STATE OF NEW YORK

2136

2019-2020 Regular Sessions

IN SENATE

January 22, 2019

Introduced by Sens. SANDERS, FUNKE -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to establishing the infant vision information, education and wellness program

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Short title. This act shall be known and may be cited as 2 the "Infant Vision Information, Education and Wellness Act".

§ 2. Article 25 of the public health law is amended by adding a new title II-B to read as follows:

TITLE II-B

INFANT VISION INFORMATION, EDUCATION AND WELLNESS PROGRAM

Section 2560. Definitions.

- 2561. Newborn vision screening advisory committee.
- 2562. Newborn vision screening education and assessment.
- 10 2563. Reporting and referral.
- 11 2564. Confidentiality of records.
- 2565. Regulatory authority. 12

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- 13 § 2560. Definitions. The following words and phrases, as used in this 14 section shall have the following meanings unless the context clearly 15 <u>indicates otherwise:</u>
- 1. "Birth admission" shall mean the time after birth that a newborn remains in a hospital or birth center prior to discharge. 17
- 2. "Child" shall mean an individual who is under twenty-one years of 19 **age.**
- 3. "Committee" shall mean the department of health's newborn vision 21 <u>screening advisory committee.</u>
- 4. "Health care facility" shall mean a hospital providing clinically 22 23 related health services for obstetrical and newborn care, or a birth center. The term includes a hospital providing clinically related health 25 services for obstetrical and newborn care, or a birth center operated by

EXPLANATION--Matter in italics (underscored) is new; matter in brackets [-] is old law to be omitted.

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an agency, the state or local government. The term does not include an office used primarily for private or group practice by health care practitioners if no reviewable clinically related health services are offered.

- 5 <u>5. "Infant" shall mean a child thirty days of age up to twenty-four</u> 6 months of age.
- 7 <u>6. "Newborn" shall mean a child up to and including twenty-nine days</u> 8 <u>of age.</u>
- 9 <u>7. "Parent" shall mean a natural parent, stepparent, adoptive parent,</u>
 10 <u>legal quardian or legal custodian of a child.</u>
- 11 <u>8. "Program" shall mean the infant vision information, education and</u> 12 <u>wellness program.</u>
- 13 § 2561. Newborn vision screening advisory committee. 1. Membership.
 14 The commissioner shall appoint a six-member newborn vision screening
 15 advisory committee within the department. The committee shall:
- 16 <u>(a) advise and make recommendations on issues relating to the follow-</u>
 17 <u>ing:</u>
- 18 (i) Program regulation and administration;
 - (ii) Diagnostic testing;
- 20 (iii) Technical support;
 - (iv) Follow-up.

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- 22 <u>(b) be comprised of members with experience with infant eye pathology,</u>
 23 <u>pediatric ophthalmology, optometry and common vision screening and</u>
 24 <u>assessment tests.</u>
- 25 <u>2. Compensation. Members shall serve without compensation but may be</u> 26 <u>reimbursed for necessary travel and other expenses in accordance with</u> 27 <u>applicable law and regulations.</u>
- 3. Protocol. On or before June thirtieth, two thousand twenty, the 28 29 department shall adopt the protocol developed by the American Academy of Pediatrics to optimally detect the presence of treatable causes of 30 31 blindness in infants by two months of age. If a protocol is not devel-32 oped on or before such date, the department, in consultation with the committee, shall establish a protocol to optimally detect the presence 33 34 of treatable causes of blindness in infants by two months of age on or 35 before January first, two thousand twenty-one.
- § 2562. Newborn vision screening education and assessment. 1. Establishment. The department shall establish the infant vision information, education and wellness program, consisting of the following components:
 - (a) A system to screen each newborn in the state for vision abnormalities before leaving a hospital.
- 41 (b) A system to screen each newborn who is not born in a hospital 42 within the first thirty days of life.
- 43 (c) A system to provide information and instruction to the parents of 44 each newborn and infant on the merits of having vision screening 45 performed and receiving follow-up care.
 - 2. Program administration. The department shall, in cooperation with the committee, provide technical support, including ophthalmological, optometric and administrative technical support, to the health care facilities and individuals implementing the requirements of subdivision one of this section.
- 3. Refusal of test. Screening shall not be required if a parent of the newborn or infant objects to the screening for any reason. The refusal must be documented in writing, made a part of the medical record of the newborn or infant and reported to the department in a manner prescribed by the department.
 - 4. Implementation. The program shall be implemented as follows:

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(a) By July first, two thousand twenty-one, newborn and infant vision screening shall be conducted on each live birth in health care facilities in the state during birth admissions using procedures recommended by the department's advisory committee, except as provided in subdivision three of this section. If a newborn is born in a location other than a hospital, the parents must be instructed on the merits of having the vision screening performed and given information to assist the parents in having the screening performed within thirty days of the newborn's birth. The department shall determine the appropriate screening venue for a newborn born outside a hospital.

