

# FLORIDA HOUSE OF REPRESENTATIVES

## BILL ANALYSIS

*This bill analysis was prepared by nonpartisan committee staff and does not constitute an official statement of legislative intent.*

**BILL #:** [CS/HB 411](#)

**TITLE:** Terminology Associated with Autism

**SPONSOR(S):** Maggard

**COMPANION BILL:** [SB 1652](#) (Burgess)

**LINKED BILLS:** None

**RELATED BILLS:** [SB 1652](#) (Burgess)

### Committee References

[Human Services](#)

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## SUMMARY

### **Effect of the Bill:**

HB 411 requires the Agency for Persons with Disabilities (APD) to recognize Tatton-Brown-Rahman syndrome as a qualifying condition for APD services, including the iBudget waiver, subject to existing prioritization criteria.

### **Fiscal or Economic Impact:**

The bill may have an indeterminate, negative recurring negative fiscal impact on APD to expand eligibility criteria for services, determine an applicant's eligibility for services, and the cost to deliver such services, to the extent that newly eligible individuals apply and are approved for APD services.

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## ANALYSIS

### **EFFECT OF THE BILL:**

HB 411 expands the eligibility criteria for services provided by the Agency for Persons with Disabilities (APD), including [iBudget](#) services, for individuals with developmental disabilities by adding [Tatton-Brown-Rahman syndrome](#) (TBRS) to the list of disorders or syndromes to which a [developmental disability](#) is attributable. This will create a new population of individuals who may qualify to receive APD services, including services delivered under the iBudget waiver. (Section 1)

Since the iBudget waiver is slot-limited and not an entitlement, adding a new eligible population may result in a reshuffling of priorities on the preenrollment list, potentially delaying services for those currently waiting.

The bill provides that TBRS is a disorder caused by a genetic mutation and characterized by:

- Mild to severe intellectual disability;
- Height and weight greater than or equal to two standard deviations from the mean for a person's age and sex;
- An enlarged head; and
- Any of the following features that present in infancy, childhood, or adolescence:
  - Mild facial dysmorphism.
  - Joint hypermobility.
  - Hypotonia (low muscle tone).
  - Kyphoscoliosis (a spinal deformity with forward rounding of the upper back, or hunchback, and sideways curvature of the spine)
  - Seizures.
  - Cryptorchidism (undescended testicles).
  - Deficits in behavior.
  - Hematologic malignancies (blood and bone marrow cancers). (Section 1)

**STORAGE NAME:** h0411.HSS

**DATE:** 2/13/2026

The bill is effective July 1, 2026. (Section 2)

## FISCAL OR ECONOMIC IMPACT:

### STATE GOVERNMENT:

The bill may have an indeterminate, negative recurring negative fiscal impact on APD to review and process applications for iBudget waiver services and determine eligibility for and deliver such services to the extent that newly eligible individuals apply and are approved for enrollment in the iBudget waiver.

## RELEVANT INFORMATION

### SUBJECT OVERVIEW:

#### Developmental Disability

A developmental disability is a disorder or syndrome that manifests before age 18 and constitutes a substantial handicap that can be expected to continue indefinitely. Such disorders or syndromes include autism, cerebral palsy, spina bifida, intellectual disabilities, Down syndrome, Prader-Willi syndrome, and Phelan-McDermid syndrome.<sup>1</sup>

The Agency for Persons with Disabilities (APD) was created to serve the needs of Floridians with developmental disabilities. APD works in partnership with local communities and private providers to assist people who have developmental disabilities and their families. APD serves more than 60,000 individuals with developmental disabilities.<sup>2</sup>

#### Tatton-Brown-Rahman Syndrome

Tatton-Brown-Rahman Syndrome (TBRS), first identified in 2014, is a rare genetic overgrowth disorder caused by mutations in the DNMT3A gene.<sup>3</sup> It is associated with tall stature, increased weight or obesity, abnormal spine curvature, large head circumference, joint hypermobility, cardiac issues, blood cancers, seizures, and mild to severe intellectual disability. However, not all individuals have every clinical finding reported and the syndrome varies considerably in its severity.<sup>4</sup> Individuals have been diagnosed at different ages and the syndrome seems to affect males and females equally.<sup>5</sup>

The incidence and prevalence of TBRS is unknown. Since 2014, there approximately 450 known TBRS diagnoses worldwide.<sup>6</sup> In 2022, a known sample of 202 TBRS cases showed 90 cases were from North America and 89 were from Europe.<sup>7</sup>

#### Causes

<sup>1</sup> S. 393.063(11), F.S., and Agency for Persons With Disabilities, *Agency Glossary of Terms and Acronyms*, available at <https://apd.myflorida.com/docs/Glossary%20of%20Terms%20and%20Acronyms.pdf> (last visited Feb. 5, 2026).

