

By Senator Wasserman Schultz

32-1454A-02

See HB

1 A bill to be entitled
2 An act relating to birth defects; creating s.
3 381.00323, F.S.; requiring the Department of
4 Health or a contractual designee to maintain
5 and expand the Florida Birth Defects Registry;
6 providing confidentiality of certain
7 information held by the department; providing
8 legislative intent regarding funding; directing
9 the Office of Program Policy Analysis and
10 Government Accountability to conduct research
11 regarding passive vs. active birth defects
12 surveillance; requiring a report to the
13 Legislature; providing requirements for a
14 program of pilot projects for an active birth
15 defects reporting and prevention system;
16 requiring the department to establish a birth
17 defects education program; providing program
18 requirements; creating a birth defects advisory
19 council; providing council duties; requiring an
20 annual report; providing membership and
21 organization; providing for members' per diem
22 and travel expenses; amending s. 411.203, F.S.;
23 conforming provisions relating to interagency
24 coordination for a continuum of comprehensive
25 services for high-risk pregnant women and
26 high-risk handicapped children; providing an
27 effective date.

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29 WHEREAS, birth defects are the leading cause of infant
30 mortality and contribute substantially to illness and
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1 long-term disability and continue to be a major cause of death
2 through age 14 years, and

3 WHEREAS, birth defects are a major cause of morbidity,
4 mortality, and disability in the state, and

5 WHEREAS, the handicapping and fatal conditions
6 resulting from birth defects represent problems of significant
7 health importance, about which little is known, but which
8 frequently requires expensive medical care, and

9 WHEREAS, these conditions influence the overall quality
10 of life of affected individuals and their families and
11 increase the need for social services and special educational
12 programs, and

13 WHEREAS, birth defects surveillance systems are vital
14 for monitoring and detecting trends in birth defects,
15 providing the basis for studies of the causes of birth
16 defects, and planning and evaluating the effects of prevention
17 activities, and

18 WHEREAS, working with maternal and child health
19 programs, birth defects surveillance systems can help improve
20 prevention and intervention services, and

21 WHEREAS, an enhanced birth defects reporting system
22 will provide information that is timely and accurate and will
23 result in appropriate referral for services and development of
24 effective prevention programs, and

25 WHEREAS, the Legislature intends with this legislation
26 to codify, enhance, and expand the Florida Birth Defects
27 Registry, an existing birth defects surveillance program
28 presently operating within the Department of Health under Rule
29 64D-3.027, Florida Administrative Code, NOW, THEREFORE,

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31 Be It Enacted by the Legislature of the State of Florida:

1 Section 1. Section 381.00323, Florida Statutes, is
2 created to read:
3 381.00323 Statewide birth defects reporting and
4 prevention system.--The department or a contractual designee
5 shall maintain the Florida Birth Defects Registry, with
6 information collected in accordance with s. 381.0031, to
7 support activities and studies directed toward the prevention
8 of birth defects and the reduction of morbidity, mortality,
9 and disability resulting from birth defects. The birth defects
10 reporting and prevention program shall operate statewide, and
11 the department may use information collected by the Florida
12 Birth Defects Registry to notify affected individuals and
13 their families about available services and programs. All
14 information and records held by the department or its
15 authorized representatives relating to birth defects is
16 confidential and exempt from the requirements of s. 119.07(1),
17 as provided in s. 381.0031. The current passive,
18 population-based birth defects registry shall continue until
19 over 50 percent of the state's population is served by an
20 active surveillance system. It is the intent of the
21 Legislature that adequate resources be allocated annually for
22 the current system to continue operating within the department
23 under Rule 64D-3.027, Florida Administrative Code, and that
24 funding shall be provided for a program of pilot projects,
25 leading to a statewide active reporting and prevention system
26 over a 10-year period, according to an assessment of the
27 number of the births and birth defects in the state, the scope
28 of program activities, and any special situations or
29 commitments requiring increased resources.
30 (1) ACTIVE SURVEILLANCE FOR BIRTH DEFECTS; BIRTH
31 DEFECTS REPORTING AND PREVENTION SYSTEM PILOT PROGRAM.--The

