

The statutory provisions relating to a continuum of comprehensive services for high-risk pregnant women and high-risk handicapped children and their families, are amended to change references to the Department of Health and Rehabilitative Services to the Department of Children and Family Services.

This bill creates section 381.00323, Florida Statutes.

This bill amends s. 411.203, F.S.

II. Present Situation:

Department of Health

The Department of Health, in carrying out its public health mission, may identify, assess and control the presence and spread of communicable diseases; monitor and regulate factors in the environment which may impair the public's health; and ensure the availability of and access to preventative and primary health care, including acute and episodic care, prenatal and postpartum care, child health, family planning, school health, chronic disease prevention, child and adult immunization, dental health, nutrition, and health education and promotion services. The department also implements a public health system that includes state laboratory and pharmacy services, the state vital statistics system, emergency medical services coordination and support, and recruitment, retention, and development of preventive and primary health care professionals and managers.

The department provides public health services through 67 county health departments in partnership with county governments, as specified in part I, of chapter 154, Florida Statutes. The department has the duty to: assess the public health status and needs of the state through statewide data collection and other appropriate means; formulate general powers affecting the public health of the state; administer and enforce laws and rules relating to sanitation, control of communicable diseases, illnesses, injuries, and hazards to health among humans and from animals to humans, and the general health of the people of the state; cooperate with and accept assistance from federal, state, and local officials for prevention and suppression of communicable and other diseases, illnesses, injuries, and hazards to human health; and declare, enforce, modify, and abolish quarantine of persons, animals, and premises as the circumstances indicate for controlling communicable diseases or providing protection from unsafe conditions that pose a threat to public health, except as provided for the control of sexually transmissible disease under s. 384.28, F.S., and ss. 392.545-392.60, F.S., for the control of tuberculosis.¹

Under s. 381.0031, F.S., any practitioner licensed to practice medicine, osteopathic medicine, chiropractic medicine, naturopathy, or veterinary medicine and any licensed hospital or clinical laboratory that diagnoses or suspects the existence of a disease of public health significance must immediately report the fact to the Department of Health. The department must issue a list of infectious or noninfectious diseases determined by it to be a threat to public health and of significance to public health and must furnish a copy of the list to these health care providers.

¹ Section 381.0011, F.S.

Information submitted in reports under s. 381.0031, F.S., is confidential and exempt from the Public Records Law, and is made public only when necessary to protect the public health.

Birth Defects in Florida

Birth defects are one of the leading causes of infant mortality in Florida. The Florida Birth Defects Registry within the Department of Health estimates that each year one in forty-three infants is born with a major birth defect. Birth defects contribute substantially to illness and long-term disability. For those children affected, birth defects continue to be a major cause of death through age fourteen. Birth defects increase the need for the Children's Medical Services program that provides social services, care, and special education programs to children with special health care needs.

According to the Department of Health, in 1998, over 20 percent of deaths prior to age one were due to birth defects. An even larger percentage of stillbirths and miscarriages were caused by birth defects. Yet over 90 percent of babies born with birth defects live beyond their first birthday. Many children with long-term developmental disabilities must face long-term medical and rehabilitation expenses. Average lifetime medical costs for a child with spina bifida is over \$530,000; for Down's syndrome the medical costs average \$500,000. The Department of Health estimated that the medical costs for selected birth defects in a total of 1,515 cases in Florida during 1998 was equal to \$636,558,000.²

Some birth defects may be prevented. Recent research has shown that the daily consumption of vitamin B (folic acid) during the first trimester of pregnancy can reduce the incidence of neural tube defects, major anomalies of the brain and spine, by 50 to 70 percent. Although recent efforts have been made to increase consumption of folic acid by women during their reproductive years, many women of childbearing age do not receive enough folic acid in their diet to provide maximal protection against neural tube defects.

The Department of Health conducts passive birth defects surveillance³ pursuant to its authority under s. 381.0031, F.S. The department collects data on major congenital birth defects, including major structural congenital defects, genetic disorders, and other congenital disorders.⁴ Notifiable congenital defects include all those diagnosed in: infants who are born alive and who have the anomaly diagnosed before their first birthday, including infants who at the time of death are so diagnosed; or fetuses that are not born alive, but have completed 19 weeks of gestation. A practitioner licensed to practice medicine, osteopathic medicine, chiropractic medicine, naturopathy, or veterinary medicine and any licensed hospital must report information to the Florida Birth Defects Registry within the Department of Health regarding each congenital defect

² The birth defects include: spina bifida, truncus arteriosus, transposition/double outlet, right ventricle, tetralogy of fallot, tracheoesophageal fistula, colorectal atresia, cleft lip or palate, renal agenesis, obstructive genitourinary defect, lower-limb reduction, upper limb reduction, Down's syndrome, and diaphragmatic hernia.

³ A passive birth defects surveillance system depends on the identification of cases from vital records, or from reports from hospitals, clinics and other facilities. An active birth defects surveillance system depends on program personnel actively seeking cases in hospitals, clinics, or other facilities by systematically reviewing medical and other records. Source: Florida Department of Health.

⁴ See Rule 64D-3.027, Florida Administrative Code.

according to the definitions, coding schemes, instructions, and reporting forms the department has adopted by rule.⁵

III. Effect of Proposed Changes:

Section 1. Creates s. 381.00323, F.S., to require the Department of Health or its contractual designee to maintain the Florida Birth Defects Registry with information collected in accordance with s. 381.0031, F.S., to support activities and studies directed toward the prevention of birth defects and the reduction of morbidity, mortality, and disability resulting from birth defects. The birth defects reporting and prevention program must operate statewide, and the Department of Health may use information collected by the registry to notify affected individuals and their families about available services and programs.

All information and records held by the Department of Health or its authorized representatives relating to birth defects is confidential and exempt from the requirements of the Public Records Law as provided in s. 381.0031, F.S. The current passive, population-based birth defects registry must continue until over 50 percent of the state's population is served by an active birth defects surveillance system. Legislative intent is expressed that the current registry in the department continue and that funding must be provided for that program and a program of pilot projects over a 10-year period leading to a statewide, active reporting and prevention system. Such funding allocations should be based on an assessment of the number of births and birth defects in Florida, the scope of program activities, and any special situations or commitments requiring increased resources.

The Office of Program Policy Analysis and Government Accountability must conduct research and provide findings to the Legislature by January 1, 2003, regarding passive versus active birth defects surveillance systems and must provide recommendations as to protocol and feasibility for expanding the Florida Birth Defects Registry into an active birth defects reporting and prevention system, beginning as a pilot program in fiscal year 2003-2004. The pilot program must authorize the Department of Health to set program parameters based on a recommended protocol. Initial active birth defects reporting and prevention system pilot projects are established in Hillsborough, Pinellas, and Broward Counties, beginning fiscal year 2003-2004. The pilot projects must be designed to support epidemiological research and facilitate collaborative partnerships among state agencies, advocacy organizations, health care providers, hospitals, laboratories, and other organizations working to identify and prevent birth defects. The requirements of the active birth defects reporting and prevention system are specified.

The Department of Health must establish a program to educate the public and health care providers about the public health importance of birth defects. The birth defects education program must use media and must emphasize educational materials that can be used by businesses, schools, advocacy organizations, and health care providers in their regular course of business. The requirements of the birth defects education program are specified and include: education to all Floridians; outreach to non-English speaking and other minority groups within Florida; education to health care providers and the public about causes of birth defects and opportunities for prevention, fetal alcohol syndrome, the importance of consuming folic acid

⁵ See Rule 64D-3.027, F.A.C.

prior to pregnancy to prevent serious birth defects, and the role of genetics and the environment in birth defects.

A 17-member Birth Defects Advisory Council is established to assist the Department of Health and guide a statewide comprehensive approach to birth defects prevention, diagnosis, education, care, treatment, impact, and the costs thereof. The council's duties include providing leadership to improve the lives of those in Florida with birth defects, to reduce the burden of birth defects, and to serve as a forum for discussion of the delivery of health care services to those affected by birth defects. The council must provide an annual report to the Legislature by July 1 of each year. The Secretary of the Department of Health must appoint the council members who shall serve 2-year terms. The criteria for appointment, procedures, and reimbursement for per diem and travel expenses of the council are specified. The council records may be inspected by members of the council and must be kept on file with the Department of Health.

