



**ASSEMBLY SUBSTITUTE AMENDMENT 3,
TO 2007 ASSEMBLY BILL 185**

February 25, 2008 – Offered by Representative TOWNSEND.

1 **AN ACT** *to renumber and amend* 253.12 (1) (b); *to amend* 69.03 (12), 69.20 (2)
2 (a) (intro.), 69.20 (3) (b) 3., 69.20 (3) (c), 69.20 (3) (d), 253.12 (1) (a) (intro.),
3 253.12 (1) (a) 1., 253.12 (2) (a) (intro.), 253.12 (2) (am), 253.12 (2) (b), 253.12 (2)
4 (d), 253.12 (2) (e), 253.12 (3) (a) 1. (intro.), 253.12 (3) (c), 253.12 (4) (a), 253.12
5 (5) (a) 1. and 253.12 (5) (a) 4.; and *to create* 69.20 (2) (a) 3., 253.12 (1) (e), 253.12
6 (2) (a) 3., 253.12 (2) (a) 4. and 253.12 (5) (b) 5m. of the statutes; **relating to:** the
7 birth defect prevention and surveillance system.

Analysis by the Legislative Reference Bureau

Under the birth defect prevention and surveillance system (system) in current law, pediatric specialty clinics and physicians are required to report to the Department of Health and Family Services (DHFS) any birth defects of infants or children who are diagnosed or treated in the clinics or by the physicians. A “birth defect” is defined as a structural deformation, disruption, or dysplasia or a genetic, inherited, or biochemical disease that occurs prior to or at birth and that requires medical or surgical intervention or interferes with normal growth and development. An “infant or child” is defined as a human being from birth to the age of two years.

DHFS may not require a pediatric specialty clinic or physician to report the name of a reported infant or child if the parent or guardian of the infant or child refuses in writing to consent to the release of the name or address of the infant or child.

Currently, information that is contained in a vital record and is designated as being collected for statistical and medical use or statistical use only or that involves the birth of a child to an unmarried mother may be disclosed only in certain instances. One instance is disclosure of this information, under an interstate cooperation agreement, from the vital record of the resident of another state or a resident of this state born in another state, for use by the state registrar in compiling statistics. Another instance is disclosure of statistical or medical information for use in the conduct of official duties of a federal agency, a Wisconsin governmental agency, or the agency of a county, city, town, or village. In addition, hospitals and funeral directors must provide and the state registrar must accept reports of certain fetal deaths. Before destroying these reports, the state registrar may record the reports' information for use in medical research and use the information to compile statistics.

Also under current law, DHFS may release confidential information that identifies the subject of a birth defect to a person proposing to conduct research if DHFS approves the person's application to conduct the research, the research is to study birth defects surveillance and prevention, DHFS determines that any direct contact with a family meets certain requirements, and the person agrees in writing to certain requirements.

Lastly, under current law, DHFS must establish and maintain an up-to-date registry that documents the diagnosis in this state of any infant or child who has a birth defect. Among the information that DHFS is required to include in the registry is information that will facilitate the development of primary preventive strategies to decrease the occurrence of birth defects without increasing abortions.

This substitute amendment includes stillbirths, as defined in the substitute amendment, under the requirements of the system and expands the definition of "birth defect" to include structural malformations.

The substitute amendment requires the division of DHFS that deals with vital statistics to report to the system, for use in the registry, information that is contained in a vital record and is designated as being collected for statistical and medical use or statistical use only, including this type of information that is available under an interstate cooperation agreement, if this disclosure is agreed to by the other state. However, if this information is not confirmed by another reporting entity, DHFS must, before releasing the information to anyone who is proposing to conduct research, remove from the registry all information that would identify the stillbirth, infant, or child other than the address of the infant or child or place of delivery of the stillbirth that DHFS has encoded to refer to the same geographical location. In addition, the substitute amendment requires the entity that contracts with the Department of Administration for collecting, analyzing, and disseminating health care information of hospitals and ambulatory surgery centers to report to the system concerning birth defects as recorded in public use data files of hospitals and ambulatory surgery centers.

