

2020 Regular Session

SENATE BILL NO. 126

BY SENATOR BARROW

EXCEPTIONAL PERSONS. Establishes the Commission for Identifying Risk Factors for Cortical Visual Impairment. (8/1/20)

1 AN ACT

2 To enact R.S. 36:259(B)(37) and R.S. 46:2271, relative to the establishment of the
3 Commission for Identifying Risk Factors for Cortical Visual Impairment; to provide
4 for legislative intent; to provide for definitions; to provide for a program to be
5 established within the office of public health, Louisiana Department of Health; to
6 provide for the responsibilities of the office in administering the program; to provide
7 for membership of the commission; to provide for responsibilities of the
8 commission; and to provide for related matters.

9 Be it enacted by the Legislature of Louisiana:

10 Section 1. R.S. 36:259(B)(37) is hereby enacted to read as follows:

11 §259. Transfer of agencies and functions to Louisiana Department of Health

12 * * *

13 B. The following agencies, as defined in R.S. 36:3, are placed within the
14 Louisiana Department of Health and shall perform and exercise their powers, duties,
15 functions, and responsibilities as otherwise provided by law:

16 * * *

17 **(37) The Commission for Identifying Risk Factors for Cortical Visual**

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29

Impairment (R.S. 46:2271).

* * *

Section 2. R.S. 46:2271 is hereby enacted to read as follows:

§2271. Commission for Identifying Risk Factors for Cortical Visual Impairment; legislative intent; program creation; establishment of the commission

A. The legislature finds and declares that:

(1) The purpose of the program for early identification of blind and visually impaired infants is to identify impaired infants at the earliest possible time so that medical treatment, early evaluation and assessment of visual function, and early educational intervention can be provided.

(2) Early education intervention and vision services are required under the Individuals with Disabilities Education Act of 2004.

(3) Early identification and management of a blind or visually impaired infant is essential if that infant is to acquire vital compensatory, orientation and mobility, sensory efficiency, independent living, recreational, social, and self-determination skills needed to achieve maximum potential educationally, emotionally, and socially.

(4) Appropriate screening and identification of newborns and infants with vision loss will therefore serve the public purpose of promoting the healthy development of children and reducing public expenditures for healthcare, special education, and related services.

B. As used in this Section, the following definitions shall apply:

(1) "Commission" means the Commission for Identifying Risk Factors for Cortical Visual Impairment created pursuant to this Section.

(2) "Department" means the Louisiana Department of Health.

(3) "Blind or visually impaired infant" means an infant who has a disorder of the ocular system or disorder of the visual pathways and visual centers in the brain, including the pathways serving visual perception,

1 cognition, and visual guidance of movement of any type or degree.

2 (4) "Infants susceptible to a visual disability" means those infants who
3 are susceptible to visual impairment because they have one or more risk factors.

4 (5) "Office" means the office of public health within the department.

5 (6) "Program" means the program that the office of public health
6 establishes to provide for the early identification and follow-up of infants
7 susceptible to a visual disability and of infants who have a risk factor for
8 developing progressive visual loss.

9 (7)(a) "Risk factors" means those criteria or factors, any one of which
10 identifies an infant as being susceptible to vision impairment.

11 (b) The risk factors that identify neonates, infants from birth through the
12 first twenty-eight days, who are susceptible to ocular or neurological vision loss
13 include the following:

14 (i) Premature birth of less than thirty-two weeks.

15 (ii) In vitro alcohol or substance abuse.

16 (iii) Birth complications.

17 (iv) Congenital infection.

18 (v) History of neurological disorder.

19 (vi) Diagnosis of seizure disorder, cerebral palsy, intrauterine stroke,
20 hydrocephalus, cerebral dysplasia such as schizencephaly, cranial dysplasia
21 such as apert's syndrome, meningitis, encephalitis, brain tumor, or traumatic
22 brain injury.

23 (vii) Birth weight of less than one thousand two hundred fifty grams.

24 (c) The risk factors that identify infants aged twenty-nine days to two
25 years who are susceptible to ocular or neurological vision loss include the
26 following:

27 (i) Genetic predisposition.

