



↑
STAYS

2005 BILL

change on pp. 2+9

ReGen vt

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) (a) 1. c., 253.12 (3) (c), 253.12 (4) (a),
5 253.12 (5) (a) 1., 253.12 (5) (a) 2. and 253.12 (5) (a) 4.; **to repeal and recreate**
6 253.12 (2) (d); and **to create** 69.20 (2) (a) 3., 253.12 (1) (e), 253.12 (1) (f), 253.12
7 (2) (a) 3., 253.12 (2) (a) 4., 253.12 (5) (c) and 253.12 (5m) of the statutes; **relating**
8 **to:** the 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

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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.

Also under current law, 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 resulting from miscarriages. Before destroying these reports, the state registrar may record the reports' information for use in medical research and use the information to compile statistics.

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 bill changes the process by which the parent or guardian of an infant or child may decide not to consent to the release of the 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 bill specifies a process by which, using the DHFS form, the parent or guardian of an infant or child may effect withdrawal of consent to the release of identifying information about the infant or child, and requires that DHFS remove the information from the system. DHFS must prescribe and distribute to pediatric specialty clinics and local health departments the form for these purposes by ~~July 1, 2004~~ January 1, 2007.

The bill requires the division of DHFS that deals with vital statistics to report to the system 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. In addition, the bill 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 bill authorizes DHFS to contract with an entity to perform the development of primary preventive strategies to decrease the occurrence of birth defects as information to be included in the birth defect registry.

The bill also permits the state registrar to record information from reports of miscarriages for use in research conducted under the system.

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Lastly, the bill includes stillborns, as defined in the bill, under the requirements of the system, expands the definition of “birth defect” to include structural malformations, and makes other minor changes.

For further information see the *state and local* fiscal estimate, which will be printed as an appendix to this bill.

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
19 the office responsible for keeping the vital statistics in such state under an interstate

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

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

9 69.20 (3) (c) ~~Notwithstanding sub. (2), a~~ A local registrar may disclose
10 information on a birth certificate or issue a copy of the certificate to a local health
11 department, as defined in s. 250.01 (4), for health or demographic research or a public
12 health program if the local health department pays the copying costs and if the birth
13 of the registrant occurred within the boundaries of the political subdivision served
14 by the local health department or the registrant is a resident of the political
15 subdivision. The local health department may not disclose any information from any
16 copy which it receives under this paragraph to any person and shall destroy the copy
17 no later than one year after receipt.

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

19 69.20 (3) (d) Subject to par. (f), the state or a local registrar may disclose
20 information from the vital record of a specified registrant, ~~except information under~~
21 ~~sub. (2) (a),~~ to a federal agency, to any agency of the government of this state, or to
22 any agency of a county, city, town, or village if the agency requests the information
23 for use in the conduct of its official duties, except that the state registrar may disclose
24 information under sub. (2) (a) only in order to meet requirements for reporting under
25 s. 253.12 (2) (a) 3.

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

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

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

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

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

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

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

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

19 **SECTION 11.** 253.12 (1) (f) of the statutes is created to read:

20 253.12 (1) (f) “Stillborn” means a human being who is dead at birth, from a
21 cause other than an abortion.

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

23 253.12 (2) (a) (intro.) Except as provided in par. (b), all of the following shall
24 report in the manner prescribed by the department under sub. (3) (a) 3. a birth defect
25 in a stillborn or an infant or child:

BILL**SECTION 13**

1 **SECTION 13.** 253.12 (2) (a) 3. of the statutes is created to read:

2 253.12 (2) (a) 3. The division of the department that deals with vital statistics,
3 with respect to the information received under s. 69.20 (3) (b) 3. or available under
4 s. 69.20 (3) (d).

5 **SECTION 14.** 253.12 (2) (a) 4. of the statutes is created to read:

6 253.12 (2) (a) 4. The entity under contract under s. 153.05 (2m) (a), with respect
7 to public use data files under s. 153.46 (1) (b).

