

2007 DRAFTING REQUEST

Assembly Substitute Amendment (ASA-AB185)

Received: 02/19/2008

Received By: dkennedy

Wanted: As time permits

Identical to LRB:

For: John Townsend (608) 266-3156

By/Representing: Minette Lawrence

This file may be shown to any legislator: NO

Drafter: dkennedy

May Contact:

Addl. Drafters:

Subject: Health - public health

Extra Copies:

Submit via email: YES

Requester's email: Rep.Townsend@legis.wisconsin.gov

Carbon copy (CC:) to: robin.ryan@legis.wisconsin.gov

Pre Topic:

No specific pre topic given

Topic:

No specific topic given

Instructions:

See Attached

Drafting History:

<u>Vers.</u>	<u>Drafted</u>	<u>Reviewed</u>	<u>Typed</u>	<u>Proofed</u>	<u>Submitted</u>	<u>Jacketed</u>	<u>Required</u>
/?	dkennedy 02/19/2008	jdyer 02/20/2008		_____			
/1			jfrantze 02/20/2008	_____	cduerst 02/20/2008	cduerst 02/20/2008	

FE Sent For:

<END>

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Topic:

Birth defect prevention and surveillance system

Instructions:

See Attached

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/?	dkennedy	1 2/19 jld	to 9/20	dkennedy 2/20			

FE Sent For:

<END>

LRB
 ~

Fiscal Estimate - 2007 Session

Original Updated Corrected Supplemental

LRB Number 07-0947/1	Introduction Number AB-0185
Description The birth defect prevention and surveillance system	
Fiscal Effect	
State:	
<input type="checkbox"/> No State Fiscal Effect <input type="checkbox"/> Indeterminate <input type="checkbox"/> Increase Existing Appropriations <input type="checkbox"/> Increase Existing Revenues <input type="checkbox"/> Decrease Existing Appropriations <input type="checkbox"/> Decrease Existing Revenues <input type="checkbox"/> Create New Appropriations	
<input checked="" type="checkbox"/> Increase Costs - May be possible to absorb within agency's budget <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> Decrease Costs	
Local:	
<input checked="" type="checkbox"/> No Local Government Costs <input type="checkbox"/> Indeterminate	
1. <input type="checkbox"/> Increase Costs 3. <input type="checkbox"/> Increase Revenue <input type="checkbox"/> Permissive <input type="checkbox"/> Mandatory <input type="checkbox"/> Permissive <input type="checkbox"/> Mandatory 2. <input type="checkbox"/> Decrease Costs 4. <input type="checkbox"/> Decrease Revenue <input type="checkbox"/> Permissive <input type="checkbox"/> Mandatory <input type="checkbox"/> Permissive <input type="checkbox"/> Mandatory	
5. Types of Local Government Units Affected <input type="checkbox"/> Towns <input type="checkbox"/> Village <input type="checkbox"/> Cities <input type="checkbox"/> Counties <input type="checkbox"/> Others <input type="checkbox"/> School Districts <input type="checkbox"/> WTCS Districts	
Fund Sources Affected	
<input type="checkbox"/> GPR <input type="checkbox"/> FED <input type="checkbox"/> PRO <input type="checkbox"/> PRS <input type="checkbox"/> SEG <input type="checkbox"/> SEGS	
Affected Ch. 20 Appropriations	
Agency/Prepared By	Authorized Signature
DHFS/ Ellen Hadidian (608) 266-8155	Andy Forsaith (608) 266-7684
	Date
	3/30/2007

2/19/08 From Minette: Remove language that is referred to in Fiscal Estimate as costing DHFS \$.

✓

Fiscal Estimate Narratives

DHFS 3/30/2007

LRB Number	07-0947/1	Introduction Number	AB-0185	Estimate Type	Original
Description The birth defect prevention and surveillance system					

Assumptions Used in Arriving at Fiscal Estimate

This bill makes several changes to state law regarding the definition of birth defects and the way in which birth defects of infants or children are reported to the Department's birth defect prevention and surveillance system.