1 Office of Program Policy Analysis and Government
2 Accountability shall conduct research and provide findings to
3 the Legislature by January 1, 2003, regarding passive vs.
4 active birth defects surveillance systems and, based on
5 research findings that demonstrate the value of active
6 surveillance for birth defects, shall provide recommendations
7 as to protocol and feasibility for expanding the Florida Birth
8 Defects Registry into an active birth defects reporting and
9 prevention system, beginning as a pilot program in fiscal year
10 2003-2004. The pilot program shall authorize the department to
11 set program parameters according to the recommended protocol.
12 Initial active birth defects reporting and prevention system
13 pilot projects shall be established in Hillsborough, Pinellas,
14 and Broward Counties, beginning in fiscal year 2003-2004,
15 shall be designed to support epidemiological research in
16 accordance with s. 381.0032 and Rule 64D-3.027, Florida
17 Administrative Code, and shall facilitate collaborative
18 partnerships among state agencies, advocacy organizations,
19 health care providers, hospitals, laboratories, and other
20 organizations working to identify and prevent birth defects.
21 The active birth defects reporting and prevention system
22 shall:
23 (a) Identify and describe birth defects.
24 (b) Detect trends and clusters of birth defects.
25 (c) Quantify morbidity, mortality, and disability of
26 birth defects.
27 (d) Stimulate epidemiological research regarding birth
28 defects.
29 (e) Identify risk factors for birth defects.
30 (f) Facilitate intervention in and prevention of birth
31 defects, including secondary conditions.

1 (g) Facilitate access to support services and
2 treatment for birth defects.

3 (h) Inform and educate health care professionals about
4 birth defects.

5 (i) Inform and educate the public about birth defects.

6 (2) BIRTH DEFECTS EDUCATION.--The department shall
7 establish a program to educate the public and health care
8 providers about the public health importance of birth defects.
9 The birth defects education program shall use all forms of
10 media and shall emphasize educational materials that can be
11 used by businesses, schools, advocacy organizations, and
12 health care providers in their regular course of business. The
13 birth defects education program shall:

14 (a) Be designed to reach all segments of Florida's
15 population.

16 (b) Contain special components designed to reach
17 non-English-speaking and other minority groups within the
18 state.

19 (c) Inform health care providers and the public about
20 the causes of birth defects and opportunities for prevention.

21 (d) Educate health care providers and the public about
22 fetal alcohol syndrome.

23 (e) Educate health care providers and the public about
24 the importance of consuming folic acid prior to pregnancy to
25 prevent serious birth defects.

26 (f) Educate health care providers and the public about
27 the role of genetics and the environment in birth defects.

28 (3) BIRTH DEFECTS ADVISORY COUNCIL.--To guide a
29 statewide comprehensive approach to birth defects prevention,
30 diagnosis, education, care, treatment, and impact, and the
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1 costs thereof, a birth defects advisory council is created to
2 advise and assist the department.

3 (a) The council shall:

4 1. Provide statewide leadership to continuously
5 improve the lives of Floridians with birth defects and reduce
6 the burden of birth defects.

7 2. Serve as a forum for the discussion and study of
8 issues related to the public health approach for the delivery
9 of health care services to persons and families affected by
10 birth defects.

11 3. By July 1 of each year, beginning in 2003, after
12 meeting with the Secretary of Health or the secretary's
13 designee, provide an annual report to the Legislature making
14 specific recommendations regarding the public health aspects
15 of the prevention of birth defects.

16 (b) The Secretary of Health shall appoint 17 council
17 members who shall serve 2-year terms. These council members
18 shall be persons who have knowledge of, or work in, the area
19 of birth defects, as follows:

20 1. Two interested citizens, one of whom is an
21 individual affected by birth defects and one of whom is a
22 parent whose affected child is served by the public school
23 system.

24 2. Ten members comprising one representative from each
25 of the following areas: epidemiology/biostatistics,
26 perinatology/neonatology, obstetrics, county health
27 department, pediatrics, clinical genetics, genetic counseling,
28 hospital administration, minority health, and environmental
29 health.

30 3. Five members comprising one representative from
31 each of the following organizations: the Florida Chapter of

1 the March of Dimes, the Florida Chapter of the Spina Bifida
2 Association of America, the Florida Developmental Disabilities
3 Council, the Florida Healthy Start coalitions, and the
4 Association of Retarded Citizens (ARC).

5 (c) The advisory council may also include
6 representatives from the following state agencies: the
7 Department of Health, the Agency for Health Care
8 Administration, the Department of Education, and the
9 Department of Children and Family Services.

10 (d) The council shall annually elect a chair and vice
11 chair from among its members and shall meet at least two times
12 each year.