The substitute amendment also requires that a person who is proposing to conduct research, to whom DHFS releases certain confidential birth defect information, agree in writing that the information will not be used by an insurer to limit or deny health care coverage or a policy of life insurance to an individual.

Lastly, the substitute amendment permits the state registrar to record information from reports of certain fetal deaths for use in research conducted under the system.

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

1 **SECTION 1.** 69.03 (12) of the statutes is amended to read:

2 69.03 (12) Accept fetal death reports under s. 69.18 (1) (e). The state registrar
3 may record the information on the reports for use in medical research, including
4 research conducted under s. 253.12 (5) (b), and may use the information to compile
5 statistics. After recording the information on a fetal death report, the state registrar
6 shall destroy the report.

7 **SECTION 2.** 69.20 (2) (a) (intro.) of the statutes is amended to read:

8 69.20 (2) (a) (intro.) ~~Except as provided under sub. (3), information~~ Information
9 in the part of a certificate of birth or divorce or annulment or a marriage document
10 that is designated on the form as being collected for statistical or medical and
11 statistical use only and information in the part of a death certificate that is
12 designated on the form as being collected as statistical-use-only information under
13 s. 69.18 (1m) (c) may not be disclosed to any person except the following:

14 **SECTION 3.** 69.20 (2) (a) 3. of the statutes is created to read:

15 69.20 (2) (a) 3. As provided under sub. (3).

16 **SECTION 4.** 69.20 (3) (b) 3. of the statutes is amended to read:

17 69.20 (3) (b) 3. The information is from the vital record of a registrant who is
18 a resident of another state or who was born in another state and is transmitted to

1 the office responsible for keeping the vital statistics in such state under an interstate
2 cooperation agreement which requires that the information be used for statistical
3 and administrative purposes only and which provides for the retention and
4 disposition of such copies. If under such an agreement the state registrar receives
5 information from an office responsible for keeping the vital statistics in another
6 state, the state registrar may not use the information for any purpose except for the
7 compilation of statistics and, if agreed to by the other state, in meeting requirements
8 for reporting under s. 253.12 (2) (a) 3.

9 **SECTION 5.** 69.20 (3) (c) of the statutes is amended to read:

10 69.20 (3) (c) ~~Notwithstanding sub. (2), a~~ A local registrar may disclose
11 information on a birth certificate or issue a copy of the certificate to a local health
12 department, as defined in s. 250.01 (4), for health or demographic research or a public
13 health program if the local health department pays the copying costs and if the birth
14 of the registrant occurred within the boundaries of the political subdivision served
15 by the local health department or the registrant is a resident of the political
16 subdivision. The local health department may not disclose any information from any
17 copy which it receives under this paragraph to any person and shall destroy the copy
18 no later than one year after receipt.

19 **SECTION 6.** 69.20 (3) (d) of the statutes is amended to read:

20 69.20 (3) (d) Subject to par. (f), the state or a local registrar may disclose
21 information from the vital record of a specified registrant, ~~except information under~~
22 ~~sub. (2) (a),~~ to a federal agency, to any agency of the government of this state, or to
23 any agency of a county, city, town, or village if the agency requests the information
24 for use in the conduct of its official duties.

25 **SECTION 7.** 253.12 (1) (a) (intro.) of the statutes is amended to read:

1 253.12 (1) (a) (intro.) “Birth defect” means any of the following conditions
2 affecting a stillbirth or an infant or child that occurs prior to or at birth and that
3 requires medical or surgical intervention or interferes with normal growth and
4 development:

5 **SECTION 8.** 253.12 (1) (a) 1. of the statutes is amended to read:

6 253.12 (1) (a) 1. A structural malformation, deformation, disruption, or
7 dysplasia.

8 **SECTION 9.** 253.12 (1) (b) of the statutes is renumbered 253.12 (1) (cm) and
9 amended to read:

10 253.12 (1) (cm) “Pediatric specialty clinic” means a clinic that is located in a
11 hospital or is a freestanding clinic, the primary purpose of which is to provide
12 pediatric specialty diagnostic, counseling and medical management services to
13 persons with birth defects by a physician subspecialist.