This bill changes the process by which an infant or child's parent may decide not to consent to the release of that child's identifying information. The bill requires the Department, by July 1, 2009, to prescribe and distribute to pediatric specialty clinics and local health departments copies of a form that is to be used by a parent or guardian who decides to refuse to consent to the release of a identifying information about the child or to remove information from the birth defect system. The Department is required to remove this information from the system when the form requesting this action is received.

This provision would result in an increased workload which could not be absorbed. An additional 1.0 FTE Program and Planning Analyst would be needed to carry out the provisions of this bill. The position would have to develop and send out the new form, review forms that are returned, periodically review with providers the use of the form, and ensure that information is removed from the system as required by the form. The cost of an additional staff person would be \$64,500 GPR annually. Costs for printing and distributing the form would be \$500 GPR annually. Total costs of this bill to the Department are estimated to be \$65,000 annually.

Long-Range Fiscal Implications

Fiscal Estimate Worksheet - 2007 Session

Detailed Estimate of Annual Fiscal Effect

Original
 Updated
 Corrected
 Supplemental

LRB Number 07-0947/1		Introduction Number AB-0185	
Description The birth defect prevention and surveillance system			
I. One-time Costs or Revenue Impacts for State and/or Local Government (do not include in annualized fiscal effect):			
II. Annualized Costs:		Annualized Fiscal Impact on funds from:	
		Increased Costs	Decreased Costs
A. State Costs by Category			
State Operations - Salaries and Fringes	\$61,500		\$
(FTE Position Changes)	(1.0 FTE)		
State Operations - Other Costs	3,500		
Local Assistance			
Aids to Individuals or Organizations			
TOTAL State Costs by Category	\$65,000		\$
B. State Costs by Source of Funds			
GPR	65,000		
FED			
PRO/PRS			
SEG/SEG-S			
III. State Revenues - Complete this only when proposal will increase or decrease state revenues (e.g., tax increase, decrease in license fee, etc.)			
	Increased Rev	Decreased Rev	
GPR Taxes	\$	\$	
GPR Earned			
FED			
PRO/PRS			
SEG/SEG-S			
TOTAL State Revenues	\$	\$	
NET ANNUALIZED FISCAL IMPACT			
	State	Local	
NET CHANGE IN COSTS	\$65,000	\$	
NET CHANGE IN REVENUE	\$	\$	
Agency/Prepared By Authorized Signature Date			
DHFS/ Ellen Hadidian (608) 266-8155		Andy Forsaith (608) 266-7684	3/30/2007

MINETTE,

PLEASE GIVE

ME A CALL.

608-310-8833

OR 608-234-2940

THANKS, MIKE

**ASSEMBLY SUBSTITUTE AMENDMENT 2,
TO 2007 ASSEMBLY BILL 185**

*includes
amendment
to
AB 185*

September 6, 2007 - 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 **(e), 253.12 (3) (a) 1. (intro.), 253.12 (3) (c), 253.12 (4) (a), 253.12 (5) (a) 1., 253.12**
5 **(5) (a) 2. and 253.12 (5) (a) 4.; to repeal and recreate 253.12 (2) (d); and to**
6 **create 69.20 (2) (a) 3., 253.12 (1) (e), 253.12 (2) (a) 3., 253.12 (2) (a) 4., 253.12**
7 **(5) (b) 5m., 253.12 (5) (c) and 253.12 (5m) of the statutes; relating to: the birth**
8 **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 changes the process by which the parent or guardian of a stillbirth, infant, or child may decide not to consent to the release of the stillbirth’s, infant’s, or child’s identifying information, to require that a physician or physician’s designee first inform the parent or guardian of the intent of the system and to require signature of the parent or guardian on a DHFS form. Further, the substitute amendment specifies a process by which, using the DHFS form, the parent or guardian of a stillbirth, infant, or child may effect withdrawal of consent to the release of identifying information about the stillbirth, infant, or child, and requires that, if consent to the release is withdrawn, DHFS remove the information from the system. DHFS must prescribe and periodically distribute to pediatric specialty clinics, hospitals in which deliveries are performed, and local health departments the form for these purposes, beginning July 1, 2009.~~

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 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.