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

9 253.12 (2) (am) Any hospital in which a birth defect is diagnosed in a stillborn
10 or an infant or child or treatment is provided to the infant or child may report the
11 birth defect in the manner prescribed by the department under sub. (3) (a) 3.

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

13 253.12 (2) (b) No person specified under par. (a) need report under par. (a) if
14 that person knows that another person specified under par. (a) or (am) has already
15 reported to the department the required information with respect to the same birth
16 defect of the same stillborn or infant or child.

17 **SECTION 17.** 253.12 (2) (d) of the statutes is repealed and recreated to read:

18 253.12 (2) (d) If the parent or guardian of a stillborn or an infant or child for
19 whom a report is made under par. (a) decides, after having been informed by a
20 physician or a physician's designee of the intent of the system under this section, not
21 to consent to the release of identifying information concerning the stillborn or infant
22 or child and signs the form specified in sub. (5) (c), the department may not require
23 a person specified under par. (a) 1., 2., or 3. to report information identifying the
24 stillborn or infant or child.

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

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1 253.12 (2) (e) If the address of an infant or child or the place of delivery of a
2 stillborn 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 19.** 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 stillborn 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 stillborn. The department shall include in the registry information that will
9 facilitate all of the following:

10 **SECTION 20.** 253.12 (3) (a) 1. c. of the statutes is amended to read:

11 253.12 (3) (a) 1. c. Development of primary preventive strategies to decrease
12 the occurrence of birth defects without increasing abortions. The department may
13 contract with an entity to perform the development required under this subd. 1. c.

14 **SECTION 21.** 253.12 (3) (c) of the statutes is amended to read:

15 253.12 (3) (c) The department shall, not more than 10 years from the date of
16 receipt of a report under sub. (2), delete from any file of the department the name of
17 a stillborn or an infant or child that is contained in the report.

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

19 253.12 (4) (a) Make recommendations to the department regarding the
20 establishment of a registry that documents the diagnosis in the state of a stillborn
21 or an infant or child who has a birth defect, as required under sub. (3) (a) 1. and
22 regarding the rules that the department is required to promulgate under sub. (3) (a)
23 2. and 3. on the birth defects to be reported under sub. (2) and on the general content
24 and format of the report under sub. (2) and procedures for submitting the report. The
25 council shall also make recommendations regarding the content of a report that,

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1 because of the application of sub. (2) (d), does not contain the name of the subject of
2 the report.

3 **SECTION 23.** 253.12 (5) (a) 1. of the statutes is amended to read:

4 253.12 (5) (a) 1. The parent or guardian of a stillborn or an infant or child for
5 whom a report is made under sub. (2).

6 **SECTION 24.** 253.12 (5) (a) 2. of the statutes is amended to read:

7 253.12 (5) (a) 2. A local health officer, a local birth-to-3 coordinator or an
8 agency under contract with the department to administer the children with special
9 health care needs program, ~~upon receipt of a written request and informed written~~
10 ~~consent from the parent or guardian of the infant or child~~ under the requirements
11 of subs. (2) (d) and (5m). The local health officer may disclose information received
12 under this subdivision only to the extent necessary to render and coordinate services
13 and follow-up care for the infant or child or to conduct a health, demographic or
14 epidemiological investigation. The local health officer shall destroy all information
15 received under this subdivision within one year after receiving it.

16 **SECTION 25.** 253.12 (5) (a) 4. of the statutes is amended to read:

17 253.12 (5) (a) 4. A representative of a federal or state agency upon written
18 request and to the extent that the information is necessary to perform a legally
19 authorized function of that agency, including investigation of causes, mortality,
20 methods of prevention and early intervention, treatment or care of birth defects,
21 associated diseases or disabilities. The information may not include the name or
22 address of an infant or child or the place of delivery of a stillborn with a condition
23 reported under sub. (2). The department shall notify the parent or guardian of a
24 stillborn or an infant or child about whom information is released under this
25 subdivision, of the release. The representative of the federal or state agency may

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1 disclose information received under this paragraph only as necessary to perform the
2 legally authorized function of that agency for which the information was requested.