28 (ii) Family history of congenital vision impairment or vision loss.

29 (iii) Family history of autism spectrum disorder.

1 (iv) History of neurological disorder including seizure disorder, cerebral
2 palsy, intrauterine stroke, hydrocephalus, cerebral dysplasia such as
3 schizencephaly, cranial dysplasia such as apert's syndrome, meningitis,
4 encephalitis, brain tumor, or traumatic brain injury.

5 (v) History of metabolic disorders including hypoglycemia,
6 3-methylpropionic anemia, Refsum's disease, mucopolysaccharidosis, neuronal
7 ceroid lipofuscinosis, disorders of glycosylation or Tay-Sachs disease.

8 (vi) History of malnourishment.

9 (vii) Sensory processing disorder.

10 (viii) Malabsorption syndromes.

11 (ix) Parent or caregiver concern regarding developmental, vision, or
12 speech delay.

13 (8) "Screening for vision impairment" means employing the Neonatal
14 Assessment Visual European Grid, "NAVEG".

15 C.(1) There is hereby created within the office of public health, Louisiana
16 Department of Health, a program for the early identification and care for
17 infants that are susceptible to a visual disability, blind or visually impaired
18 infants, and infants susceptible to developing progressive vision loss.

19 (2) The office shall, at a minimum:

20 (a) Develop criteria or factors to identify those infants who are likely
21 blind or visually impaired and infants who may develop a progressive vision
22 loss, including the risk factors set forth in this Section, and develop a
23 susceptibility questionnaire for infant vision loss.

24 (b) Create a susceptibility registry to include but not be limited to the
25 identification of infants susceptible to vision loss, blind or visually impaired
26 infants, and infants susceptible to developing progressive vision loss.

27 (c) Provide to hospitals and other birthing sites the susceptibility
28 questionnaire for infant vision loss and require that the form be completed for
29 any newborn prior to discharge from the hospital or other birthing site. As to

1 infants susceptible to a vision disability, copies of the completed susceptibility
2 questionnaire shall be distributed to the susceptibility registry of the office, the
3 parent or guardian, and, if known, the infant's primary care physician and the
4 provider of vision services.

5 (d) Develop and provide to the hospitals or other birthing sites
6 appropriate written materials regarding vision loss, and require that the
7 hospitals or other birthing sites provide this written material to all parents or
8 guardians of newborn infants.

9 (e) Develop methods to contact parents or guardians of infants
10 susceptible to a visual disability, of blind and visually impaired infants, and of
11 infants susceptible to developing progressive vision loss.

12 (f) Establish a telephone hotline to communicate information about
13 vision loss, vision screening, functional vision evaluation, and other services for
14 blind and visually impaired infants.

15 (g) Provide that when a screening indicates vision impairment, an
16 evaluation of functional vision or functional use of vision shall be done as soon
17 as practical. The parents or guardians of the infant shall be provided with
18 information on locations at which medical follow-up can be obtained and
19 referral to early intervention services.

20 (h) Consult with the commission.

21 (i) Develop a system for the collection of data, determine the
22 cost-effectiveness of the program, and disseminate statistical reports.

23 (j) In cooperation with the state Department of Education, develop a
24 plan to coordinate early educational and vision services for infants identified as
25 blind or visually impaired.

26 D.(1) There is hereby created within the Louisiana Department of Health
27 the Commission for Identifying Risk Factors for Cortical Visual Impairment.
28 The commission shall be comprised of the following thirteen members:

29 (a) One member who is licensed and practices as a pediatric

1 ophthalmologist or neuro-ophthalmologist.

2 (b) One member who is licensed and practices as a neonatologist.

3 (c) One member who is licensed and practices as a pediatrician.

4 (d) One member who is a person with a visual impairment.

5 (e) One member who is a hospital administrator.

6 (f) One member who is an early interventionist.

7 (g) One member who is a special education teacher or administrator
8 certified in education of the visually impaired.

9 (h) One member who is a parent of a child with ocular blindness or low
10 vision.

11 (i) One member who is a parent of a child with brain based or
12 neurological vision impairment.

13 (j) One member who represents the state Department of Education,
14 designated by the superintendent of education.