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

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

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

1 designated on the form as being collected as statistical–use–only information under
2 s. 69.18 (1m) (c) may not be disclosed to any person except the following:

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

4 69.20 (2) (a) 3. As provided under sub. (3).

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

6 69.20 (3) (b) 3. The information is from the vital record of a registrant who is
7 a resident of another state or who was born in another state and is transmitted to
8 the office responsible for keeping the vital statistics in such state under an interstate
9 cooperation agreement which requires that the information be used for statistical
10 and administrative purposes only and which provides for the retention and
11 disposition of such copies. If under such an agreement the state registrar receives
12 information from an office responsible for keeping the vital statistics in another
13 state, the state registrar may not use the information for any purpose except for the
14 compilation of statistics and, if agreed to by the other state, in meeting requirements
15 for reporting under s. 253.12 (2) (a) 3.

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

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

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

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

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

8 253.12 (1) (a) (intro.) “Birth defect” means any of the following conditions
9 affecting a stillbirth or an infant or child that occurs prior to or at birth and that
10 requires medical or surgical intervention or interferes with normal growth and
11 development:

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

13 253.12 (1) (a) 1. A structural malformation, deformation, disruption, or
14 dysplasia.

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

17 253.12 (1) (cm) “Pediatric specialty clinic” means a clinic that is located in a
18 hospital or is a freestanding clinic, the primary purpose of which is to provide
19 pediatric specialty diagnostic, counseling and medical management services to
20 persons with birth defects by a physician subspecialist.

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

22 253.12 (1) (e) “Research” means a systematic study through scientific inquiry
23 for the purpose of expanding a field of knowledge, including environmental or
24 epidemiological research or special studies.

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

1 253.12 (2) (a) (intro.) Except as provided in par. (b), all of the following shall
2 report in the manner prescribed by the department under sub. (3) (a) 3. a birth defect
3 in a stillbirth or an infant or child:

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

5 253.12 (2) (a) 3. The division of the department that deals with vital statistics,
6 with respect to the information received under s. 69.20 (3) (b) 3. or available under
7 s. 69.20 (3) (d). If a report is made under this subdivision and the report is not
8 confirmed by a report made by another reporting entity, the department shall remove
9 from the registry under sub. (3) all information that would identify the stillbirth,
10 infant, or child before releasing the information to another party under sub. (5) (b),
11 other than the address of the infant or child or place of delivery of the stillbirth that
12 the department has encoded to refer to the same geographical location.

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

14 253.12 (2) (a) 4. The entity under contract under s. 153.05 (2m) (a), with respect
15 to public use data files under s. 153.46 (1) (b).

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

17 253.12 (2) (am) Any hospital in which a birth defect is diagnosed in a stillbirth
18 or an infant or child or treatment is provided to the infant or child may report the
19 birth defect in the manner prescribed by the department under sub. (3) (a) 3.

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

21 253.12 (2) (b) No person specified under par. (a) need report under par. (a) if
22 that person knows that another person specified under par. (a) or (am) has already
23 reported to the department the required information with respect to the same birth
24 defect of the same stillbirth or infant or child.

25 ~~**SECTION 16.** 253.12 (2) (d) of the statutes is repealed and recreated to read:~~

1 ~~253.12 (2) (d) If the parent or guardian of a stillbirth or an infant or child for~~
2 ~~whom a report is made under par. (a) decides, after having been informed by a~~
3 ~~physician or a physician's designee of the intent of the system under this section, not~~
4 ~~to consent to the release of identifying information concerning the stillbirth or infant~~
5 ~~or child and signs the form specified in sub. (5) (c), the department may not require~~
6 ~~a person specified under par. (a) 1., 2., or 3. to report information identifying the~~
7 ~~stillbirth or infant or child.~~

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

9 253.12 (2) (e) If the address of an infant or child or the place of delivery of a
10 stillbirth for whom a report is made under par. (a) is included in the report, the
11 department shall encode the address to refer to the same geographical location.