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

4 253.12 (5) (c) By ~~July 1, 2004~~, the department shall prescribe and distribute
5 to pediatric speciality clinics and local health departments copies of a form to be used
6 by the parent or guardian of a stillborn or an infant or child for whom a report is made
7 under sub. (2) (a) in indicating any of the following:

8 1. Refusal under sub. (2) (d) by the parent or guardian to consent to the release
9 of identifying information concerning the stillborn or infant or child.

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

12 **SECTION 27.** 253.12 (5m) of the statutes is created to read:

13 253.12 (5m) REMOVAL OF IDENTIFYING INFORMATION. If the parent or guardian
14 of a stillborn or an infant or child for whom a report is made under sub. (2) (a) decides
15 to withdraw consent to the release of identifying information concerning the stillborn
16 or infant or child, the parent or guardian may request from the local health
17 department or the stillborn's or infant's or child's physician the form specified in sub.
18 (5) (c). If the parent or guardian decides, after having been informed by the stillborn's
19 or infant's or child's physician or physician's designee of the information contained
20 in the system under this section, and signs the form, the local health department,
21 physician, or physician's designee shall forward the form to the division of the
22 department that deals with public health. On receipt of the signed form, the
23 department shall remove from the system under this section any information
24 identifying the stillborn or infant or child.

25

(END)

Kennedy, Debora

From: Lawrence, Minette
Sent: Wednesday, February 15, 2006 11:16 AM
To: Kennedy, Debora
Subject: FW: Stillborn language

Hi Debora --- I just received this.....forwarding to you!
Minette

From: Lisa B Nelson [mailto:lbn@charter.net]
Sent: Wednesday, February 15, 2006 11:13 AM
To: Lawrence, Minette
Cc: Theresa Roetter; tim.hovenconsulting@tds.net; Michael Welsh
Subject: Stillborn language

Minette,
Below is some feedback from an attorney that is on our March of Dimes Public Affairs committee regarding the definition of stillborn in the draft.

~ Lisa

From: Theresa Roetter[SMTP:TROETTER@HILL-LAW-FIRM.COM]
Sent: Wednesday, February 15, 2006 10:15:10 AM

Auto forwarded by a Rule

Hi, everyone - I think your idea to link the definition of "stillborn" to the current statute would actually be preferred by the legislature. In my experience, drafters usually do make those links to existing statutory definitions. Either it was missed this time or, for some reason, they thought the requestor wanted a specific definition to be included.

I think we should ask our legislative sponsor to request that change in the bill from the LRB drafter.

- Theresa

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From: Nelson, Lisa [mailto:LNelson2@marchofdimes.com]
Sent: Tuesday, February 14, 2006 2:21 PM
To: 'mbasir@mail.mcw.edu'; Theresa Roetter; 'Mmalloy@mail.mcw.edu'; 'Hines, Ronald'; 'pauli@waisman.wisc.edu'; 'cmokrohisky@yahoo.com'
Cc: 'mike.hovenconsulting@tds.net'; 'tim.hovenconsulting@tds.net'
Subject: Gestational references/stillborn

I don't see why we shouldn't be able to just reference this definition, for consistency. Something like, "Stillborn is defined as a birth for which a fetal death report is required under section 69.18(1)(e)1." Maybe Theresa has some insight?

Wisconsin statutes 69.18(1)(e)1.

