HLS 14RS-251 ENGROSSED

Regular Session, 2014

HOUSE BILL NO. 513

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BY REPRESENTATIVE HENRY

EXCEP PERSON/DISABLED: Requires the Department of Health and Hospitals to provide information concerning velocardiofacial syndrome and 22q11.2 deletion syndrome

AN ACT

2 To enact Part LXXV of Chapter 5 of Title 40 of the Louisiana Revised Statutes of 1950, to 3 be comprised of R.S. 40:1300.381 through 1300.382, relative to chromosome 4 deletion disorders; to provide for definitions; to provide for dissemination of 5 information regarding velocardiofacial syndrome and 22q11.2 deletion syndrome; to provide for rulemaking authority; to authorize the use of available resources for 6 7 cost containment; and to provide for related matters. 8 Be it enacted by the Legislature of Louisiana: 9 Section 1. Part LXXV of Chapter 5 of Title 40 of the Louisiana Revised Statutes of 10 1950, comprised of R.S. 40:1300.381 through 1300.382, is hereby enacted to read as 11 follows: PART LXXV. CHROMOSOME DELETION DISORDERS 12 13 §1300.381. Definitions 14 In this Part, unless the context otherwise requires, the following definitions 15 are applicable: 16 (1) "Department" means the Department of Health and Hospitals. 17 (2) "Early intervention services" means services that are designed to meet the developmental needs of an infant or toddler with a disability, in any one or more 18 19 of the following areas:

CODING: Words in struck through type are deletions from existing law; words <u>underscored</u> are additions.

| 1 | (a) Physical development. |
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| 2 | (b) Cognitive development. |
| 3 | (c) Communication development. |
| 4 | (d) Social or emotional development. |
| 5 | (e) Adaptive development. |
| 6 | (3) "Early intervention services provider" means any provider of early |
| 7 | intervention services to infants and toddlers with disabilities and their families. |
| 8 | "Early intervention services provider" includes but is not limited to the following: |
| 9 | (a) Special educators. |
| 10 | (b) Speech-language pathologists and audiologists. |
| 11 | (c) Occupational therapists. |
| 12 | (d) Physical therapists. |
| 13 | (e) Psychologists. |
| 14 | (f) Social workers. |
| 15 | (g) Nurses. |
| 16 | (h) Registered dieticians. |
| 17 | (i) Family therapists. |
| 18 | (j) Vision specialists, including ophthalmologists and optometrists. |
| 19 | (k) Orientation and mobility specialists. |
| 20 | (1) Pediatricians and other physicians. |
| 21 | §1300.382. Velocardiofacial syndrome and 22q11.2 deletion syndrome; |
| 22 | dissemination of information; rulemaking authority; costs |
| 23 | A. The department shall make available materials regarding velocardiofacial |
| 24 | syndrome and 22q11.2 deletion syndrome to each early intervention services |
| 25 | provider in this state. |
| 26 | B. Each early intervention services provider may offer the materials to |
| 27 | parents of a child who is known by the provider to have at least two of the following |
| 28 | conditions: |
| 29 | (1) Hypotonicity. |

| 1 | (2) Communication delay. |
|----|----------------------------------------------------------------------------------------|
| 2 | (3) Articulation disorder. |
| 3 | (4) Resonance disorder. |
| 4 | (5) Nasal regurgitation during feeding as an infant with no history of a cleft |
| 5 | palate. |
| 6 | (6) Recurrent ear infections as well as diagnosis of cardiac anomaly, feeding |
| 7 | disorder, cleft palate, or submucosal cleft palate. |
| 8 | (7) Fine motor or gross motor skills delay. |
| 9 | C.(1) The department shall develop the materials required pursuant to this |
| 10 | Section using medically accurate, peer-reviewed literature. |
| 11 | (2) The materials made available by the department pursuant to this Section |
| 12 | shall include, at a minimum, all of the following: |
| 13 | (a) An explanation of velocardiofacial syndrome and 22q11.2 deletion |
| 14 | syndrome symptoms, diagnosis, and treatment options. |
| 15 | (b) Information on relevant state agency and nonprofit resources, parent |
| 16 | support groups, and available Medicaid waiver programs. |
| 17 | (c) A recommendation for follow-up with a healthcare provider for |
| 18 | evaluation of the underlying etiology and an explanation that the existence of any of |
| 19 | the conditions listed in Subsection B of this Section will not necessarily result in a |
| 20 | diagnosis of velocardiofacial syndrome or 22q11.2 deletion syndrome. |
| 21 | D. The department may adopt, in accordance with the Administrative |
| 22 | Procedure Act, any rules and regulations necessary to implement this Section. |
| 23 | E. In developing the materials required by this Section, the department may |
| 24 | utilize any available resources for the purposes of minimizing costs to the |
| 25 | department. |

DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

Henry HB No. 513

Abstract: Requires the Dept. of Health and Hospitals to provide information concerning velocardiofacial syndrome and 22q11.2 deletion syndrome.

<u>Proposed law</u> defines "department", "early intervention services", and "early intervention services provider".

<u>Proposed law</u> requires the Dept. of Health and Hospitals (DHH) to make available materials regarding velocardiofacial syndrome and 22q11.2 deletion syndrome to each early intervention services provider in this state.

<u>Proposed law</u> authorizes each early intervention services provider to offer the materials to parents of a child who is known by the agency to have at least two of the following conditions:

- (1) Hypotonicity.
- (2) Communication delay.
- (3) Articulation disorder.
- (4) Resonance disorder.
- (5) Nasal regurgitation during feeding as an infant with no history of a cleft palate.
- (6) Recurrent ear infections as well as diagnosis of cardiac anomaly, feeding disorder, cleft palate, or submucosal cleft palate.
- (7) Fine motor or gross motor skills delay.

<u>Proposed law</u> requires DHH to develop the materials using medically accurate, peer-reviewed literature.

<u>Proposed law</u> requires the materials to include, at a minimum, all of the following:

- (1) An explanation of velocardiofacial syndrome and 22q11.2 deletion syndrome symptoms, diagnosis, and treatment options.
- (2) Information on relevant state agency and nonprofit resources, parent support groups, and available Medicaid waiver programs.
- (3) A recommendation for follow-up with a healthcare provider for evaluation of the underlying etiology and an explanation that the existence of any of the conditions listed in <u>proposed law</u> will not necessarily result in a diagnosis of velocardiofacial syndrome or 22q11.2 deletion syndrome.

<u>Proposed law</u> authorizes DHH to adopt, in accordance with the Administrative Procedure Act, any rules and regulations necessary to implement <u>proposed law</u>.

CODING: Words in struck through type are deletions from existing law; words <u>underscored</u> are additions.

<u>Proposed law</u> authorizes DHH, in developing the materials required by <u>proposed law</u>, to utilize any available resources for the purposes of minimizing costs.

(Adds R.S. 40:1300.381-1300.382)

Summary of Amendments Adopted by House

Committee Amendments Proposed by <u>House Committee on Health and Welfare</u> to the <u>original</u> bill.

- 1. Changed the requirement that each early intervention services provider offer the materials to an authorization to offer the materials.
- 2. Made technical changes.