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

13 253.12 (3) (a) 1. (intro.) Establish and maintain an up-to-date registry that
14 documents the diagnosis in this state of any stillbirth or infant or child who has a
15 birth defect, regardless of the residence of the infant or child or place of delivery of
16 the stillbirth. The department shall include in the registry information that will
17 facilitate all of the following:

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

19 253.12 (3) (c) The department shall, not more than 10 years from the date of
20 receipt of a report under sub. (2), delete from any file of the department the name of
21 a stillbirth or an infant or child that is contained in the report.

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

23 253.12 (4) (a) Make recommendations to the department regarding the
24 establishment of a registry that documents the diagnosis in the state of a stillbirth
25 or an infant or child who has a birth defect, as required under sub. (3) (a) 1. and

1 regarding the rules that the department is required to promulgate under sub. (3) (a)
2 2. and 3. on the birth defects to be reported under sub. (2) and on the general content
3 and format of the report under sub. (2) and procedures for submitting the report. The
4 council shall also make recommendations regarding the content of a report that,
5 because of the application of sub. (2) (d), does not contain the name of the subject of
6 the report.

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

8 253.12 (5) (a) 1. The parent or guardian of a stillbirth or an infant or child for
9 whom a report is made under sub. (2).

10 **SECTION 22.** 253.12 (5) (a) 2. of the statutes is amended to read:

11 253.12 (5) (a) 2. A local health officer, a local birth-to-3 coordinator or an
12 agency under contract with the department to administer the children with special
13 health care needs program, upon receipt of a written request and informed written
14 consent from the parent or guardian of the infant or child under the requirements
15 of subs. (2) (d) and (5m). The local health officer may disclose information received
16 under this subdivision only to the extent necessary to render and coordinate services
17 and follow-up care for the infant or child or to conduct a health, demographic or
18 epidemiological investigation. The local health officer shall destroy all information
19 received under this subdivision within one year after receiving it.

20 **SECTION 23.** 253.12 (5) (a) 4. of the statutes is amended to read:

21 253.12 (5) (a) 4. A representative of a federal or state agency upon written
22 request and to the extent that the information is necessary to perform a legally
23 authorized function of that agency, including investigation of causes, mortality,
24 methods of prevention and early intervention, treatment or care of birth defects,
25 associated diseases or disabilities. The information may not include the name or

1 address of an infant or child or the place of delivery of a stillbirth with a condition
2 reported under sub. (2). The department shall notify the parent or guardian of a
3 stillbirth or an infant or child about whom information is released under this
4 subdivision, of the release. The representative of the federal or state agency may
5 disclose information received under this paragraph only as necessary to perform the
6 legally authorized function of that agency for which the information was requested.

7 **SECTION 24.** 253.12 (5) (b) 5m. of the statutes is created to read:

8 253.12 (5) (b) 5m. The person agrees in writing that the information provided
9 will not be used by an insurer, as defined in s. 600.03 (27), to limit or deny health care
10 coverage or a policy of life insurance to an individual.

11 **SECTION 25.** 253.12 (5) (c) of the statutes is created to read:

12 ~~253.12 (5) (c) By July 1, 2009, the department shall prescribe and distribute,
13 and periodically distribute thereafter, to pediatric speciality clinics, hospitals in
14 which deliveries are performed, and local health departments copies of a form to be
15 used by the parent or guardian of a stillbirth or an infant or child for whom a report
16 is made under sub. (2) (a) in indicating any of the following:~~

17 ~~1. Refusal under sub. (2) (d) by the parent or guardian to consent to the release
18 of identifying information concerning the stillbirth or infant or child.~~

19 ~~2. The decision under sub. (5m) by the parent or guardian to remove from the
20 system any identifying information entered for the stillbirth or infant or child.~~