1. If a death is a miscarriage and 20 weeks or more have elapsed between the mother's last normal menstrual period and delivery or the stillbirth weighs 350 grams or more, one of the following shall submit, within 5 days after delivery, a fetal death report to the state registrar:

69.145 Certificate of birth resulting in stillbirth.
 (1) INFORMATION ABOUT PREPARATION. If a birth that occurs in this state on or after August 1, 2004, results in a stillbirth for which a fetal death report is required under s. 69.18 (1) (e) 1., the party responsible for filing the fetal death report under s. 69.18 (1) (e) 1. shall advise the parent or parents of the stillbirth of all of the following:

- (a) That they may request preparation of a certificate of birth resulting in stillbirth.
- (b) That preparation of the certificate is optional.
- (c) How to obtain a certified copy of the certificate if one is requested and prepared.

(2) TIMELY PREPARATION AND FILING. (a) If the parent or parents of the stillbirth, after being advised as provided in sub. (1), wish to have a certificate of birth resulting in stillbirth prepared, the party responsible for filing the fetal death report under s. 69.18 (1) (e) 1. shall, within 5 days after delivery of the stillbirth, prepare and file the certificate with the state registrar.

(b) If the parent or parents of the stillbirth do not wish to provide a name for the stillbirth, the person who prepares the certificate of birth resulting in stillbirth shall leave blank any reference to the name of the stillbirth.

Minnesota Statutes say:

144.222 Reports of fetal or infant death.

Subdivision 1. **Fetal death report required.** A fetal death report must be filed within five days of the death of a fetus for whom **20 or more weeks of gestation** have elapsed, except for abortions defined under section 145.4241. A fetal death report must be prepared in a format prescribed by the state registrar and filed in accordance with Minnesota Rules, parts 4601.0100 to 4601.2600 by:

Illinois Statutes say:

(a) The State Registrar shall prescribe and distribute a form for a certificate of stillbirth. The certificate shall be in the same format as a certificate of live birth prepared under Section 12 and shall be filed in the same manner as a certificate of live birth.

(b) After each fetal death that occurs in this State after a gestation period of at least 26 completed weeks, the person who files a fetal death certificate in connection with that death as required under Section 20 shall, only upon request by the woman who delivered the stillborn fetus, also prepare a certificate of stillbirth. The person shall prepare the certificate on the form prescribed and furnished by the State Registrar and in accordance with the rules adopted by the State Registrar.

Lisa B. Nelson

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Kennedy, Debora

To: Lawrence, Minette
Subject: RE: BDS Bill

With respect to why miscarriages are directed in the bill to be reported to the registry: that provision has been in the bill since the first redraft from the 2003 session; it is located in s. 69.03 (12). If your don't want miscarriages to be reported, I can, of course, remove that provision.

Debora Kennedy

From: Lawrence, Minette
Sent: Monday, February 13, 2006 10:31 AM
To: Kennedy, Debora
Subject: FW: BDS Bill
Importance: High

Hi Debora -- I got this email from Mike Welsh regarding the Birth Defects Bill. Let me know if I should be doing anything on this.

Thanks,

Minette

From: Michael Welsh [mailto:mike.hovenconsulting@tds.net]
Sent: Friday, February 10, 2006 10:52 AM
To: Lawrence, Minette
Subject: BDS Bill
Importance: High

Minette,

I know this is bad timing, but I will be out of the office from Monday, Feb. 13 until Thursday, Feb. 16. However, I can be reached on my cell at 608-234-2940.

I have a couple of things for you regarding the BDS draft. First I think we should keep the co-sponsorship period open for another week for the following reasons:

- We need more co-sponsors, and with more time, our (MOD) advocacy network will be more effective and will be able to obtain more co-signers.
- I sent Pro-Life Wisconsin & Wisconsin Right to Life a copy of the draft (to look over) so John doesn't get into any trouble with those groups. I am still waiting to hear back from them.

On another note, I have a few small changes (to the draft) that I would like to request:

- A small error, but an error nonetheless, in the relating clause. On page 1, line 8 there is a comma after birth defect and before prevention.
- Could you ask the drafter why miscarriages are directed (in the analysis - page 2, last paragraph) to be reported to the Registry? I don't believe that is consistent with our intent or the actual language in the bill. Of course, I could be all wet. I would just like clarification.

