AN ACT to create 146.028 of the statutes, relating to establishing a birth and developmental outcome monitoring program and granting rule-making authority.

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

SECTION 1. Legislative intent. The legislature recognizes that the occurrence of an adverse neonatal outcome, a birth defect or a developmental disability or other severe disability is a matter of public concern for the child, the family and the community. In order to address these concerns and promote the health of the citizens of the state, the legislature finds that a birth and developmental outcome monitoring program within the department of health and social services for compiling information and statistics on adverse neonatal outcomes, birth defects, developmental disabilities and other severe disabilities is necessary.

SECTION 2. 146.028 of the statutes is created to read:

146.028 Birth and developmental outcome monitoring program. (1) Definitions. In this section:

(a) “Adverse neonatal outcome” means one of the following resulting to an infant at birth or in the first month following birth:

1. Birth weight of less than 2,500 grams.
2. A condition of a chronic nature, including central nervous system hemorrhage or infection of the central nervous system, which may result in a need for long-term care.
3. An apgar score of 3 or less at 5 minutes following birth.

(b) “Apgar score” means a numerical expression of the condition of a newborn infant which is the sum of points achieved after assessing the infant’s heart rate, respiratory effort, muscle tone, reflex irritability and color.

(c) “Birth defect” means one or more of the following conditions resulting to an infant or child:

1. A structural deformation.
2. A developmental malformation.
3. A genetic, inherited or biochemical disease.

(d) “Developmental disability” has the meaning specified under s. 51.01 (5) (a).

(e) “Infant or child” means a human from birth to the age of 6 years.

(f) “Local health officer” has the meaning specified under s. 143.01.

(g) “Other severe disability” means a severe sensory impairment, severe physical handicap or developmental delay that results from injury, infection or disease, is chronic in nature and requires long-term care.

(2) Reporting. (a) Beginning on January 1, 1989, the persons specified in par. (b) shall report all of the following to the department:

1. The appearance of the condition, within 60 days after a suspected or confirmed diagnosis.
2. Information which disputes, augments or clarifies the suspected or confirmed diagnosis under subd. 1, within 60 days after receipt of the information.

(b) The persons required to report under par. (a) are the following:

1. A physician licensed under ch. 448 who is the primary treating physician for an infant or child treated or visited by the physician and who makes a diagnosis or suspects with reasonable medical certainty that the infant or child has a condition resulting from an adverse neonatal outcome, a birth defect or a developmental disability or other severe disability.

2. If no physician licensed under ch. 448 has treated an infant or child, a nurse registered, permitted or licensed under ch. 441 who knows or suspects with reasonable medical certainty that an infant or child visited by the nurse has a condition resulting from an adverse neonatal outcome, a birth defect or a developmental disability or other severe disability.

(3) Departmental powers and duties. From the appropriations under s. 20.435 (1) (md) and (8) (n), the department shall perform all of the following for the program under this section:

(a) Develop and implement a system for the collection, updating and analysis of information reported under sub. (2), including the publication and distribution of report forms.

(b) Disseminate data and information, publish an annual report, submit the report annually to the chief clerk of each house of the legislature for distribution to the appropriate standing committees under s. 13.172 (3) and provide county-specific information to counties in this state on the results of information collected under sub. (2).

(c) Coordinate data dissemination activities of the department with those of the division for handicapped children and pupil services in the department of public instruction with respect to the information collected under sub. (2).
(4) **Rule-making authority.** (a) The department, following consultation with the early intervention interagency coordinating council, shall promulgate rules:

1. To define a condition requiring report under sub. (2).
2. To determine form content and format and procedures necessary for submittal to the department of a report under sub. (2).

(b) The department may promulgate rules specifying the types of information and the conditions under which that information may be released under sub. (5) (a).

