

Regular Session, 2014

HOUSE BILL NO. 513

BY REPRESENTATIVE HENRY

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

1 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 require dissemination of information
5 regarding velocardiofacial syndrome and 22q11.2 deletion syndrome; to provide for
6 rulemaking authority; to authorize the use of available resources for cost
7 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:

12 PART LXXV. CHROMOSOME DELETION DISORDERS

13 §1300.381. Definitions

14 In this Part, unless the context otherwise requires, the following definitions
15 are be applicable:

16 (1) "Department" means the Department of Health and Hospitals.

17 (2) "Early intervention services" means services that are designed to meet
18 the developmental needs of an infant or toddler with a disability, in any one or more
19 of the following areas:

20 (a) Physical development.

21 (b) Cognitive development.

1 (c) Communication development.

2 (d) Social or emotional development.

3 (e) Adaptive development.

4 (3) "Early intervention services provider" means any provider of early
5 intervention services to infants and toddlers with disabilities and their families.

6 "Early intervention services provider" includes but is not limited to the following:

7 (a) Special educators.

8 (b) Speech-language pathologists and audiologists.

9 (c) Occupational therapists.

10 (d) Physical therapists.

11 (e) Psychologists.

12 (f) Social workers.

13 (g) Nurses.

14 (h) Registered dietitians.

15 (i) Family therapists.

16 (j) Vision specialists, including ophthalmologists and optometrists.

17 (k) Orientation and mobility specialists.

18 (l) Pediatricians and other physicians.

19 §1300.382. Velocardiofacial syndrome and 22q11.2 deletion syndrome;
20 dissemination of information; rulemaking authority; costs

21 A. The department shall make available materials regarding velocardiofacial
22 syndrome and 22q11.2 deletion syndrome to each early intervention services
23 provider in this state.

24 B. Each early intervention services provider shall offer the materials to
25 parents of a child who is known by the provider to have at least two of the following
26 conditions:

27 (1) Hypotonicity.

28 (2) Communication delay.

29 (3) Articulation disorder.

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

Proposed law defines "department", "early intervention services", and "early intervention services provider".

Proposed law 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.

Proposed law requires 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.

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

Proposed law 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 proposed law will not necessarily result in a diagnosis of velocardiofacial syndrome or 22q11.2 deletion syndrome.

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

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

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