- (b) If the number of newborns and infants receiving vision screening does not equal at least eighty-five percent of the total number of live births in the state on July first, two thousand twenty-one, as shown in the most recent data collected by the department or falls below eighty-five percent annually after July first, two thousand twenty-one, the department in consultation with the advisory committee shall immediately promulgate regulations to implement a state-administered vision screening program.
- (c) By July first, two thousand twenty, each health care facility in the state shall provide information and instruct the parents of newborns and infants concerning the importance of screening the vision of newborns and infants and of receiving follow-up care. The information shall be as follows:
- (i) An informational pamphlet developed and supplied by the department shall explain in lay terms all of the following:
 - (A) The importance and process of vision screening.
 - (B) The likelihood of a newborn or infant having vision abnormalities.
 - (C) Follow-up procedures and available early intervention services.
- (D) A description of the normal vision developmental process in children.
- 31 <u>(ii) The information under subparagraph (i) of this paragraph shall</u>
 32 <u>not preclude the health care facility from providing additional materi-</u>
 33 <u>al.</u>
 - (iii) The information may not be considered a substitute for the vision screening.
 - (d) By July first, two thousand twenty, every hospital in the state shall report to the department, in a manner prescribed by the department, the number of newborns and infants screened and the results of the screening. The department, based on the information, shall report to the legislature by January first, two thousand twenty-one, and every January first thereafter, the following:
 - (i) The number of hospitals conducting vision screenings during birth admissions.
 - (ii) The number of live births in hospitals.
 - (iii) The number of newborns screened during birth admissions.
 - (iv) The number of live births in a location other than a hospital.
 - (v) The number of newborns born in a location other than a hospital who were screened within thirty days of the date of birth.
 - (vi) The number of newborns born in a hospital who passed and the number who did not pass the birth admission screening, if administered.
- 51 (vii) The number of newborns born in a location other than a hospital 52 who passed and the number who did not pass a screening within thirty 53 days of the date of birth, if administered.
 - (viii) The number of infants who returned for follow-up rescreening.
- 55 (ix) The number of infants who passed the follow-up rescreening.

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- 1 (x) The number of infants recommended for monitoring, intervention and 2 follow up care.
 - § 2563. Reporting and referral. 1. Duties. the department shall implement a reporting and referral system that links vision screening, if necessary, with optometric and opthalmologist services and other early intervention services. The state may do all the following:
 - (a) Identify one hundred percent of newborns and infants with vision abnormalities within thirty days of the date of birth.
 - (b) Provide timely assessment if indicated.
- (c) Provide appropriate referral for treatment and intervention before 11 the age of six months.
 - 2. Program administration. The department shall, in consultation with the committee, provide administrative technical support to the facilities implementing the reporting and early intervention referral system under this section.
 - 3. Implementation. The department, in consultation with the committee, shall issue temporary quidelines by July first, two thousand twenty, implementing a reporting and early intervention referral system for newborns, infants and children who have been recommended for further assessment. The temporary quidelines shall expire on June thirtieth, two thousand twenty-one.
 - § 2564. Confidentiality of records. 1. Limitations. A person, employee or agent of a person who obtains information under this act may not disclose the information except to the parent of the infant or child or to the department for statistical recordkeeping or for appropriate treatment referral and early intervention services.
 - 2. Confidentiality. Data obtained directly from the medical records of a patient shall be considered confidential and shall be for the confidential use of the department in maintaining the tracking system and in providing appropriate services. The information shall be privileged and may not be divulged or made public in any manner that discloses the identity of the patient.
- 33 A person who acts in good faith in complying with this section by reporting newborn and infant vision screening results to the department 34 35 may not be held civilly or criminally liable for furnishing the information required by this title. 36
- 37 § 2565. Regulatory authority. The department shall promulgate such 38 rules and regulations as may be necessary to implement the provisions of this title. 39
- § 3. This act shall take effect on the ninetieth day after it shall 40 41 have become a law. Effective immediately, the addition, amendment 42 and/or repeal of any rule or regulation necessary for the implementation 43 of this act on its effective date are authorized to be made and 44 completed on or before such effective date.