21 **SECTION 26.** 253.12 (5m) of the statutes is created to read:

22 ~~253.12 (5m) REMOVAL OF IDENTIFYING INFORMATION. If the parent or guardian
23 of a stillbirth or an infant or child for whom a report is made under sub. (2) (a) decides
24 to withdraw consent to the release of identifying information concerning the
25 stillbirth or infant or child, the parent or guardian may request from the local health~~

1 department or the stillbirth's or infant's or child's physician the form specified in sub.
2 (5) (c). If the parent or guardian decides, after having been informed by the
3 stillbirth's or infant's or child's physician or physician's designee of the information
4 contained in the system under this section, and signs the form, the local health
5 department, physician, or physician's designee shall forward the form to the division
6 of the department that deals with public health. On receipt of the signed form, the
7 department shall remove from the system under this section any information
8 identifying the stillbirth or infant or child.

9 (END)

WEDNESDAY, if possible

2007 - 2008 LEGISLATURE

0290/1
LRBs0088/1
DAK/jld/aww
stays

ASSEMBLY SUBSTITUTE AMENDMENT ~~2~~,
TO 2007 ASSEMBLY BILL 185

~~September 6, 2007 - Offered by Representative TOWNSEND.~~

✓ REGENERATE

X

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 (e), 253.12 (3) (a) 1. (intro.), 253.12 (3) (c), 253.12 (4) (a), 253.12 (5) (a) 1., 253.12
5 (5) (a) 2. and 253.12 (5) (a) 4.; *to repeal and recreate* 253.12 (2) (d); and *to*
6 *create* 69.20 (2) (a) 3., 253.12 (1) (e), 253.12 (2) (a) 3., 253.12 (2) (a) 4., 253.12
7 (5) (b) 5m., 253.12 (5) (c) and 253.12 (5m) of the statutes; **relating to:** the birth
8 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 changes the process by which the parent or guardian of a stillbirth, infant, or child may decide not to consent to the release of the stillbirth's, infant's, or child's identifying information, to require that a physician or physician's designee first inform the parent or guardian of the intent of the system and to require signature of the parent or guardian on a DHFS form. Further, the substitute amendment specifies a process by which, using the DHFS form, the parent or guardian of a stillbirth, infant, or child may effect withdrawal of consent to the release of identifying information about the stillbirth, infant, or child, and requires that, if consent to the release is withdrawn, DHFS remove the information from the system. DHFS must prescribe and periodically distribute to pediatric specialty clinics, hospitals in which deliveries are performed, and local health departments the form for these purposes, beginning July 1, 2009.~~

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

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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 ~~also~~ permits the state registrar to record information from reports of certain fetal deaths for use in research conducted under the system.

~~Lastly, the~~ ^{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 ~~and makes other minor changes.~~

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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

1 designated on the form as being collected as statistical–use–only information under
2 s. 69.18 (1m) (c) may not be disclosed to any person except the following:

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

4 69.20 (2) (a) 3. As provided under sub. (3).

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

6 69.20 (3) (b) 3. The information is from the vital record of a registrant who is
7 a resident of another state or who was born in another state and is transmitted to
8 the office responsible for keeping the vital statistics in such state under an interstate
9 cooperation agreement which requires that the information be used for statistical
10 and administrative purposes only and which provides for the retention and
11 disposition of such copies. If under such an agreement the state registrar receives
12 information from an office responsible for keeping the vital statistics in another
13 state, the state registrar may not use the information for any purpose except for the
14 compilation of statistics and, if agreed to by the other state, in meeting requirements
15 for reporting under s. 253.12 (2) (a) 3.

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

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

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

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

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

8 253.12 (1) (a) (intro.) “Birth defect” means any of the following conditions
9 affecting a stillbirth or an infant or child that occurs prior to or at birth and that
10 requires medical or surgical intervention or interferes with normal growth and
11 development:

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

13 253.12 (1) (a) 1. A structural malformation, deformation, disruption, or
14 dysplasia.

