# SENATE, No. 887 **STATE OF NEW JERSEY** 221st LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2024 SESSION

Sponsored by: Senator ANTHONY M. BUCCO District 25 (Morris and Passaic)

### SYNOPSIS

Prohibits reporting medical information of children without consent of parent or legal guardian.

## **CURRENT VERSION OF TEXT**

Introduced Pending Technical Review by Legislative Counsel.



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AN ACT concerning the medical information of children and

amending and supplementing various parts of Title 26 of the

3 **Revised Statutes.** 4 5 **BE IT ENACTED** by the Senate and General Assembly of the State 6 of New Jersey: 7 8 1. (New section) a. As used in this section, "health care 9 provider" means a health care facility licensed pursuant to 10 P.L.1971, c.136 (C.26:2H-1 et seq.) or a health care professional whose practice is regulated pursuant to Title 45 of the Revised 11 12 Statutes. 13 b. Notwithstanding the provision of any law, rule, order, 14 regulation, or statute to the contrary, no information of a child shall 15 be reported by a health care provider to, or otherwise shared with, 16 the Department of Health, or any other local or State governmental 17 employee or entity, without first obtaining the express, informed,

18 and written consent of the child's parent or legal guardian.

c. The provisions of this section shall not prohibit reporting or
sharing a child's information if a health care provider has
reasonable cause to believe that the child has been subjected to
child abuse, including sexual abuse.

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24 2. Section 6 of P.L.2001, c.373 (C.26:2-103.6) is amended to 25 read as follows:

6. a. The commissioner shall establish a central registry of newborns identified as having or being at risk of developing a hearing loss. The information in the central registry shall be used for the purposes of compiling statistical information and providing follow-up counseling, intervention and educational services to the parents of the newborns listed in the registry.

b. A hospital, birthing center or health care professional who
performs testing required by this act shall report the results of such
testing when a hearing loss is indicated to the department in a
manner and on forms prescribed by the commissioner.

<u>c. No information shall be reported to, or otherwise shared</u>
 with, the department pursuant to this section, without first obtaining
 the express, informed, and written consent of the child's parent or
 <u>legal guardian.</u>

40 (cf: P.L.2001, c.373, s.6)

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42 3. Section 4 of P.L.1995, c.328 (C.26:2-137.5) is amended to 43 read as follows:

44 4. a. All lead screening blood samples collected by a physician,45 registered professional nurse or a health care facility pursuant to

**EXPLANATION** – Matter enclosed in **bold-faced brackets** [thus] in the above bill is not enacted and is intended to be omitted in the law.

Matter underlined <u>thus</u> is new matter.

this act shall be sent to a laboratory licensed by the Department of 1 2 Health, pursuant to the "New Jersey Clinical Laboratory 3 Improvement Act," P.L.1975, c.166 (C.45:9-42.26 et seq.), for 4 analysis of blood lead levels. 5 b. A laboratory which performs a lead screening test pursuant 6 to this act shall report the test results to the department, the local 7 health department in the municipality in which the child who is the 8 subject of the test resides, and the physician, registered professional 9 nurse or health care facility, agency or program that submitted the 10 specimen, within five business days of obtaining the test result. 11 c. No information shall be reported to, or otherwise shared 12 with, the Department of Health pursuant to this section, without 13 first obtaining the express, informed, and written consent of the 14 child's parent or legal guardian. 15 (cf: P.L.1995, c.328, s.4) 16 17 4. Section 2 of P.L.2007, c.170 (C.26:2-186) is amended to read 18 as follows: 19 2. a. A physician, psychologist, and any other health care 20 professional licensed pursuant to Title 45 of the Revised Statutes who is qualified by training to make the diagnosis and who then 21 22 makes the diagnosis that a child has an autism spectrum disorder 23 shall report this diagnosis to the Department of Health in a form and 24 manner prescribed by the Commissioner of Health. 25 b. The report shall be in writing and shall include the name and 26 address of the person submitting the report, the name, age, place of 27 birth, and address of the child diagnosed as having an autism 28 spectrum disorder, and other pertinent information as may be 29 required by the commissioner **[**; except that, if the child's parent or 30 guardian objects to the reporting of the child's diagnosis for any 31 reason, the report shall not include any information that could be 32 used to identify the child ]. 33 The commissioner shall specify procedures for the health c. 34 care professional to inform the child's parent or guardian of the requirements of subsections a. and b. of this section and the purpose 35 36 served by including this information in the registry established 37 pursuant to section 3 of P.L.2007, c.170 (C.26:2-187) [, as well as 38 the parent's or guardian's right to refuse to permit the reporting of 39 any information that could be used to identify the child ]. 40 d. No information shall be reported to, or otherwise shared 41 with, the Department of Health pursuant to this section, without 42 first obtaining the express, informed, and written consent of the 43 child's parent or legal guardian. 44 (cf: P.L.2012, c.17, s.139) 45 46 5. Section 4 of P.L.2013, c.143 (C.26:2H-144) is amended to 47 read as follows:

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4. a. A health care professional who makes the diagnosis of a
 sudden cardiac event in a child, or who makes the actual
 determination and pronouncement of death for a child, as
 applicable, shall report the sudden cardiac event to the department
 on a form and in a manner prescribed by the commissioner.
 b. The report shall be in writing and shall include the name and

address of the health care professional submitting the report, the name, age, and address of the child, and other pertinent information as may be required by the commissioner **[**; except that, if the child's parent or guardian objects to the reporting of the child's condition for any reason, the report shall not include any information that could be used to identify the child**]**.

c. The commissioner shall specify procedures for the health requirements of subsections a. and b. of this section and the purpose served by including this information in the registry **[**, as well as the parent's or guardian's right to refuse to permit the reporting of any information that could be used to identify the child **]**.

<u>d. No information shall be reported to, or otherwise shared with,</u>
 <u>the Department of Health pursuant to this section, without first</u>
 <u>obtaining the express, informed, and written consent of the child's</u>
 <u>parent or legal guardian.</u>

23 (cf: P.L.2013, c.143, s.4)

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25 6. Section 4 of P.L.2004, c.138 (C.26:4-134) is amended to read
26 as follows:

4. a. There is established a Statewide automated and electronic
immunization registry, to be designated as the New Jersey
Immunization Information System, in the Department of Health.
The registry shall be designed to serve as a single repository of
immunization records to aid, coordinate, and help promote effective
and cost-efficient disease screening, prevention, and control efforts
in the State.

b. A newborn infant in New Jersey, who is born on or after January 1, 1998, shall be enrolled in the registry [immediately following birth unless the parent or legal guardian of the infant provides a written request to not participate in the registry] <u>only if</u> the express, informed, and written consent to enrollment in the registry is first obtained from the child's parent or legal guardian.

40 A child born prior to January 1, 1998 may be enrolled in the 41 registry at the parent's or legal guardian's written request.

c. Access to the information in the registry shall be limited to:
health care providers, schools, colleges, licensed child care centers,
and public agencies, and private organizations as determined by
regulation of the commissioner. A registrant, or the registrant's
parent or legal guardian if the registrant is a minor, shall have

access to the registrant's immunization and other preventive health
 screening information in the registry.

3 d. The information contained in the registry shall be used for4 the following purposes:

5 (1) to help ensure that registrants receive all recommended 6 immunizations in a timely manner by providing access to the 7 registrants' immunization records;

8 (2) to help improve immunization rates by providing notice to 9 registrants of overdue or upcoming immunizations; and

(3) to help control communicable diseases by assisting in the
identification of persons who require immediate immunization in
the event of a vaccine-preventable disease outbreak.

13 e. The authentic immunization and other preventive health 14 screening record of a child, which shall consist of a paper or 15 electronic copy of the registry entry that is a true and accurate representation of the information contained therein, obtained from 16 17 the registry shall be accepted as a valid immunization and 18 preventive health screening record of the registrant for the purpose 19 of meeting immunization and preventive health screening 20 documentation requirements for admission to a school, college, or 21 licensed child care center.

f. A health care provider shall not discriminate in any way
against a person solely because the person elects not to participate
in the registry.

g. An authorized user granted access as provided in subsection
c. of this section shall only access information in the registry on a
specific patient or client who is presently receiving services, is
under the user's care or is within the applicable governmental health
authority's jurisdiction.