<sup>2</sup> Agency for Persons with Disabilities, *About Us*, <https://apd.myflorida.com/about/> (last visited Feb. 5, 2026).

<sup>3</sup> National Library of Medicine, *Tatton-Brown-Rahman Syndrome*, available at <https://www.ncbi.nlm.nih.gov/books/NBK581652/#> (last visited Feb. 5, 2025).

<sup>4</sup> National Organization for Rare Disorders, *Tatton Brown Rahman Syndrome*, available at <https://rarediseases.org/rare-diseases/tatton-brown-rahman-syndrome/> (last visited Feb. 5, 2026).

<sup>5</sup> *Supra*, note 3 **Error! Bookmark not defined.**

<sup>6</sup> TBRS Community, *Tatton Brown Rahman Syndrome (TBRS) and DNMT3A Patient Registry*, available at <https://tbrsregistry.iamrare.org/> (last visited Feb. 5, 2026).

<sup>7</sup> National Library of Medicine, *DNMT3A Overgrowth Syndrome is Associated with the Development of Hematopoietic Malignancies in Children and Young Adults*, available at [DNMT3A overgrowth syndrome is associated with the development of hematopoietic malignancies in children and young adults - PMC](#) (last visited Feb. 5, 2026).

TBRS is typically caused by a de novo (new) genetic variant, meaning it does not tend to have a family history. However, some clusters have been reported in families and the risk of passing the gene variant from affected parent to child is 50% for each pregnancy.<sup>8</sup>

### Diagnosis

TBRS is diagnosed using genetic testing that shows a pathogenic variant in the DNMT3A gene.<sup>9</sup> Due to the similarities between this syndrome and other overgrowth syndromes, genetic testing may include a gene panel consisting of many genes that are associated with different overgrowth syndromes.<sup>10</sup>

### Therapies

Current therapies for TBRS involve management of symptoms. For example, speech therapy and occupational therapy may help individuals with TBRS develop necessary skills. Behavioral therapy may also be helpful for individuals with TBRS and physical therapy may be useful to treat low muscle tone and orthopedic problems.<sup>11</sup>

### **iBudget Home and Community-Based Services Waiver for Persons with Developmental Disabilities**

Under federal law, Medicaid provides coverage for health care services to cure or ameliorate diseases; generally, Medicaid does not cover services that will not cure or mitigate the underlying diagnosis, or social services. However, people with developmental disabilities, while certainly requiring traditional medical services, need other kinds of services to maintain their independence and avoid institutionalization. Home- and community-based services (HCBS) are an alternative to institutionalizing people with developmental disabilities.

To obtain federal Medicaid funding for HCBS, Florida obtained a Medicaid waiver.<sup>12</sup> This allows coverage of non-medical services to avoid institutionalization, and allows the state to limit the scope of the program to the number of enrollees deemed affordable by the state.<sup>13</sup> In this way, the HCBS waiver is not an entitlement; it is a first-come-first-served, slot-limited program.

The HCBS waiver program, called iBudget Florida, serves eligible<sup>14</sup> persons with developmental disabilities. Eligible diagnoses include disorders or syndromes attributable to intellectual disability, cerebral palsy, autism, spina bifida, Down syndrome, Phelan-McDermid syndrome, or Prader-Willi syndrome. The disorder must manifest before the age of 18, and it must constitute a substantial handicap that can reasonably be expected to continue indefinitely.<sup>15</sup>

Unlike other Medicaid waiver programs, which are administered by the Agency for Health Care Administration (AHCA), APD administers the iBudget program. The iBudget program allocates available funding to clients, providing each one with an established budget with the flexibility to choose from the authorized array of services that best meet their individual needs within their community.<sup>16</sup> Individual waiver support coordinators assist each client with determination of his or her unique needs and the coordination of necessary providers to provide those services.

<sup>8</sup> *Supra*, note 4.