02/13/2006

However, before you ask the drafter to make any changes, we should probably wait until we hear back from the pro-life groups to see if we have to make any other changes.

Also, as you recall, the current BDS system prevents linkage of the Birth Defects Registry with other health-related databases (e.g., birth records, hospital discharge data). It was always our understanding that by allowing parents the opportunity to opt out of the inclusion of identifying data instead of having to opt-in (this is the change we made in the draft), the BDS registry would then be automatically linked to other health-related databases.

Do you think you could ask Leg. Counsel if our assumption is correct or if we have to explicitly state in the bill that the registry must be able to be populated with other databases?

Thanks for all your help on this. Again, even though I am out of the office, please do not hesitate to contact me on my cell.

Have a great week!

Michael Welsh
Government Affairs Specialist
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44 E. Mifflin St, Suite 600
Madison, WI 53703

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Fax: (608) 310-8834
mike.hovenconsulting@tds.net

Kennedy, Debora

From: Lawrence, Minette
Sent: Monday, February 20, 2006 2:48 PM
To: Kennedy, Debora
Subject: FW: BDS bill amendment

Mike Welsh just forwarded this to me.

Minette

From: Michael Welsh [mailto:mike.hovenconsulting@tds.net]
Sent: Monday, February 20, 2006 2:46 PM
To: Lawrence, Minette
Subject: BDS bill amendment

Minette,

Do you think you could forward the following amendment language to Deborah Kennedy for the BDS bill?
Thanks?

BDS amendment language:

Page 5, Line 20: after *means* delete lines 20 and 21 and substitute "*a birth for which a fetal death report is required under section 69.18.(1)(e).*"

Michael Welsh
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Fax: (608) 310-8834
mike.hovenconsulting@tds.net

Kennedy, Debora

From: Lawrence, Minette
Sent: Monday, February 20, 2006 3:39 PM
To: Kennedy, Debora
Subject: FW: BDS bill amendment

From: Michael Welsh [mailto:mike.hovenconsulting@tds.net]
Sent: Monday, February 20, 2006 3:36 PM
To: Lawrence, Minette
Subject: Re: BDS bill amendment

Let's go redraft.

----- Original Message -----

From: Lawrence, Minette
To: Michael Welsh
Sent: Monday, February 20, 2006 3:27 PM
Subject: RE: BDS bill amendment

Debora just called and asked if we want this to be a redraft or amendment..... I told her redraft..... Correct?????????????

From: Michael Welsh [mailto:mike.hovenconsulting@tds.net]
Sent: Monday, February 20, 2006 2:59 PM
To: Lawrence, Minette
Subject: Re: BDS bill amendment

Also, were you able to ask Leg. Council the database population question?

Thanks.

----- Original Message -----

From: Lawrence, Minette
To: Michael Welsh
Sent: Monday, February 20, 2006 2:47 PM
Subject: RE: BDS bill amendment

I will forward this email. Are there any other changes other than this?

From: Michael Welsh [mailto:mike.hovenconsulting@tds.net]
Sent: Monday, February 20, 2006 2:46 PM
To: Lawrence, Minette
Subject: BDS bill amendment

Minette,

Do you think you could forward the following amendment language to Deborah Kennedy for the BDS bill?
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BDS amendment language:

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Michael Welsh

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TODAY, please
State of Wisconsin
2005 - 2006 LEGISLATURE

LRB-3715/23

DAK:jld:pg

D-NOTE

↓
E. J. F.

2005 BILL

Regen
REGENERATE

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) (a) 1. c., 253.12 (3) (c), 253.12 (4) (a),
5 253.12 (5) (a) 1., 253.12 (5) (a) 2. and 253.12 (5) (a) 4.; *to repeal and recreate*
6 253.12 (2) (d); and *to create* 69.20 (2) (a) 3., 253.12 (1) (e), 253.12 (1) (f), 253.12
7 (2) (a) 3., 253.12 (2) (a) 4., 253.12 (5) (c) and 253.12 (5m) of the statutes; **relating**
8 **to:** the 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

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, if consent to the release is withdrawn,

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.

