

## CHAPTER 1687

### BIRTH DEFECTS PROGRAM

#### §8941. Birth Defects Program

There is established, within the Bureau of Health, the Birth Defects Program, referred to in this chapter as the "program," to identify and investigate birth defects in children. The program shall identify and research birth defects in children and maintain a central registry of cases of birth defects. [PL 1999, c. 344, §1 (NEW).]

**1. Duties.** The program shall collect, analyze and distribute information and undertake necessary research to identify the following with regard to birth defects: causes, risk factors and strategies for prevention and the provision of services. [PL 1999, c. 344, §1 (NEW).]

**2. Data collection.** The program shall establish systems for data collection that are medically recognized and scientific, that identify prevalence and incidence rates by region and population group and that identify the morbidity and mortality rates resulting from birth defects. [PL 1999, c. 344, §1 (NEW).]

**3. Submission of information.** Providers of health care licensed under this Title and Title 32 must make available to the program health care records and information relating to the occurrence of birth defects in the form and manner provided by the department. [PL 1999, c. 344, §1 (NEW).]

**4. Contact with families.** The department may contact families to provide information about available services. [PL 1999, c. 344, §1 (NEW).]

**5. Contracts.** The department may enter into contracts with nonprofit institutions and entities to perform its functions under this chapter. [PL 1999, c. 344, §1 (NEW).]

#### SECTION HISTORY

PL 1999, c. 344, §1 (NEW).

#### §8942. Investigations and inspections

The department may conduct investigations and inspections, including medical, demographic, environmental, epidemiological and toxicological investigations, of current or past cases of suspected birth defects in order to determine the nature and extent of disease or known or suspected causes of the birth defects, to improve access to services and to formulate and evaluate control measures to protect the public health. Persons requested to provide information and access to health care and other records for the purposes of an investigation or inspection under this section shall provide information and access. [PL 1999, c. 344, §1 (NEW).]

#### SECTION HISTORY

PL 1999, c. 344, §1 (NEW).

#### §8943. Central registry

The department shall establish and maintain a central registry for cases of birth defects to accomplish the purposes of this chapter and facilitate research on birth defects. The submission of information to and distribution of information from the central registry are subject to the requirements of this chapter and other provisions of law. Information that directly or indirectly identifies individual

persons contained within the registry is confidential and must be distributed from the registry in accordance with rules adopted by the department. The department shall adopt rules according to which it will in a timely fashion refer to the Child Development Services System children with confirmed birth defects who may be eligible for early intervention. The department and the Department of Education shall execute an interagency agreement to facilitate the referrals under this section. In accordance with the interagency agreement, the Department of Education shall offer a single point of contact for the Department of Health and Human Services to use in making referrals. Also in accordance with the interagency agreement, the Child Development Services System may make direct contact with the families who are referred. The referrals may take place electronically. For purposes of quality assurance and improvement, the Child Development Services System shall supply to the department aggregate data at least annually on the number of children referred under this section who were found eligible for early intervention services and on the number of children found not eligible for early intervention services. In addition, the department shall supply data at least annually to the Child Development Services System on how many children had data entered into the registry. For a child whose parent or legal guardian objects on the basis of sincerely held religious belief, the department may not require the reporting of information about that child to the central registry or enter into the central registry information regarding birth defects of that child. [PL 2007, c. 450, Pt. A, §9 (AMD).]

#### SECTION HISTORY

PL 1999, c. 344, §1 (NEW). PL 2007, c. 450, Pt. A, §9 (AMD).

#### §8944. Rules

The department shall adopt rules to implement this chapter. Rules adopted pursuant to this section are routine technical rules as defined by Title 5, chapter 375, subchapter II-A. [PL 1999, c. 344, §1 (NEW).]

#### SECTION HISTORY

PL 1999, c. 344, §1 (NEW).

#### §8945. Report

By the last business day of each year the department shall report to the joint standing committee of the Legislature having jurisdiction over health and human services matters regarding the operation of the program and the central registry. The report must include information on any findings and activities of the department with regard to birth defects and a summary of statistical information from the program and the central registry. The report may include recommendations from the department to improve the operation of the program and the central registry. [PL 1999, c. 344, §1 (NEW).]

#### SECTION HISTORY

PL 1999, c. 344, §1 (NEW).

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