13 (e) Council records shall be kept on file with the
14 department, and these and other documents about matters within
15 the jurisdiction of the council may be inspected by members of
16 the council.

17 (f) Members of the council shall serve without
18 remuneration but may be reimbursed for per diem and travel
19 expenses as provided in s. 112.061, to the extent resources
20 are available.

21 Section 2. Section 411.203, Florida Statutes, is
22 amended to read:

23 411.203 Continuum of comprehensive services.--The
24 Department of Education,~~and~~ the Department of Health,~~and~~ the
25 Department of Children and Family ~~Rehabilitative~~ Services
26 shall utilize the continuum of prevention and early assistance
27 services for high-risk pregnant women and for high-risk and
28 handicapped children and their families, as outlined in this
29 section, as a basis for the intraagency and interagency
30 program coordination, monitoring, and analysis required in
31 this chapter. The continuum shall be the guide for the

1 comprehensive statewide approach for services for high-risk
2 pregnant women and for high-risk and handicapped children and
3 their families, and may be expanded or reduced as necessary
4 for the enhancement of those services. Expansion or reduction
5 of the continuum shall be determined by intraagency or
6 interagency findings and agreement, whichever is applicable.
7 Implementation of the continuum shall be based upon applicable
8 eligibility criteria, availability of resources, and
9 interagency prioritization when programs impact both agencies,
10 or upon single agency prioritization when programs impact only
11 one agency. The continuum shall include, but not be limited
12 to:

13 (1) EDUCATION AND AWARENESS.--

14 (a) Education of the public concerning, but not
15 limited to, the causes of handicapping conditions, normal and
16 abnormal child development, the benefits of abstinence from
17 sexual activity, and the consequences of teenage pregnancy.

18 (b) Education of professionals and paraprofessionals
19 concerning, but not limited to, the causes of handicapping
20 conditions, normal and abnormal child development, parenting
21 skills, the benefits of abstinence from sexual activity, and
22 the consequences of teenage pregnancy, through preservice and
23 inservice training, continuing education, and required
24 postsecondary coursework.

25 (2) INFORMATION AND REFERRAL.--

26 (a) Providing information about available services and
27 programs to families of high-risk and handicapped children.

28 (b) Providing information about service options and
29 providing technical assistance to aid families in the
30 decisionmaking process.

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- 1 (c) Directing the family to appropriate services and
2 programs to meet identified needs.
- 3 (3) CASE MANAGEMENT.--
- 4 (a) Arranging and coordinating services and activities
5 for high-risk pregnant women, and for high-risk children and
6 their families, with identified service providers.
- 7 (b) Providing appropriate casework services to
8 pregnant women and to high-risk children and their families.
- 9 (c) Advocating for pregnant women and for children and
10 their families.
- 11 (4) SUPPORT SERVICES PRIOR TO PREGNANCY.--
- 12 (a) Basic needs, such as food, clothing, and shelter.
- 13 (b) Health education.
- 14 (c) Family planning services, on a voluntary basis.
- 15 (d) Counseling to promote a healthy, stable, and
16 supportive family unit, to include, but not be limited to,
17 financial planning, stress management, and educational
18 planning.
- 19 (5) MATERNITY AND NEWBORN SERVICES.--
- 20 (a) Comprehensive prenatal care, accessible to all
21 pregnant women and provided for high-risk pregnant women.
- 22 (b) Adoption counseling for unmarried pregnant
23 teenagers.
- 24 (c) Nutrition services for high-risk pregnant women.
- 25 (d) Perinatal intensive care.
- 26 (e) Delivery services for high-risk pregnant women.
- 27 (f) Postpartum care.
- 28 (g) Nutrition services for lactating mothers of
29 high-risk children.
- 30 (h) A new mother information program at the birth
31 site, to provide an informational brochure about

1 immunizations, normal child development, abuse avoidance and
2 appropriate parenting strategies, family planning, and
3 community resources and support services for all parents of
4 newborns and to schedule Medicaid-eligible infants for a
5 health checkup.

6 (i) Appropriate screenings, to include, but not be
7 limited to, metabolic screening, sickle-cell screening,
8 hearing screening, developmental screening, and categorical
9 screening.

10 (j) Followup family planning services for high-risk
11 mothers and mothers of high-risk infants.