Also under current law, 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 ~~resulting from miscarriages~~. Before destroying these reports, the state registrar may record the reports' information for use in medical research and use the information to compile statistics.

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 bill changes the process by which the parent or guardian of an infant or child may decide not to consent to the release of the 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 bill specifies a process by which, using the DHFS form, the parent or guardian of an infant or child may effect withdrawal of consent to the release of identifying information about the infant or child, and requires that DHFS remove the information from the system. DHFS must prescribe and distribute to pediatric specialty clinics and local health departments the form for these purposes by January 1, 2007.

The bill requires the division of DHFS that deals with vital statistics to report to the system 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. In addition, the bill 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 bill authorizes DHFS to contract with an entity to perform the development of primary preventive strategies to decrease the occurrence of birth defects as information to be included in the birth defect registry.

The bill also permits the state registrar to record information from reports of ~~miscarriages~~ for use in research conducted under the system.

certain fetal deaths

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Lastly, the bill includes stillborns, ^{humans} as defined in the bill, under the requirements of the system, expands the definition of “birth defect” to include structural malformations, and makes other minor changes.

For further information see the *state and local* fiscal estimate, which will be printed as an appendix to this bill.

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
19 the office responsible for keeping the vital statistics in such state under an interstate

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

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

9 69.20 (3) (c) ~~Notwithstanding sub. (2), a~~ A local registrar may disclose
10 information on a birth certificate or issue a copy of the certificate to a local health
11 department, as defined in s. 250.01 (4), for health or demographic research or a public
12 health program if the local health department pays the copying costs and if the birth
13 of the registrant occurred within the boundaries of the political subdivision served
14 by the local health department or the registrant is a resident of the political
15 subdivision. The local health department may not disclose any information from any
16 copy which it receives under this paragraph to any person and shall destroy the copy
17 no later than one year after receipt.

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

19 69.20 (3) (d) Subject to par. (f), the state or a local registrar may disclose
20 information from the vital record of a specified registrant, ~~except information under~~
21 ~~sub. (2) (a),~~ to a federal agency, to any agency of the government of this state, or to
22 any agency of a county, city, town, or village if the agency requests the information
23 for use in the conduct of its official duties, except that the state registrar may disclose
24 information under sub. (2) (a) only in order to meet requirements for reporting under
25 s. 253.12 (2) (a) 3.

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

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

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

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

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

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

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

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

19 **SECTION 11.** 253.12 (1) (f) of the statutes is created to read:

20 253.12 (1) (f) "~~Stillborn~~" means a ~~human being who is dead at birth, from a~~
21 ~~cause other than an abortion.~~

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

23 253.12 (2) (a) (intro.) Except as provided in par. (b), all of the following shall
24 report in the manner prescribed by the department under sub. (3) (a) 3. a birth defect
25 in a stillborn or an infant or child:

Stillbirth

birth for which a fetal death report is required under s. 67.18 (1)(e) 1a

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1 **SECTION 13.** 253.12 (2) (a) 3. ✓ of the statutes is created to read:

2 253.12 (2) (a) 3. The division of the department that deals with vital statistics,
3 with respect to the information received under s. 69.20 (3) (b) 3. or available under
4 s. 69.20 (3) (d).

5 **SECTION 14.** 253.12 (2) (a) 4. ✓ of the statutes is created to read:

6 253.12 (2) (a) 4. The entity under contract under s. 153.05 (2m) (a), with respect
7 to public use data files under s. 153.46 (1) (b).

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

9 253.12 (2) (am) Any hospital in which a birth defect is diagnosed in a stillborn
10 or an infant or child or treatment is provided to the infant or child may report the
11 birth defect in the manner prescribed by the department under sub. (3) (a) 3.

12 **SECTION 16.** 253.12 (2) (b) ✓ of the statutes is amended to read:

13 253.12 (2) (b) No person specified under par. (a) need report under par. (a) if
14 that person knows that another person specified under par. (a) or (am) has already
15 reported to the department the required information with respect to the same birth
16 defect of the same stillborn or infant or child.

17 **SECTION 17.** 253.12 (2) (d) of the statutes is repealed and recreated to read:

18 253.12 (2) (d) If the parent or guardian of a stillborn or an infant or child for
19 whom a report is made under par. (a) decides, after having been informed by a
20 physician or a physician's designee of the intent of the system under this section, not
21 to consent to the release of identifying information concerning the stillborn or infant
22 or child and signs the form specified in sub. (5) (c), the department may not require
23 a person specified under par. (a) 1., 2., or 3. to report information identifying the
24 stillborn or infant or child.

25 **SECTION 18.** 253.12 (2) (e) ✓ of the statutes is amended to read:

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1 253.12 (2) (e) If the address of an infant or child or the place of delivery of a
2 stillborn 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 19.** 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 stillborn 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 stillborn. The department shall include in the registry information that will
9 facilitate all of the following:

10 **SECTION 20.** 253.12 (3) (a) 1. c. of the statutes is amended to read:

11 253.12 (3) (a) 1. c. Development of primary preventive strategies to decrease
12 the occurrence of birth defects without increasing abortions. The department may
13 contract with an entity to perform the development required under this subd. 1. c.

14 **SECTION 21.** 253.12 (3) (c) of the statutes is amended to read:

15 253.12 (3) (c) The department shall, not more than 10 years from the date of
16 receipt of a report under sub. (2), delete from any file of the department the name of
17 a stillborn or an infant or child that is contained in the report.

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

19 253.12 (4) (a) Make recommendations to the department regarding the
20 establishment of a registry that documents the diagnosis in the state of a stillborn
21 or an infant or child who has a birth defect, as required under sub. (3) (a) 1. and
22 regarding the rules that the department is required to promulgate under sub. (3) (a)
23 2. and 3. on the birth defects to be reported under sub. (2) and on the general content
24 and format of the report under sub. (2) and procedures for submitting the report. The
25 council shall also make recommendations regarding the content of a report that,

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1 because of the application of sub. (2) (d), does not contain the name of the subject of
2 the report.

3 SECTION 23. 253.12 (5) (a) 1. of the statutes is amended to read:

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4 253.12 (5) (a) 1. The parent or guardian of a stillborn or an infant or child for
5 whom a report is made under sub. (2).

6 SECTION 24. 253.12 (5) (a) 2. of the statutes is amended to read:

7 253.12 (5) (a) 2. A local health officer, a local birth-to-3 coordinator or an
8 agency under contract with the department to administer the children with special
9 health care needs program, upon receipt of a written request and informed written
10 consent from the parent or guardian of the infant or child under the requirements
11 of subs. (2) (d) and (5m). The local health officer may disclose information received
12 under this subdivision only to the extent necessary to render and coordinate services
13 and follow-up care for the infant or child or to conduct a health, demographic or
14 epidemiological investigation. The local health officer shall destroy all information
15 received under this subdivision within one year after receiving it.

16 SECTION 25. 253.12 (5) (a) 4. of the statutes is amended to read:

17 253.12 (5) (a) 4. A representative of a federal or state agency upon written
18 request and to the extent that the information is necessary to perform a legally
19 authorized function of that agency, including investigation of causes, mortality,
20 methods of prevention and early intervention, treatment or care of birth defects,
21 associated diseases or disabilities. The information may not include the name or
22 address of an infant or child or the place of delivery of a stillborn with a condition
23 reported under sub. (2). The department shall notify the parent or guardian of a
24 stillborn or an infant or child about whom information is released under this
25 subdivision, of the release. The representative of the federal or state agency may

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1 disclose information received under this paragraph only as necessary to perform the
2 legally authorized function of that agency for which the information was requested.