Section 2. Amends s. 411.203, F.S., relating to a continuum of comprehensive services for high-risk pregnant women and high-risk handicapped children and their families, to change references to the Department of Health and Rehabilitative Services to the Department of Children and Family Services.

Section 3. Provides an effective date of July 1, 2002.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

The provisions of this bill have no impact on municipalities and the counties under the requirements of Art. VII, s. 18 of the Florida Constitution.

B. Public Records/Open Meetings Issues:

On page 3, lines 13-17, the bill provides that all information and records held by the Department of Health or its authorized representatives relating to birth defects is confidential and exempt from the requirements of the Public Records Law as provided in s. 381.0031, F.S. It is unclear whether this creates a public records exemption. If the information collected by the Florida Birth Defects Registry constitutes reports of public health significance as provided in s. 381.0031, F.S., then the records will be confidential and exempt from the Public Records Law, and may be made public by the Department of Health only when necessary to protect the public health.

Section 119.07(3)(dd), F.S., provides an public records exemption for all personal identifying information; bank account numbers; and debit, charge, and credit card numbers contained in records relating to an individual's personal health or eligibility for health-related services made or received by the Department of Health or its service providers, with specified exceptions. Therefore, the confidentiality of such information contained in the Florida Birth Defects Registry may be maintained without further act of the Legislature.

To the extent a public records exemption is created on page 3, lines 13-17, the language should be removed from the bill because the bill contains substantive provisions that are not exemptions to the Public Records Law. Alternatively, the language may be amended to clarify that such records are confidential and exempt as otherwise provided by law. Section 24(c), Article I of the State Constitution provides that legislation enacting public records exemptions or public meetings exemptions may only contain such exemptions and may only relate to one subject.

C. Trust Funds Restrictions:

The provisions of this bill have no impact on the trust fund restrictions under the requirements of Art. III, s. 19(f) of the Florida Constitution.

V. Economic Impact and Fiscal Note:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

To the extent the bill decreases birth defects, children and their families will benefit.

C. Government Sector Impact:

The Department of Health will incur costs to support a public awareness campaign on birth defects, including mass media, professional educational programs, development of culturally appropriate materials and the purchase of folic acid for distribution through the network of county health departments. The department estimates that it will incur \$1,020,150 in each fiscal year 2002-2003 and 2003-2004.

The Department of Health will incur estimated costs of \$1,159,000 in fiscal year 2003-2004, to implement intensive surveillance as part of the active surveillance projects. The funds will support analysis, medical records abstractors, research studies, public information, family services, program planning, cluster investigations, database maintenance, and published reports. The department assumes it will find 2,318 cases at a cost of \$500 per case. The number of cases was estimated by taking five percent of the total live births for 2000 in Broward (22,089); Hillsborough (14,662); and Pinellas (9,596) Counties. The Department estimates that its total costs for the bill will be \$1,102,353 for fiscal year 2002-2003 and \$2,317,688 for fiscal year 2003-2004.

The Department of Health indicated that a recurring General Revenue appropriation of \$460,000 currently supports the Florida Birth Defects Registry. Such funds are used to support passive surveillance, limited health promotion and professional education, and the costs associated with supporting the current Birth Defects Advisory Council. The department's estimate does not include any costs associated with the 17-member advisory council created under the bill. Costs for per diem and travel of the council members will be incurred by the department, in addition to support of their activities.

The Office of Program Policy Analysis and Government Accountability will incur costs to complete a report required by the bill.

VI. Technical Deficiencies:

None.

VII. Related Issues:

The bill refers to both a passive birth defects registry system and an active system that includes reporting and prevention activities. Perhaps it may be more clear, if a definition of both systems was provided to clarify the distinction between the two types of systems (active versus passive), for purposes of the Florida Birth Defects Registry.

VIII. Amendments:

Amendment #1 by Health, Aging and Long-Term Care:

Deletes a provision that would make all information and records held by the Department of Health or its authorized representatives relating to birth defects confidential and exempt from the Public Records Law as provided in s. 381.0031, Florida Statutes. (WITH TITLE AMENDMENT)

Amendment #2 by Health, Aging and Long-Term Care:

Defines “passive birth defects surveillance system” and “active birth defects surveillance system.” (WITH TITLE AMENDMENT)

This Senate staff analysis does not reflect the intent or official position of the bill’s sponsor or the Florida Senate.
