

MAINE STATE LEGISLATURE

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119th MAINE LEGISLATURE

FIRST REGULAR SESSION-1999

Legislative Document

No. 1905

H.P. 1322

House of Representatives, March 16, 1999

An Act to Establish the Birth Defects Program.

Reference to the Committee on Health and Human Services suggested and ordered printed.

A handwritten signature in black ink that reads "Joseph W. Mayo".

JOSEPH W. MAYO, Clerk

Presented by Representative FULLER of Manchester.
Cosponsored by Senator MITCHELL of Penobscot and
Representatives: BRAGDON of Bangor, BULL of Freeport, DUPLESSIE of Westbrook,
KANE of Saco, MATTHEWS of Winslow, Senator: PARADIS of Aroostook.

2 **Be it enacted by the People of the State of Maine as follows:**

4 **Sec. 1. 22 MRSA c. 1687 is enacted to read:**

6 **CHAPTER 1687**

8 **BIRTH DEFECTS PROGRAM**

10 **§8941. Birth Defects Program**

12 There is established, within the Bureau of Health, the Birth
14 Defects Program, referred to in this chapter as the "program," to
16 identify and investigate birth defects in children. The program
18 shall identify and research birth defects in children and
20 maintain a central registry of cases of birth defects.

22 1. Duties. The program shall collect, analyze and
24 distribute information and undertake necessary research to
26 identify the following with regard to birth defects: causes, risk
28 factors and strategies for prevention and the provision of
30 services.

32 2. Data collection. The program shall establish systems
34 for data collection that are medically recognized and scientific,
36 that identify prevalence and incidence rates by region and
38 population group and that identify the morbidity and mortality
40 rates resulting from birth defects.

42 3. Submission of information. Providers of health care
44 licensed under this Title and Title 32 must make available to the
46 program health care records and information relating to the
48 occurrence of birth defects in the form and manner provided by
the department.

4. Contact with families. The department may contact
families to provide information about available services.

5. Contracts. The department may enter into contracts with
nonprofit institutions and entities to perform its functions
under this chapter.

42 **§8942. Investigations and inspections**

44 The department may conduct investigations and inspections,
46 including medical, demographic, environmental, epidemiological
48 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

2 evaluate control measures to protect the public health. Persons
3 requested to provide information and access to health care and
4 other records for the purposes of an investigation or inspection
5 under this section shall provide information and access.

6 **§8943. Central registry**

8 The department shall establish and maintain a central
9 registry for cases of birth defects to accomplish the purposes of
10 this chapter and facilitate research on birth defects. The
11 submission and distribution of information from the central
12 registry are subject to the requirements of this chapter and
13 other provisions of law. Information that directly or indirectly
14 identifies individual persons contained within the registry is
15 confidential and must be distributed from the registry in
16 accordance with rules adopted by the department.

18 **§8944. Rules**

20 The department shall adopt rules to implement this chapter.
21 Rules adopted pursuant to this section are routine technical
22 rules as defined by Title 5, chapter 375, subchapter II-A.

24 **§8945. Report**

26 By January 1st of each year the department shall report to
27 the joint standing committee of the Legislature having
28 jurisdiction over health and human services matters regarding the
29 operation of the program and the central registry. The report
30 must include information on any findings and activities of the
31 department with regard to birth defects and a summary of
32 statistical information from the program and the central
33 registry. The report may include recommendations from the
34 department to improve the operation of the program and the
35 central registry.

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SUMMARY

40 This bill establishes a program within the Department of
41 Human Services to identify and collect information on birth
42 defects. The program will undertake research, is authorized to
43 collect information, has access to health care records and
44 information and may provide information to families on available
45 services. The bill requires a report to the joint standing
46 committee of the Legislature having jurisdiction over health and
47 human services matters by January 1st of each year on the
48 operation of the program.