<sup>9</sup> *Supra*, note 3.

<sup>10</sup> *Supra*, note 4.

<sup>11</sup> *Id.*

<sup>12</sup> Florida Developmental Disabilities Individual Budgeting Waiver (0867.R02.00), March 4, 2011, authorized under s. 1915b of the Social Security Act.

<sup>13</sup> The waiver also waives income eligibility requirements for the program, allowing the state to disregard household income and consider each waiver applicant as a 'family of one'.

<sup>14</sup> The HCBS waiver retains the Medicaid requirement that enrollees be low-income, but measures only the developmentally disabled person's income; not the income generated by the whole household.

<sup>15</sup> S. 393.063(11), F.S.

<sup>16</sup> *Id.*

The waiver services are delivered through a fee-for-service delivery model, which means that providers are enrolled and reimbursed for services directly by the state agency, not a managed care plan. While providers and individual waiver support coordinators each have a role in helping the iBudget enrollee assess and coordinate their care, the program essentially operates with no comprehensive care management in the traditional sense. The HCBS services are not integrated with acute medical services or behavioral health services, which are administered separately by AHCA.

As of January 5, 2026, there are 36,707 iBudget waiver enrollees.<sup>17</sup>

### iBudget Allocation Algorithm

Each client's established budget is determined by application of the allocation algorithm, the mathematical formula based upon statistically validated relationships between individual characteristics (variables) and the client's level of need for services provided through the iBudget waiver.<sup>18</sup>

A client can request supplemental funding, in addition to that allocated through the algorithm, that if not provided would place the health and safety needs of the client, the client's caregiver, or public in serious jeopardy.<sup>19</sup> This supplemental funding, known as "Significant Additional Need" (SAN), is categorized as an extraordinary need, a significant need for one time or temporary support or services, or a significant increase in the need for services after the beginning of the service plan year, or a significant need for transportation services.<sup>20</sup>

APD may authorize additional funding based on one or more significant additional needs that cannot be accommodated within the funding determined by the algorithm and having no other resources, supports, or services available to meet the needs so long as the waiver support coordinator has documented the availability of all nonwaiver resources.<sup>21</sup> The process for approval of a SAN can take anywhere from 30 days to more than 60 days, if APD determines that it needs additional documentation to reach a decision.

### iBudget Waiver Benefits

The iBudget Waiver provides the following home and community-based benefits:<sup>22</sup>

<b>iBudget Home and Community-Based Benefits</b>	
Adult day training services	Social services
Family care services	Specialized therapies
Guardian advocate referral services	Supported employment
Parent training	Supported living
Personal care services	Training, including behavioral analysis services
Recreation	Transportation
Residential facility services	Other habilitative and rehabilitative services as needed
Respite services	

iBudget waiver benefits also include Medicaid coverage for medical, non-HCBS services, administered by AHCA.

<sup>17</sup> Agency for Persons with Disabilities, *Home and Community Based Services (HCBS) Waiver Monthly Report for Waiver Enrollment Offers FY 2025-26* (January 2026), available at: [APD Enrollment Report 2025-01-30.pdf](#) (last visited Feb. 5, 2026).

<sup>18</sup> R. 65G-4.0213(1), F.A.C.

<sup>19</sup> S. [393.0662\(1\), F.S.](#)

<sup>20</sup> R. 65G-4.0213(26), F.A.C.

<sup>21</sup> S. [393.0662\(1\)\(b\), F.S.](#)

<sup>22</sup> Agency for Persons with Disabilities, *Quarterly Report on Agency Services to Floridians with Developmental Disabilities and Their Costs, First Quarter Fiscal Year 2025-26 (July, August, September)*, available at [FY 25-26 Q1 Quarter Report on Agency Services Nov 15 2025.pdf](#) (last visited Feb. 5, 2026)

The vast majority of Medicaid recipients receive services through the Statewide Medicaid Managed Care managed care model, in which the recipient can choose from different health plans – including health maintenance organizations and provider service networks – to provide their care. Using the managed care model is an option for iBudget enrollees; not a requirement. iBudget participants can opt to use the traditional fee-for-service model of service delivery.<sup>23</sup>

### iBudget Waiver Preenrollment List

Because the waiver program covers a limited number of people (based on the amount appropriated by the legislature each year), APD maintains a preenrollment list, or waitlist, of people who would like to enroll in the waiver. As of January 5, 2026, 16,996 individuals were on the preenrollment list to receive services.<sup>24</sup>