15 (k) One member who represents the office of public health, designated
16 by the assistant secretary of the office.

17 (l) One member who is a representative of the Louisiana Center for the
18 Blind.

19 (m) One member who is a representative of the Louisiana Deafblind
20 Project.

21 (2) Members of the commission shall be appointed by the governor,
22 subject to confirmation by the Senate.

23 (3) Members of the commission representing offices and departments of
24 state government shall serve four-year terms concurrent with that of the
25 governor. Other members shall serve three-year terms, except that in making
26 the initial appointments, four members shall be appointed for a one-year term,
27 four shall be appointed for two-year terms, and three shall be appointed for
28 three-year terms. No member may serve more than two consecutive terms.

29 (4) Each member shall serve without compensation.

1 **(5) A majority of the members of the commission shall constitute a**
2 **quorum for the transaction of all business.**

3 **(6) The members of the commission shall elect from their membership**
4 **a chairman and a vice chairman.**

5 **E. The commission shall advise the office on the following:**

6 **(1) Recommend risk factors or criteria for infants who are likely blind**
7 **or visually impaired and infants who may develop a progressive vision loss.**

8 **(2) Setting standards for the program, monitoring and reviewing the**
9 **program, and providing quality assurance for the program.**

10 **(3) Integrating the program for early identification of blind and visually**
11 **impaired infants with existing medical and early infant education programs.**

12 **(4) Materials to be distributed to the public concerning blind and**
13 **visually impaired infants.**

14 **(5) Implementation of the program for early identification and follow-up**
15 **of infants susceptible to a visual disability, blind or visually impaired infants,**
16 **and infants who are at risk of developing progressive vision loss.**

The original instrument and the following digest, which constitutes no part
of the legislative instrument, were prepared by Christine Arbo Peck.

DIGEST

SB 126 Original

2020 Regular Session

Barrow

Proposed law establishes the Commission for Identifying Risk Factors for Cortical Visual Impairment and a program within the Louisiana Department of Health, office of public health, to provide for early identification of blind and visually impaired infants.

Proposed law provides risk factors for neonates, infants from birth through the first 28 days, who are susceptible to vision impairment to be premature birth of less than 32 weeks, in vitro alcohol or substance abuse, birth complications, congenital infection, history of neurological disorder, diagnosis of seizure disorder, cerebral palsy, intrauterine stroke, hydrocephalus, cerebral dysplasia such as schizencephaly, cranial dysplasia such as apert's syndrome, meningitis, encephalitis, brain tumor, or traumatic brain injury, and birth weight of less than 1,250 grams.

Proposed law provides risk factors for infants from 29 days to 2 years old who are susceptible to vision impairment to be genetic predisposition, family history of congenital vision impairment or vision loss, family history of autism spectrum disorder, history of neurological disorder including seizure disorder, cerebral palsy, intrauterine stroke, hydrocephalus, cerebral dysplasia such as schizencephaly, cranial dysplasia such as apert's syndrome, meningitis, encephalitis, brain tumor, or traumatic brain injury, history of metabolic disorders including hypoglycemia, 3-methylpropionic anemia, Refsum's disease,

mucopolysaccharidosis, neuronal ceroid lipofuscinosis, disorders of glycosylation or Tay-Sachs disease, history of malnourishment, sensory processing disorder, malabsorption syndromes, and parent or caregiver concern regarding developmental, vision, or speech delay.

Proposed law creates a program for the early identification and care for infants that are susceptible to a visual disability, blind or visually impaired infants, and infants susceptible to developing progressive vision loss. Proposed law provides that the program shall include development of a susceptibility questionnaire and registry, written materials, methods to contact parents or guardians, a telephone hotline, a system to collect data, and a coordinated effort with the state Department of Education.

Proposed law provides for the composition of the 13 member commission, provides that members are appointed by the governor subject to confirmation by the Senate, shall serve staggering terms, and shall serve without compensation.

Proposed law provides that the commission advises the office of public health on the development and implementation of the program.

Effective August 1, 2020.

(Adds R.S. 36:259(B)(37) and R.S. 46:2271)