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

4 253.12 (5) (c) By January 1, 2007, the department shall prescribe and
5 distribute to pediatric speciality clinics and local health departments copies of a form
6 to be used by the parent or guardian of a stillborn or an infant or child for whom a
7 report is made under sub. (2) (a) in indicating any of the following:

8 1. Refusal under sub. (2) (d) by the parent or guardian to consent to the release
9 of identifying information concerning the stillborn or infant or child.

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

12 **SECTION 27.** 253.12 (5m) of the statutes is created to read:

13 253.12 (5m) REMOVAL OF IDENTIFYING INFORMATION. If the parent or guardian
14 of a stillborn or an infant or child for whom a report is made under sub. (2) (a) decides
15 to withdraw consent to the release of identifying information concerning the stillborn
16 or infant or child, the parent or guardian may request from the local health

17 department or the stillborn's or infant's or child's physician the form specified in sub.

18 (5) (c). If the parent or guardian decides, after having been informed by the stillborn's
19 or infant's or child's physician or physician's designee of the information contained
20 in the system under this section, and signs the form, the local health department,
21 physician, or physician's designee shall forward the form to the division of the
22 department that deals with public health. On receipt of the signed form, the
23 department shall remove from the system under this section any information
24 identifying the stillborn or infant or child.

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(END)

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D-NOTE

SECTION#; CR 253.12 (1) NS 5-21
(B) (g)

(CR) 253.12 (1)(f) "Stillborn human" means

a human whose birth resulted in stillbirth.



D-NOTE

Date

LRB-3715/3dn
DAK:lgf

Townsend

To Representative Townsend:

Merriam

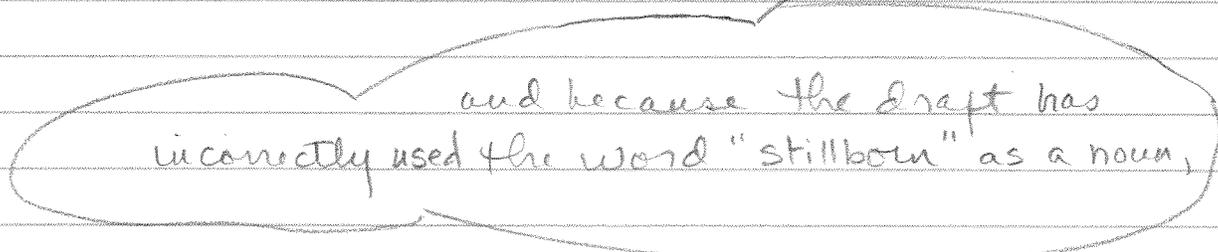
Because the Merriam-Webster'sCollegiate Dictionary, Eleventh Edition,lists "^{stillborn}stillborn" as an adjective only,and "stillbirth" as a noun only, 

I have changed "stillborn" to "stillbirth" in

this redraft. I have used the

definition proposed by Lisa

Nelson.


and because the draft has
incorrectly used the word "stillborn" as a noun,not I have, further, defined "stillborn human"
for the purposes of the draft; the

definition is keyed to the definition of

X "stillbirth". Lisa Nelson and Michael Walsh
have approved these changes. DAK

**DRAFTER'S NOTE
FROM THE
LEGISLATIVE REFERENCE BUREAU**

LRB-3715/3dn
DAK:kjf:jf

February 23, 2006

To representative Townsend:

Because the Merriam-Webster's Collegiate Dictionary, Eleventh Edition, lists "stillborn" as an adjective only, and "stillbirth" as a noun only, and because the draft has incorrectly used the word "stillborn" as a noun, I have changed "stillborn" to "stillbirth" in this redraft. I have used the definition proposed by Lisa Nelson. I have, further, defined "stillborn human" for the purposes of the draft; the definition is keyed to the definition of "stillbirth." Lisa Nelson and Michael Welsh have approved these changes.

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