As people leave the program or as new funding becomes available, APD is expected to enroll people from the preenrollment list in a statutory order of priority in seven categories, described below.<sup>25</sup>

Category	Description
1	Crisis, as defined by APD.
2	Individuals: <ul style="list-style-type: none"> <li>From the child welfare system with an open case who are either:               <ul style="list-style-type: none"> <li>Transitioning out of the child welfare system at the finalization of an adoption, a reunification with family members, a permanent placement with a relative, or a guardianship with a nonrelative; or</li> <li>At least 18 years but not yet 22 years of age and who need both waiver services and extended foster care services; or</li> </ul> </li> <li>18-21 years old who chose not to remain in extended foster care.</li> </ul>
3	Individuals: <ul style="list-style-type: none"> <li>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;</li> <li>At substantial risk of incarceration or court commitment without supports;</li> <li>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</li> <li>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 or whose caregiver is unable to provide the care needed.</li> </ul>
4	Individuals whose caregivers are 60 years of age or older and for whom a caregiver is required but no alternate caregiver is available.
5	Individuals expected to graduate from high school within the next 12 months who need support to obtain a meaningful day activity, maintain competitive employment, or attend postsecondary education.
6	Individuals age 21 or older who do not meet the criteria for Categories 1-5.
7	Individuals under age 21 who do not meet the criteria for Categories 1-4.

### iBudget Waiver Enrollment Trends

Historically, despite the utilization management tools authorized in law<sup>26</sup> and legislative funding increases, APD has frequently been unable to manage the waiver program within the budget appropriated by the legislature, resulting in significant deficit spending. For example, the legislature made retroactive appropriations to address

<sup>23</sup> [S. 409.972\(1\)\(e\), F.S.](#)

<sup>24</sup> *Supra*, note 17 at p. 2.

<sup>25</sup> [S. 393.065\(5\), F.S.](#)

<sup>26</sup> [S. 393.0662, F.S.](#), requires APD, in consultation with the AHCA, to provide a quarterly reconciliation report of all HCBS waiver expenditures from AHCA's claims management system with service utilization from APD's Allocation, Budget and Contract Control system to the Governor and Legislature.

APD deficits that occurred in FY 17-18 (\$56,895,137), FY 18-19 (\$107,848,988), and FY 19-20 (\$133,505,542). See Sections 30, 30, and 29, respectively, of the respective General Appropriations Acts in those years.

Conversely, in recent years APD moved to the other extreme. Now, APD stays within its annual appropriation but fails to spend significant amounts of its budget, even when directed by the legislature to enroll more people and reduce the preenrollment list. Instead, APD has been reverting appropriations back to the state, as indicated by the table below.

<b>APD General Revenue Reversions FY 2019-20 – FY 2023-24</b>	
<b>Fiscal Year</b>	<b>Amount Reverted (GR)</b>
2019-2020	\$-11,287,781
2020-2021	\$-983,836
2021-2022	\$-39,567,230
2022-2023	\$-59,135,133
2023-2024	\$-73,676,927
<b>TOTAL</b>	\$-184,650,907 GR
	\$-246,877,270 Fed
	<b>\$-431,528,177</b>

According to APD, the current average cost per client enrolled in the iBudget waiver is \$58,000 per year.<sup>27</sup>

## BILL HISTORY

<b>COMMITTEE REFERENCE</b>	<b>ACTION</b>	<b>DATE</b>	<b>STAFF DIRECTOR/ POLICY CHIEF</b>	<b>ANALYSIS PREPARED BY</b>
<a href="#">Human Services Subcommittee</a>	14 Y, 0 N, As CS	2/12/2026	Mitz	Morris
THE CHANGES ADOPTED BY THE COMMITTEE:	Removed language revising the definition of autism and replaced it with language adding Tatton-Brown-Rahman syndrome to the list of developmental disabilities for which APD provides services.			

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**THIS BILL ANALYSIS HAS BEEN UPDATED TO INCORPORATE ALL OF THE CHANGES DESCRIBED ABOVE.**  
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<sup>27</sup> Agency for Persons with Disabilities, Agency Analysis of 2025 House Bill 411, p. 6 (Dec. 9, 2025).