14 **SECTION 10.** 253.12 (1) (e) of the statutes is created to read:

15 253.12 (1) (e) “Research” means a systematic study through scientific inquiry
16 for the purpose of expanding a field of knowledge, including environmental or
17 epidemiological research or special studies.

18 **SECTION 11.** 253.12 (2) (a) (intro.) of the statutes is amended to read:

19 253.12 (2) (a) (intro.) Except as provided in par. (b), all of the following shall
20 report in the manner prescribed by the department under sub. (3) (a) 3. a birth defect
21 in a stillbirth or an infant or child:

22 **SECTION 12.** 253.12 (2) (a) 3. of the statutes is created to read:

23 253.12 (2) (a) 3. The division of the department that deals with vital statistics,
24 with respect to the information received under s. 69.20 (3) (b) 3. or available under
25 s. 69.20 (3) (d). If a report is made under this subdivision and the report is not

1 confirmed by a report made by another reporting entity, the department shall remove
2 from the registry under sub. (3) all information that would identify the stillbirth,
3 infant, or child before releasing the information to another party under sub. (5) (b),
4 other than the address of the infant or child or place of delivery of the stillbirth that
5 the department has encoded to refer to the same geographical location.

6 **SECTION 13.** 253.12 (2) (a) 4. of the statutes is created to read:

7 253.12 (2) (a) 4. The entity under contract under s. 153.05 (2m) (a), with respect
8 to public use data files under s. 153.46 (1) (b).

9 **SECTION 14.** 253.12 (2) (am) of the statutes is amended to read:

10 253.12 (2) (am) Any hospital in which a birth defect is diagnosed in a stillbirth
11 or an infant or child or treatment is provided to the infant or child may report the
12 birth defect in the manner prescribed by the department under sub. (3) (a) 3.

13 **SECTION 15.** 253.12 (2) (b) of the statutes is amended to read:

14 253.12 (2) (b) No person specified under par. (a) need report under par. (a) if
15 that person knows that another person specified under par. (a) or (am) has already
16 reported to the department the required information with respect to the same birth
17 defect of the same stillbirth or infant or child.

18 **SECTION 16.** 253.12 (2) (d) of the statutes is amended to read:

19 253.12 (2) (d) The department may not require a person specified under par.
20 (a) 1. ~~or~~ 2., or 3. to report the name of an infant or child for whom a report is made
21 under par. (a) if the parent or guardian of the infant or child refuses to consent in
22 writing to the release of the name or address of the infant or child.

23 **SECTION 17.** 253.12 (2) (e) of the statutes is amended to read:

1 253.12 (2) (e) If the address of an infant or child or the place of delivery of a
2 stillbirth for whom a report is made under par. (a) is included in the report, the
3 department shall encode the address to refer to the same geographical location.

4 **SECTION 18.** 253.12 (3) (a) 1. (intro.) of the statutes is amended to read:

5 253.12 (3) (a) 1. (intro.) Establish and maintain an up-to-date registry that
6 documents the diagnosis in this state of any stillbirth or infant or child who has a
7 birth defect, regardless of the residence of the infant or child or place of delivery of
8 the stillbirth. The department shall include in the registry information that will
9 facilitate all of the following:

10 **SECTION 19.** 253.12 (3) (c) of the statutes is amended to read:

11 253.12 (3) (c) The department shall, not more than 10 years from the date of
12 receipt of a report under sub. (2), delete from any file of the department the name of
13 a stillbirth or an infant or child that is contained in the report.

14 **SECTION 20.** 253.12 (4) (a) of the statutes is amended to read:

15 253.12 (4) (a) Make recommendations to the department regarding the
16 establishment of a registry that documents the diagnosis in the state of a stillbirth
17 or an infant or child who has a birth defect, as required under sub. (3) (a) 1. and
18 regarding the rules that the department is required to promulgate under sub. (3) (a)
19 2. and 3. on the birth defects to be reported under sub. (2) and on the general content
20 and format of the report under sub. (2) and procedures for submitting the report. The
21 council shall also make recommendations regarding the content of a report that,
22 because of the application of sub. (2) (d), does not contain the name of the subject of
23 the report.

24 **SECTION 21.** 253.12 (5) (a) 1. of the statutes is amended to read:

