

1999 SENATE BILL 290

1 AN ACT *to amend* 146.82 (1) and 253.13 (2); *to repeal and recreate* 253.12; and
2 *to create* 15.197 (12) of the statutes; **relating to:** birth defects prevention
3 surveillance.

Analysis by the Legislative Reference Bureau

The people of the state of Wisconsin, represented in senate and assembly, do enact as follows:

4 **SECTION 1.** 15.197 (12) of the statutes is created to read:
5 15.197 (12) COUNCIL ON BIRTH DEFECT PREVENTION AND SURVEILLANCE. There is
6 created in the department of health and family services a council on birth defect
7 prevention and surveillance. The council shall consist of the following members
8 appointed for a 4-year term by the secretary of health and family services:
9 (a) A representative of the University of Wisconsin Medical School who has
10 technical expertise in birth defects epidemiology.

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1 (b) A representative from the Medical College of Wisconsin who has technical
2 expertise in birth defects epidemiology.

3 (bn) A pediatric nurse or a nurse with expertise in birth defects.

4 (c) A representative from the subunit of the department that is primarily
5 responsible for the children with special health needs program.

6 (d) A representative from the subunit of the department that is primarily
7 responsible for early intervention services.

8 (e) A representative from the subunit of the department that is primarily
9 responsible for health statistics research and analysis.

10 (f) A representative of the State Medical Society of Wisconsin.

11 (g) A representative of the Wisconsin Health and Hospital Association.

12 (h) A representative of the American Academy of Pediatrics — Wisconsin
13 Chapter.

14 (i) A representative of the council on developmental disabilities.

15 (j) A representative of a nonprofit organization that has as its primary purpose
16 the prevention of birth defects and does not promote abortion as a method of
17 prevention.

18 (k) A parent or guardian of a child with a birth defect.

19 (L) A representative of a local health department, as defined in s. 250.01 (4),
20 who is not an employe of the department of health and family services.

21 **SECTION 2.** 146.82 (1) of the statutes is amended to read:

22 146.82 (1) CONFIDENTIALITY. All patient health care records shall remain
23 confidential. Patient health care records may be released only to the persons
24 designated in this section or to other persons with the informed consent of the patient
25 or of a person authorized by the patient. This subsection does not prohibit reports

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1 made in compliance with s. 146.995, 253.12 (2) or 979.01 or testimony authorized
2 under s. 905.04 (4) (h).

3 **SECTION 3.** 253.12 of the statutes is repealed and recreated to read:

4 **253.12 Birth defect prevention and surveillance system. (1)**

5 DEFINITIONS. In this section:

6 (a) “Birth defect” means any of the following conditions affecting an infant or
7 child that occurs prior to or at birth and that requires medical or surgical
8 intervention or interferes with normal growth and development:

- 9 1. A structural deformation, disruption or dysplasia.
- 10 2. A genetic, inherited or biochemical disease.

11 (b) “Pediatric specialty clinic” means a clinic the primary purpose of which is
12 to provide pediatric specialty diagnostic, counseling and medical management
13 services to persons with birth defects by physician subspecialist.

14 (c) “Infant or child” means a human being from birth to the age of 2 years.

15 (d) “Physician” has the meaning given in s. 448.01 (5).

16 **(2) REPORTING.** (a) Except as provided in par. (b), all of the following shall report
17 in the manner prescribed by the department under sub. (3) (a) 3. a birth defect in an
18 infant or child:

- 19 1. A pediatric specialty clinic in which the birth defect is diagnosed in an infant
20 or child or treatment for the birth defect is provided to the infant or child.

- 21 2. A physician who diagnoses the birth defect or provides treatment to the
22 infant or child for the birth defect.

23 (am) Any hospital in which a birth defect is diagnosed in an infant or child or
24 treatment is provided to the infant or child may report the birth defect in the manner
25 prescribed by the department under sub. (3) (a) 3.

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1 (b) No person specified under par. (a) need report under par. (a) if that person
2 knows that another person specified under par. (a) or (am) has already reported to
3 the department the required information with respect to the same birth defect of the
4 same infant or child.

5 (c) If the department determines that there is a discrepancy in any data
6 reported under this subsection, the department may request a physician, hospital or
7 pediatric specialty clinic to provide to the department information contained in the
8 medical records of patients who have a confirmed or suspected birth defect diagnosis.
9 The physician, hospital or pediatric specialty clinic shall provide that information
10 within 10 working days after the department requests it.

11 (d) The department may not require a person specified under par. (a) 1. to 3.
12 to report the name of an infant or child for whom a report is made under par. (a) if
13 the parent or guardian of the infant or child refuses to consent in writing to the
14 release of the name or address of the infant or child.

15 (e) If the address of an infant or child for whom a report is made under par. (a)
16 is included in the report, the department shall encode the address to refer to the same
17 geographical location.

18 **(3) DEPARTMENT DUTIES AND POWERS.** (a) The department shall do all of the
19 following:

20 1. Establish and maintain an up-to-date registry that documents the
21 diagnosis in this state of any infant or child who has a birth defect, regardless of the
22 residence of the infant or child. The department shall include in the registry
23 information that will facilitate all of the following:

24 a. Identification of risk factors for birth defects.

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1 b. Investigation of the incidence, prevalence and trends of birth defects using
2 epidemiological surveys.

3 c. Development of primary preventive strategies to decrease the occurrence of
4 birth defects without increasing abortions.

5 d. Referrals for early intervention or other appropriate services.

6 2. Specify by rule the birth defects the existence of which requires a report
7 under sub. (2) to be submitted to the department.

8 3. Specify by rule the content, format and procedures for submitting a report
9 under sub. (2).

10 4. Notify the persons specified under sub. (2) (a) of their obligation to report.

11 (b) The department may monitor the data contained in the reports submitted
12 under sub. (2) to ensure the quality of that data and to make improvements in
13 reporting methods.

14 (c) The department shall, not more than 10 years from the date of receipt of a
15 report under sub. (2), delete from any file of the department the name of an infant
16 or child that is contained in the report.

17 **(4) COUNCIL ON BIRTH DEFECT PREVENTION AND SURVEILLANCE.** The council on
18 birth defect prevention and surveillance shall meet at least 4 times per year and shall
19 do all of the following:

20 (a) Make recommendations to the department regarding the establishment of
21 a registry that documents the diagnosis in the state of an infant or child who has a
22 birth defect, as required under sub. (3) (a) 1. and regarding the rules that the
23 department is required to promulgate under sub. (3) (a) 2. and 3. on the birth defects
24 to be reported under sub. (2) and on the general content and format of the report
25 under sub. (2) and procedures for submitting the report. The council shall also make

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1 recommendations regarding the content of a report that, because of the application
2 of sub. (2) (d), does not contain the name of the subject of the report.

3 (b) Coordinate with the early intervention interagency coordinating council to
4 facilitate the delivery of early intervention services to children from birth to 3 years
5 with developmental needs.

6 (c) Advise the secretary and make recommendations regarding the registry
7 established under sub. (3) (a) 1.

8 (d) Beginning April 1, 2002, and biennially thereafter, submit to the
9 appropriate standing committees under s. 13.172 (3) a report that details the
10 effectiveness, utilization and progress of the registry established under sub. (3) (a)
11 1.

12 **(5) CONFIDENTIALITY.** (a) Any information contained in a report made to the
13 department under sub. (2) that may specifically identify the subject of the report is
14 confidential. The department may not release that confidential information except
15 to the following, under the following conditions:

16 1. The parent or guardian of an infant or child for whom a report is made under
17 sub. (2).

18 2. A local health officer, a local birth-to-3 coordinator or an agency under
19 contract with the department to administer the children with special health care
20 needs program, upon receipt of a written request and informed written consent from
21 the parent or guardian of the infant or child. The local health officer may disclose
22 information received under this subdivision only to the extent necessary to render
23 and coordinate services and follow-up care for the infant or child or to conduct a
24 health, demographic or epidemiological investigation. The local health officer shall

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1 destroy all information received under this subdivision within one year after
2 receiving it.

3 3. A physician, hospital or pediatric specialty clinic reporting under sub. (2),
4 for the purpose of verification of information reported by the physician, hospital or
5 pediatric specialty clinic.

6 4. A representative of a federal or state agency upon written request and to the
7 extent that the information is necessary to perform a legally authorized function of
8 that agency, including investigation of causes, mortality, methods of prevention and
9 early intervention, treatment or care of birth defects, associated diseases or
10 disabilities. The information may not include the name or address of an infant or
11 child with a condition reported under sub. (2). The department shall notify the
12 parent or guardian of an infant or child about whom information is released under
13 this subdivision, of the release. The representative of the federal or state agency may
14 disclose information received under this paragraph only as necessary to perform the
15 legally authorized function of that agency for which the information was requested.

16 (b) The department may also release confidential information to a person
17 proposing to conduct research if all of the following conditions are met:

18 1. The person proposing to conduct the research applies in writing to the
19 department for approval to perform the research and the department approves the
20 application. The application for approval shall include a written protocol for the
21 proposed research, the person's professional qualifications to perform the proposed
22 research and any other information requested by the department.

23 2. The research is for the purpose of studying birth defects surveillance and
24 prevention.

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1 3. If the research will involve direct contact with a subject of a report made
2 under sub. (2) or with any member of the subject's family, the department determines
3 that the contact is necessary for meeting the research objectives and that the
4 research is in response to a public health need or is for the purpose of or in connection
5 with birth defects surveillance or investigations sponsored and conducted by public
6 health officials. The department must also determine that the research has been
7 approved by a certified institutional review board or a committee for the protection
8 of human subjects in accordance with the regulations for research involving human
9 subjects required by the federal department of health and human services for
10 projects supported by that agency. Contact may only be made with the written
11 informed consent of the parent or guardian of the subject of the report and in a
12 manner and method approved by the department.

13 4. The person agrees in writing that the information provided will be used only
14 for the research approved by the department.

15 5. The person agrees in writing that the information provided will not be
16 released to any person except other persons involved in the research.

17 6. The person agrees in writing that the final product of the research will not
18 reveal information that may specifically identify the subject of a report made under
19 sub. (2).

20 7. The person agrees in writing to any other conditions imposed by the
21 department.

22 **(6) INFORMATION NOT ADMISSIBLE.** Information collected under this section is not
23 admissible as evidence during the course of a civil or criminal action or proceeding
24 or an administrative proceeding, except for the purpose of enforcing this section.

SECTION 5. Nonstatutory provisions.

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1 (1) COUNCIL ON BIRTH DEFECT PREVENTION AND SURVEILLANCE. Notwithstanding
2 section 15.197 (12) of the statutes, as created by this act, the initial terms of 4 of the
3 members appointed under section 15.197 (12) of the statutes, as created by this act,
4 expire on July 1, 2002; the initial terms of 5 of the members appointed under section
5 15.197 (12) of the statutes, as created by this act, expire on July 1, 2004; and the
6 initial terms of 4 of the members appointed under section 15.197 (12) of the statutes,
7 as created by this act, expire on July 1, 2006.

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(END)