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

17 253.12 (1) (cm) “Pediatric specialty clinic” means a clinic that is located in a
18 hospital or is a freestanding clinic, the primary purpose of which is to provide
19 pediatric specialty diagnostic, counseling and medical management services to
20 persons with birth defects by a physician subspecialist.

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

22 253.12 (1) (e) “Research” means a systematic study through scientific inquiry
23 for the purpose of expanding a field of knowledge, including environmental or
24 epidemiological research or special studies.

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

1 253.12 (2) (a) (intro.) Except as provided in par. (b), all of the following shall
2 report in the manner prescribed by the department under sub. (3) (a) 3. a birth defect
3 in a stillbirth or an infant or child:

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

5 253.12 (2) (a) 3. The division of the department that deals with vital statistics,
6 with respect to the information received under s. 69.20 (3) (b) 3. or available under
7 s. 69.20 (3) (d). If a report is made under this subdivision and the report is not
8 confirmed by a report made by another reporting entity, the department shall remove
9 from the registry under sub. (3) all information that would identify the stillbirth,
10 infant, or child before releasing the information to another party under sub. (5) (b),
11 other than the address of the infant or child or place of delivery of the stillbirth that
12 the department has encoded to refer to the same geographical location.

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

14 253.12 (2) (a) 4. The entity under contract under s. 153.05 (2m) (a), with respect
15 to public use data files under s. 153.46 (1) (b).

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

17 253.12 (2) (am) Any hospital in which a birth defect is diagnosed in a stillbirth
18 or an infant or child or treatment is provided to the infant or child may report the
19 birth defect in the manner prescribed by the department under sub. (3) (a) 3.

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

21 253.12 (2) (b) No person specified under par. (a) need report under par. (a) if
22 that person knows that another person specified under par. (a) or (am) has already
23 reported to the department the required information with respect to the same birth
24 defect of the same stillbirth or infant or child.

25 ~~**SECTION 16.** 253.12 (2) (d) of the statutes is repealed and recreated to read:~~

1 253.12 (2) (d) If the parent or guardian of a stillbirth or an infant or child for
2 whom a report is made under par. (a) decides, after having been informed by a
3 physician or a physician's designee of the intent of the system under this section, not
4 to consent to the release of identifying information concerning the stillbirth or infant
5 or child and signs the form specified in sub. (5) (c), the department may not require
6 a person specified under par. (a) 1., 2., or 3. to report information identifying the
7 stillbirth or infant or child.

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

9 253.12 (2) (e) If the address of an infant or child or the place of delivery of a
10 stillbirth for whom a report is made under par. (a) is included in the report, the
11 department shall encode the address to refer to the same geographical location.

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

13 253.12 (3) (a) 1. (intro.) Establish and maintain an up-to-date registry that
14 documents the diagnosis in this state of any stillbirth or infant or child who has a
15 birth defect, regardless of the residence of the infant or child or place of delivery of
16 the stillbirth. The department shall include in the registry information that will
17 facilitate all of the following:

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

19 253.12 (3) (c) The department shall, not more than 10 years from the date of
20 receipt of a report under sub. (2), delete from any file of the department the name of
21 a stillbirth or an infant or child that is contained in the report.

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

23 253.12 (4) (a) Make recommendations to the department regarding the
24 establishment of a registry that documents the diagnosis in the state of a stillbirth
25 or an infant or child who has a birth defect, as required under sub. (3) (a) 1. and

1 regarding the rules that the department is required to promulgate under sub. (3) (a)
2 2. and 3. on the birth defects to be reported under sub. (2) and on the general content
3 and format of the report under sub. (2) and procedures for submitting the report. The
4 council shall also make recommendations regarding the content of a report that,
5 because of the application of sub. (2) (d), does not contain the name of the subject of
6 the report.

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

8 253.12 (5) (a) 1. The parent or guardian of a stillbirth or an infant or child for
9 whom a report is made under sub. (2).

