide care within the next 12 months and for whom a caregiver is required but no alternate caregiver is available;
  - Who are at substantial risk of incarceration or court commitment without supports;
  - Whose documented behaviors or physical needs place them or their caregiver at risk of serious harm and other supports are not currently available to alleviate the situation; or
  - Who are identified as ready for discharge within the next year from a state mental health hospital or skilled nursing facility and who require a caregiver but for whom no caregiver is available.
- Category 4 – Includes, but not limited to, clients whose caregivers are 70 years of age or older and for whom a caregiver is required but no alternate caregiver is available;
- Category 5 – Includes, but not limited to, clients who are expected to graduate within the next 12 months from secondary school and need support to obtain or maintain competitive employment, or to pursue an accredited program of postsecondary education to which they have been accepted.
- Category 6 – Clients 21 years of age or older who do not meet the criteria for categories 1-5.
- Category 7 – Clients younger than 21 years of age who do not meet the criteria for categories 1-4.<sup>13</sup>

### X-Linked Myotubular Myopathy (XLMTM)

XLMTM is a condition that primarily affects muscles used for movement and occurs almost exclusively in males. Individuals with XLMTM have muscle weakness (myopathy) and decreased muscle tone (hypotonia) that are usually evident at birth. Infants with XLMTM may also have difficulties with feeding due to muscle weakness.<sup>14</sup>

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<sup>10</sup> S. 393.065, F.S.

<sup>11</sup> *Supra* note 6.

<sup>12</sup> *Id.*

<sup>13</sup> S. 393.065(5), F.S.

<sup>14</sup> “X-linked myotubular myopathy,” Genetics Home Reference, National Institutes for Health. <https://ghr.nlm.nih.gov/condition/x-linked-myotubular-myopathy#resources> (last accessed March 7, 2019).

Data from the National Institutes of Health indicates that XLMTM affects about 1 in 50,000 male children born in the U.S. Approximately 80% of affected individuals present with severe XLMTM, which is often characterized by profound muscle weakness and respiratory failure. Estimates also indicate that at least 25% of boys with severe XLMTM die in the first year of life, and those who survive rarely live into adulthood.<sup>15</sup> XLMTM may also present in mild and moderate forms, in which an affected individual may live into adulthood, while still requiring significant medical treatment to address the symptoms.

Treatment of the condition is supportive in nature. Management optimally involves a team of specialists with expertise in the long-term care of children and/or adults with neuromuscular disorders, often including a pulmonologist, neurologist, physical therapist and/or rehabilitation medicine specialist, and clinical geneticist. Tracheostomy, G-tube feeding, and assistive communication devices are often required. Ophthalmologists, orthopedists, and orthodontists may be required to address specific medical complications related to the condition.<sup>16</sup>

### **Effect of Proposed Changes**

HB 869 adds X-linked myotubular myopathy (XLMTM) to the definition of “developmental disability” included in chapter 393, F.S. This addition allows individuals diagnosed with XLMTM to qualify for APD and iBudget program services if the federal Center for Medicare and Medicaid Services approves the change and if they meet other waiver eligibility criteria.

The bill provides an effective date of July 1, 2019.

#### **B. SECTION DIRECTORY:**

**Section 1:** Amends s. 393.063, F.S.; relating to definitions.

**Section 2:** Provides an effective date of July 1, 2019.

## **II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT**

#### **A. FISCAL IMPACT ON STATE GOVERNMENT:**

1. Revenues:

None.

2. Expenditures:

There will be no expenditures for Fiscal Year 2019-2020. See Fiscal Comments.

#### **B. FISCAL IMPACT ON LOCAL GOVERNMENTS:**

1. Revenues:

None.

2. Expenditures:

None.

#### **C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:**

None.

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<sup>15</sup> Dowling JJ, Lawlor MW, Das S. X-Linked Myotubular Myopathy. 2002 Feb 25 [Updated 2018 Aug 23]. In: Adam MP, Ardinger HH, Pagon RA, et al., editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2019. Available at <https://www.ncbi.nlm.nih.gov/books/NBK1432/> (last accessed March 7, 2019).

<sup>16</sup> Id.

**D. FISCAL COMMENTS:**

The Legislature determines the funding available for HCBS waiver services for individuals with developmental disabilities through the annual appropriations process. APD serves individuals previously enrolled on the waiver and enrolls additional individuals from the wait list if new funds are appropriated for that purpose.

If HB 869 becomes law, the APD would need to submit a wavier plan amendment to the federal Center for Medicare and Medicaid Services to seek approval to add XLMTM as a qualifying developmental disability under the state's HCBS waiver program. If APD receives approval, those with XLMTM may apply to be evaluated and would be placed in the appropriate wait list category.

Some individuals with XLMTM may currently be served under Medicaid, the Medically Needy Program, or Children's Medical Services. This bill does not impact those programs.

**III. COMMENTS**

**A. CONSTITUTIONAL ISSUES:**

1. Applicability of Municipality/County Mandates Provision:

Not Applicable. This bill does not appear to affect county or municipal governments.

2. Other:

None.

**B. RULE-MAKING AUTHORITY:**

Current law provides APD with sufficient rulemaking authority to execute the provisions of the bill.

**C. DRAFTING ISSUES OR OTHER COMMENTS:**

None.

**IV. AMENDMENTS/ COMMITTEE SUBSTITUTE CHANGES**