(5) **Confidentiality.** (a) The department may not release information specifically identifying an infant or child that is obtained from reports under sub. (2), except the following, under the following conditions:

1. To the parent or guardian of an infant or child for whom a report is made under sub. (2), upon receipt of a written request from the parent or guardian.
2. To a local health officer, under sub. (6).
3. To the division of handicapped children and pupil services of the department of public instruction, upon request, the name and address of an infant or child for whom a report is made under sub. (2) and other information necessary to aid the division in providing services to the infant or child. The department shall notify the parent or guardian of an infant or child about whom information is released under this subdivision, of the release. The division of handicapped children and pupil services of the department of public instruction may disclose information received under this paragraph only as necessary to provide services to the infant or child.
4. To a physician or nurse reporting under sub. (2), for the purpose of verification of information reported by the physician or nurse.
5. To a representative of a federal or state agency, upon written request, information necessary to perform a legally authorized function of that agency, including investigation of causes, mortality, methods of prevention, treatment or care of birth defects, associated diseases or disabilities, except that the information may not include the name or address of an infant or child with a condition reported under sub. (2). The department shall notify the parent or guardian of an infant or child about whom information is released under this subdivision, of the release. The representative of the federal or state agency may disclose information received under this paragraph only as necessary to perform the legally authorized function of that agency for which the information was requested.
6. To any person who has the informed, written consent of the parent or guardian of an infant or child with a condition reported under sub. (2), any information concerning that infant or child, solely for the purpose of research in accordance with rules promulgated by the department.

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

(6) **Local health officer access to information.**

(a) If a local health officer submits to the department a written request for receipt of information submitted under sub. (2), the department shall forward to the public health officer, no later than the 10th day of the month following receipt of information under sub. (2), an abstract of information received for an infant or child for whom the parent or guardian has provided informed, written consent to a release of the information and who resides in the area of jurisdiction of the public health officer.

(b) The local health officer may disclose information in the abstract under par. (a) only as necessary to aid that local health officer in rendering or coordinating follow-up care for the infant or child or for conducting a health, demographic or epidemiologic investigation. The local health officer shall destroy all information obtained under par. (a) no later than 365 days after he or she receives it, except that this requirement does not apply to information, including individual medical records, obtained by the local health officer subsequent to his or her receipt of information under par. (a).

(c) The written request submitted under par. (a) is invalid after December 31 of the year in which the department receives it.

(7) **Exception.** Nothing in this section authorizes or requires the administration of a physical examination or medical care or treatment to an infant or child if the parent or legal guardian of the infant or child objects on the ground that the examination or care or treatment conflicts with his or her religious tenets or practices.

(8) **Admissibility of information as evidence.** Information collected under this section is not admissible as evidence in any legal action or proceeding before any court, tribunal, board, agency, person or for the purpose of determining insurability, except for the purpose of enforcing this section.

**SECTION 3. Nonstatutory provisions.**

1. **Birth and developmental outcome monitoring rules.** The department of health and social services shall submit in proposed form the rules required under section 146.028 (4) (a) of the statutes to the legislative council under section 227.15 (1) of the statutes no later than the first day of the 6th month beginning after the effective date of this subsection.

2. **Position authorizations.** The authorized FTE positions for the department of health and social services are increased by 4.0 FED project positions on the effective date of this subsection, to be funded from the appropriation under section 20.435 (8) (n) of the statutes, for the period ending on November 1, 1991, for the purpose of administration of the program created by this act.
SECTION 4. **Program responsibility changes.** In the sections of the statutes listed in Column A, the program responsibilities references shown in Column B are deleted and the program responsibilities references shown in Column C are inserted:

<table>
<thead>
<tr>
<th>Statute Sections</th>
<th>References Deleted</th>
<th>References Inserted</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.371 (2)</td>
<td>none</td>
<td>146.028 (3)(c)</td>
</tr>
</tbody>
</table>

SECTION 5. **Effective dates.** This act takes effect on January 1, 1989, except as follows:

(1) The treatment of section 146.028 (4) (a) of the statutes and **SECTION 3** of this act take effect on the day after publication.