h. An agency, organization, or other entity authorized to access
information in the registry shall not use any report made by a health
care provider pursuant to this act in any punitive manner against the
provider.

i. The commissioner, in consultation with the Public Health
Council, shall adopt rules and regulations, pursuant to the
"Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et
seq.), to effectuate the purposes of this act, including, but not
limited to:

(1) the establishment and maintenance of the registry;

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40 (2) the methods for submitting, and the content of, reports of
41 immunizations to the registry, for which purpose the commissioner
42 shall provide, to the maximum extent practicable, for reporting
43 options to facilitate compliance with the requirements of subsection
44 b. of this section;

(3) procedures for the birth hospital of a newborn infant or
health care provider, as applicable, to inform the parent or legal
guardian of a newborn infant or minor of the purpose of the registry

and its potential uses by parties having authorized access to registry 1 2 information, and the content of that information; 3 (4) procedures for a registrant, or the registrant's parent or legal 4 guardian if the registrant is a minor, to review and correct 5 information contained in the registry; (5) procedures for the parent or legal guardian of a newborn 6 7 infant or minor, or a person over 18 years of age, to request [to not 8 participate in the registry at any time and ] to remove or inactivate 9 information from the registry; 10 (6) limits on, and methods of, access to the registry by those authorized pursuant to subsection c. of this section; 11 12 (7) procedures for health insurers to obtain immunization 13 information from the registry concerning only their covered persons, as well as summary statistics, which information or 14 15 statistics shall not be used or disclosed for any other purpose than 16 to: 17 (a) improve patient care; 18 (b) provide quality assurance to employers purchasing group 19 coverage and to health care providers; (c) improve outreach and education efforts with respect to their 20 21 covered persons and health care providers; and 22 (d) monitor and improve quality of care standards as developed 23 professional organizations, accreditation agencies by and 24 government agencies in collaboration with the department; and 25 (8) procedures for the department to disseminate statistical information and supporting commentary. 26 27 (cf: P.L.2012, c.17, s.340) 28 29 7. Section 3 of P.L.1983, c.291 (C.26:8-40.22) is amended to 30 read as follows: 31 3. a. The Commissioner of Health, in consultation with the 32 Public Health Council, shall require the confidential reporting to the 33 Department of Health of all cases where an infant is diagnosed with severe hyperbilirubinemia, and where a pregnancy results in a 34 35 naturally aborted fetus or infant affected by a birth defect, and an 36 electively aborted fetus that exhibits or is known to have a birth 37 defect after 15 weeks of gestation. The reporting requirement shall 38 apply to all infants from birth through five years of age. b. The Commissioner of Health shall determine the health care 39 40 providers and facilities which shall be required to report all birth 41 defects and all cases of severe hyperbilirubinemia, the types of 42 conditions or defects that shall be reported, the type of information that shall be contained in the confidential report and the method for 43 44 making the report. In reports concerning all fetuses with anomalies, 45 the name of the mother shall not be submitted. 46 c. No information shall be reported to, or otherwise shared with, 47 the Department of Health pursuant to this section, without first

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obtaining the express, informed, and written consent of the child's 1 2 parent or legal guardian. 3 (cf: P.L.2012, c.17, s.352) 4 5 8. This act shall take effect immediately. 6 7 8 **STATEMENT** 9 This bill prohibits reporting medical information of children 10 without the consent of a parent or legal guardian. 11 12 The bill supplements Title 26 of the Revised Statutes to provide 13 that no information of a child is to be reported by a health care 14 provider to, or otherwise shared with, the Department of Health, or 15 any other local or State governmental employee or entity, without first obtaining the express, informed, and written consent of the 16 17 child's parent or legal guardian. However, the bill's provisions do 18 not prohibit reporting or sharing a child's information if a health 19 care provider has reasonable cause to believe that a child has been subjected to child abuse, including sexual abuse. 20 21 Further, the bill amends various statutes within Title 26 of the 22 Revised Statues regarding registries for autism, lead screening, birth 23 defects, hearing loss, severe neonatal jaundice, sudden cardiac 24 events, and vaccines, to provide that no information is to be 25 reported to the Department of Health without first obtaining the 26 express, informed, and written consent of the child's parent or legal 27 guardian.