12 (6) HEALTH AND NUTRITION SERVICES FOR PRESCHOOL
13 CHILDREN.--

14 (a) Preventive health services for all preschool
15 children.

16 (b) Nutrition services for all preschool children,
17 including, but not limited to, the Child Care Food Program and
18 the Special Supplemental Food Program for Women, Infants, and
19 Children.

20 (c) Medical care for seriously medically impaired
21 preschool children.

22 (d) Cost-effective quality health care alternatives
23 for medically involved preschool children, in or near their
24 homes.

25 (7) EDUCATION, EARLY ASSISTANCE, AND RELATED SERVICES
26 FOR HIGH-RISK CHILDREN AND THEIR FAMILIES.--

27 (a) Early assistance, including, but not limited to,
28 developmental assistance programs, parent support and training
29 programs, and appropriate followup assistance services, for
30 handicapped and high-risk infants and their families.

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- 1 (b) Special education and related services for
2 handicapped children.
- 3 (c) Education, early assistance, and related services
4 for high-risk children.
- 5 (8) SUPPORT SERVICES FOR ALL EXPECTANT PARENTS AND
6 PARENTS OF HIGH-RISK CHILDREN.--
- 7 (a) Nonmedical prenatal and support services for
8 pregnant teenagers and other high-risk pregnant women.
- 9 (b) Child care and early childhood programs,
10 including, but not limited to, subsidized child care, licensed
11 nonsubsidized child care, family day care homes, therapeutic
12 child care, Head Start, and preschool programs in public and
13 private schools.
- 14 (c) Parent education and counseling.
- 15 (d) Transportation.
- 16 (e) Respite care, homemaker care, crisis management,
17 and other services that allow families of high-risk children
18 to maintain and provide quality care to their children at
19 home.
- 20 (f) Parent support groups, such as the community
21 resource mother or father program as established in s. 402.45,
22 the Florida First Start Program as established in s. 230.2303,
23 or parents as first teachers, to strengthen families and to
24 enable families of high-risk children to better meet their
25 needs.
- 26 (g) Utilization of the elderly, either as volunteers
27 or paid employees, to work with high-risk children.
- 28 (h) Utilization of high school and postsecondary
29 students as volunteers to work with high-risk children.
- 30 (9) MANAGEMENT SYSTEMS AND PROCEDURES.--
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1 (a) Resource information systems on services and
2 programs available for families.

3 (b) Registry of high-risk newborns and newborns with
4 birth defects, which utilizes privacy safeguards for children
5 and parents who are subjects of the registry.

6 (c) Local registry of preschoolers with high-risk or
7 handicapping conditions, which utilizes privacy safeguards for
8 children and parents who are subjects of the registry.

9 (d) Information sharing system among the Department of
10 Health, the Department of Children and Family ~~and~~
11 ~~Rehabilitative~~ Services, the Department of Education, local
12 education agencies, and other appropriate entities, on
13 children eligible for services. Information may be shared when
14 parental or guardian permission has been given for release.

15 (e) Well-baby insurance for preschoolers included in
16 the family policy coverage.

17 (f) Evaluation, to include:

18 1. Establishing child-centered and family-focused
19 goals and objectives for each element of the continuum.

20 2. Developing a system to report child and family
21 outcomes and program effectiveness for each element of the
22 continuum.

23 (g) Planning for continuation of services, to include:

24 1. Individual and family service plan by an
25 interdisciplinary team, for the transition from birth or the
26 earliest point of identification of a high-risk infant or
27 toddler into an early assistance, preschool program for
28 3-year-olds or 4-year-olds, or other appropriate programs.

29 2. Individual and family service plan by an
30 interdisciplinary team, for the transition of a high-risk
31 preschool child into a public or private school system.

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Section 3. This act shall take effect July 1, 2002.

HOUSE SUMMARY

Requires the Department of Health or a contractual designee to maintain and expand the Florida Birth Defects Registry. Provides confidentiality of certain information held by the department. Provides legislative intent regarding continued and expanded funding. Directs the Office of Program Policy Analysis and Government Accountability to conduct research regarding passive vs. active birth defects surveillance. Requires a report to the Legislature. Provides requirements for a program of pilot projects for an active birth defects reporting and prevention system. Requires the department to establish a birth defects education program and provides program requirements. Provides for creation of a birth defects advisory council to advise and assist the department. Provides council membership, organization, and duties and requires an annual report to the Legislature. Authorizes reimbursement of council members' per diem and travel expenses.