



Legislative Fiscal Bureau

One East Main, Suite 301 • Madison, WI 53703 • (608) 266-3847 • Fax: (608) 267-6873

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Joint Committee on Finance

Paper #456

Birth Defect Prevention and Surveillance Program (DHS -- Public Health)

[LFB 2009-11 Budget Summary: Page 335, #4 (part)]

CURRENT LAW

Wisconsin statutes establish the state's birth defect prevention and surveillance program, and require the Department of Health Services (DHS) to maintain a registry documenting birth defects that occur in the state. The statutes also establish a Council on Birth Defect Prevention and Surveillance, which includes representatives of organizations and families, to advise DHS on the birth defect registry and other relevant issues. DHS administers the birth defect prevention and surveillance program under the children and youth with special health care needs (CYSHCN) program. Base funding for the program is \$95,000 GPR annually. This funding is budgeted as part of the Division of Public Health's general program operations appropriation. DHS currently uses these funds to support the advisory council, conduct certain public education campaigns, and provided a stillbirth autopsy project grant.

The Wisconsin birth defects registry (WBDR) is a passive surveillance system that depends on reporting by health care providers, is based on an explicit list of birth defects, and reports on children up to two years of age. The system began collecting reports in June 2004.

GOVERNOR

Eliminate funding for the birth defect prevention and surveillance program by reducing funding for the Division of Public Health's general program operations appropriation by \$95,000 GPR annually.

DISCUSSION POINTS

1. While the bill would delete all funding currently budgeted for the program, it would

not repeal statutory references to the program or the Council. The administration has requested that the Committee amend the bill to repeal the statutory references to the program (s. 253.12 of the statutes) and the Council (s. 15.197(12) of the statutes).

2. Effective birth defect surveillance allows the tracking of epidemiological information, identifies possible environmental causes of birth defects or clusters, facilitates referral to services for affected families, and aids the development of prevention strategies or other policies.

3. The most recent report on the WBDR was released in January, 2008. This report stated that over the three years the registry had collected information on birth defects, the WBDR had received reports on 2,186 children, with a total of 2,447 reportable conditions. However, the number of reports that DHS received represented approximately 38% of the reports that DHS would have expected to receive during the first three years of reporting, based on the expected incidence of the specified birth defects.

4. The administration indicates that the current system faces limitations in effectively monitoring birth defects that occur in the state, and establishing a useful surveillance system. One of these limitations is that the WBDR is a passive surveillance system that depends on reporting of birth defects by health care providers. Physicians and special clinics are required to report the occurrence of birth defects, but DHS has no authority to assess penalties to providers who fail to report. An active surveillance system based on chart review, interviews, or other activities would be more effective, but would cost the state more to administer.

5. Another limitation is that parental consent is required to release personally identifiable information necessary to establish a linked system. This places an additional administrative burden on reporting facilities to obtain parental consent for the release of this information. Without personally identifiable information, the information collected by the WBDR cannot be linked to other information collected by the state (for example, birth and death records). A linked system would be able to reduce reporting errors and improve identification of birth defects from multiple sources. Parental permission to release individually identifiable information was obtained in approximately 25% of received reports from June, 2004, to August, 2007. Changing the parental consent requirements may make the system more effective, but may also require increases in program funding.

6. Reportable conditions are limited to those on a defined list, and must be identifiable by the time a child is two years old. Birth defects that are not diagnosed until after a child reaches two years of age would not be reported, possibly resulting in under-reporting.

7. The Department indicates that other birth defect prevention and perinatal health activities are conducted in the CYSHCN and maternal and child health programs. In light of the incomplete data reported to DHS and maintained in the registry that affects the usefulness of the information, the administration recommended that funding for this program be deleted.

8. It could be argued that, despite the incomplete data maintained in the registry, it is

useful in identifying some of the children born in Wisconsin who could benefit from services offered in other programs administered by the Department, facilitating referral to these services. However, DHS indicates that the information gathered by the current registry is rarely, if ever, used for making referrals to services.

ALTERNATIVES

1. Approve the Governor's recommendation to eliminate funding for the birth defect prevention and surveillance program (-\$95,000 GPR annually).
2. In addition to Alternative 1, repeal all statutory language relating to the program and the Council.
3. Maintain current law. Increase funding in the bill by \$95,000 GPR annually.

ALT 3	Change to Bill
	Funding
GPR	\$190,000

Prepared by: Sam Austin