2009 Regular Legislative Session
FISCAL ANALYSIS OF PROPOSED LEGISLATION
Prepared by the Oregon Legislative Fiscal Office

MEASURE NUMBER: SB 460 **STATUS:** Original
SUBJECT: Birth Anomalies and Adverse Pregnancy Outcomes Registry
GOVERNMENT UNIT AFFECTED: Department of Human Services
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REVIEWED BY: John Britton
DATE: March 27, 2009

		2009-2011		2011-2013
EXPENDITURES – General Fund:				
Personal Services	$	525,239	$	481,390
Services and Supplies				
Employee Travel, Training, Office Expenses	$	43,307	$	41,326
Facilities Rent, Furniture, Computer Equipment	$	109,482	$	51,653
Application Software (purchase and annual licensing)	$	165,000	$	30,000
State Data Center Hosting	$	20,400	$	20,400
TOTAL GENERAL FUND	**$**	**863,428**	**$**	**624,769**

POSITIONS / FTE:	2009-2011	2011-2013
Operations and Policy Analyst 4 (Limited Duration)	1/0.50	
Operations and Policy Analyst 3 (Permanent Full-Time)	1/0.75	1/1.00
Research Analyst 3 (Permanent Full-Time)	1/0.75	1/1.00
Office Specialist 2 (Permanent Part-Time)	1/0.38	1/0.50
Medical Records Consultant (Permanent Full-Time)	1/0.75	1/1.00
Information Specialist 7 (Permanent Part-Time)	1/.075	1/0.25
Total	**6/3.88**	**5/3.75**

EFFECTIVE DATE: January 1, 2010

GOVERNOR'S BUDGET: This bill is not anticipated by the Governor's recommended budget.

LOCAL GOVERNMENT MANDATE: This bill does not affect local governments' service levels or shared revenues sufficient to trigger Section 15, Article XI of the Oregon Constitution.

ANALYSIS: Senate Bill 460 requires the Department of Human Services (DHS) to establish and operate a uniform statewide registry and tracking system for birth anomalies and adverse pregnancy outcomes with the goal of monitoring and investigating occurrence statistics, ensuring effective treatment for affected individuals and implementing preventive strategies. The bill directs DHS to adopt rules requiring staff from birthing facilities to report relevant information. Adopted rules should ensure that personally identifiable information contained in the registry is not released to the public, and is in compliance with state and federal laws regarding confidentiality of health records. When collecting this data, the department is to inform the individual or the parent/guardian if the individual is a minor. Affected individuals or parents/guardians may request removal of personally identifiable information from the registry at any time. The bill also instructs DHS to appoint an advisory committee to guide the department in establishing and operating the registry and tracking system.

DHS calculates the fiscal impact of this bill to be $863,428 General Fund and 3.88 FTE for the 2009-11 biennium. The fiscal impact includes the initial investment to develop, build and implement the registry as well as ongoing training, data collection/storage, and system maintenance costs. Members of the advisory committee are not entitled to compensation or reimbursement so no expenses for advisory committee members are included in the fiscal. The proposed Office Specialist position would provide administrative support to the advisory committee. The Operations & Policy Analyst 3 position would work with stakeholders and reporting entities to develop the process for data gathering, and coordinate the rule making requirements of the bill. The Operations & Policy Analyst 4 position would serve as the informatics manager defining and developing statistical and analytical plans to support the delivery of this project. The Research Analyst position would manage data collection and reporting. The Medical Consultant position would verify completeness and accuracy of reporting and tracking. The Information Systems Specialist position would design, create and test the registry database; create implementation materials and manuals; as well as provide outreach and training to designated facilities. DHS calculates the initial investment for registry application software to be $135,000 with licensing fees of $15,000 annually. State Data Center hosting costs are estimated at $10, 200 annually.

The Legislative Fiscal Office notes that the fiscal determined by DHS may be an underestimate. The bill requires that DHS not only collect the data but also analyze the information collected to (a) investigate the incidence, trends and causes of birth anomalies and adverse pregnancy outcomes (b) develop, assess and evaluate measures to prevent birth anomalies and adverse pregnancy outcomes and (c) ensure efficient referral to, and delivery of, services for persons diagnosed with birth anomalies or discharged with adverse pregnancy outcomes. These requirements would necessitate the time and expertise of professionals beyond the qualifications of Operations and Policy Analyst, Medical Records Consultant and Research Analyst. They would require clinicians and medical researchers who can review the information submitted by required facilities to ensure the completeness, accuracy and validity of the data as well as to integrate the information from the registry with studies of genetics, molecular biology, epidemiology, etiology and environmental exposures to investigate the incidence, trends and causes of these conditions.

In addition, the Centers for Disease Control and Prevention (CDC) recognize three types of birth anomalies and adverse pregnancy outcome monitoring systems, each rated differently for completeness of data:

- Vital Records: Use of birth and fetal death certificates provided by the state's Department of Health (Rating: Poor)
- Passive Reporting: Use of medical reports submitted by staff from hospitals, clinics, or other facilities (Rating: Fair to Good)
- Active System: Use of trained personnel who systematically review records in hospitals, clinics, or other facilities (Rating: Excellent)

As written, the bill would merely require the passive reporting system of data ascertainment. DHS current process for collecting adverse pregnancy outcomes is through vital records. The Department's fiscal assumes the current vital records registries of birth certificates and fetal death certificates are sufficient to meet this measure's requirements. Therefore, this estimate of fiscal impact accounts only for the cost of creating a passive reporting birth anomaly registry.

This bill requires budgetary action for allocation of General Fund resources and position establishment.