10 **SECTION 22.** 253.12 (5) (a) 2. of the statutes is amended to read:

11 253.12 (5) (a) 2. A local health officer, a local birth-to-3 coordinator or an
12 agency under contract with the department to administer the children with special
13 health care needs program, ~~upon receipt of a written request and informed written~~
14 ~~consent from the parent or guardian of the infant or child~~ under the requirements
15 of subs. (2) (d) and (5m). The local health officer may disclose information received
16 under this subdivision only to the extent necessary to render and coordinate services
17 and follow-up care for the infant or child or to conduct a health, demographic or
18 epidemiological investigation. The local health officer shall destroy all information
19 received under this subdivision within one year after receiving it.

20 **SECTION 23.** 253.12 (5) (a) 4. of the statutes is amended to read:

21 253.12 (5) (a) 4. A representative of a federal or state agency upon written
22 request and to the extent that the information is necessary to perform a legally
23 authorized function of that agency, including investigation of causes, mortality,
24 methods of prevention and early intervention, treatment or care of birth defects,
25 associated diseases or disabilities. The information may not include the name or

1 address of an infant or child or the place of delivery of a stillbirth with a condition
2 reported under sub. (2). The department shall notify the parent or guardian of a
3 stillbirth or an infant or child about whom information is released under this
4 subdivision, of the release. The representative of the federal or state agency may
5 disclose information received under this paragraph only as necessary to perform the
6 legally authorized function of that agency for which the information was requested.

7 **SECTION 24.** 253.12 (5) (b) 5m. of the statutes is created to read:

8 253.12 (5) (b) 5m. The person agrees in writing that the information provided
9 will not be used by an insurer, as defined in s. 600.03 (27), to limit or deny health care
10 coverage or a policy of life insurance to an individual.

11 **SECTION 25.** 253.12 (5) (c) [✓] of the statutes is created to read:

12 253.12 (5) (c) By July 1, 2009, the department shall prescribe and distribute,
13 and periodically distribute thereafter, to pediatric speciality clinics, hospitals in
14 which deliveries are performed, and local health departments copies of a form to be
15 used by the parent or guardian of a stillbirth or an infant or child for whom a report
16 is made under sub. (2) (a) in indicating any of the following:

17 1. Refusal under sub. (2) (d) by the parent or guardian to consent to the release
18 of identifying information concerning the stillbirth or infant or child.

19 2. The decision under sub. (5m) by the parent or guardian to remove from the
20 system any identifying information entered for the stillbirth or infant or child.

21 **SECTION 26.** 253.12 (5m) of the statutes is created to read:

22 253.12 (5m) REMOVAL OF IDENTIFYING INFORMATION. If the parent or guardian
23 of a stillbirth or an infant or child for whom a report is made under sub. (2) (a) decides
24 to withdraw consent to the release of identifying information concerning the
25 stillbirth or infant or child, the parent or guardian may request from the local health

1 department or the stillbirth's or infant's or child's physician the form specified in sub.
2 (5) (c).[✓] If the parent or guardian decides, after having been informed by the
3 stillbirth's or infant's or child's physician or physician's designee of the information
4 contained in the system under this section, and signs the form, the local health
5 department, physician, or physician's designee shall forward the form to the division
6 of the department that deals with public health. On receipt of the signed form, the
7 department shall remove from the system under this section any information
8 identifying the stillbirth or infant or child.

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SECTION ~~1~~ 253.12 (2) (d) of the statutes is amended to read:
2 253.12 (2) (d) The department may not require a person specified under par.
3 (a) ~~1. or 2.~~ or 3. to report the name of an infant or child for whom a report is made
4 under par. (a) if the parent or guardian of the infant or child refuses to consent in
5 writing to the release of the name or address of the infant or child.

6 ^{History:} 1987 a. 371; 1991 a. 178; 1993 a. 27 ss. 347, 349; Stats. 1993 s. 253.12; 1993 a. 335; 1995 a. 27 s. 9145 (1); 1995 a. 417; 1997 a. 164, 252; 1999 a. 32, 114, 186; 2001 a. 38.

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