The Florida Senate

BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

Prepared By: The Professional Staff of the Health Regulation Committee

BILL: CS/SB 1826

INTRODUCER: Health Regulation Committee and Senator Gardiner

SUBJECT: Developmental Disabilities

DATE: January 31, 2012 REVISED: ______ ______ ______ ______

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Davlantes	Stovall	HR	**Fav/CS**
2.			BC	
3.				
4.				
5.				
6.				

I. Summary:

This bill requires a healthcare provider who diagnoses a developmental disability in a fetus based on a screening test to provide the pregnant mother with current information about the nature of the developmental disability, the accuracy of the prenatal test, and resources for support services for the diagnosed disorder. The bill authorizes the Department of Health (the department) to establish a clearinghouse of information relating to support services for people with developmental disabilities, and an advisory board is established within the department to provide technical assistance and expertise to the department in the creation of this clearinghouse.

The bill also amends provisions concerning the John M. McKay Scholarship Program to widen eligibility criteria, increase awareness of the program among military personnel, and create a pilot program which will operate for two years in certain school districts. Regional autism centers must provide information on local resources for children who have additional types of developmental disabilities and support state agencies in the development of training for early child care providers and educators with respect to additional types of developmental disabilities.

This bill creates s. 383.141, Florida Statutes, and amends ss. 1002.39, and 1004.55, Florida Statutes.

II. Present Situation:

Prenatal Screening in Medicine[1]

Prenatal testing is divided into two types, screening tests and diagnostic tests. Screening tests are safe, minimally-invasive studies performed in large, low-risk populations to detect conditions in which timely intervention can alter outcomes. Screening tests frequently produce false-positive results, so any positive finding must be confirmed with a diagnostic test.

Prenatal screening uses a combination of maternal blood tests and ultrasound to evaluate a fetus for various conditions. Diseases which may be detected on prenatal screening include Down syndrome (trisomy 21) and other trisomies; neural tube defects such as spina bifida; abdominal wall defects; kidney, skin, heart, lung, or limb malformations; ovarian tumors; abnormalities in the mother's uterus or placenta; and Tay-Sachs disease.

Diagnostic tests are more accurate, invasive, and prone to complications than screening tests. They are administered to women who have received a positive screening test result or who have risk factors or a family history for certain diseases. Such tests may involve analyzing amniotic fluid or drawing fetal blood. Diagnoses which may be made by such testing include Tay-Sachs disease, sickle-cell anemia, hemophilia, muscular dystrophy, cystic fibrosis, fetal hemolysis, Prader-Willi syndrome, thalassemia, and phenylketonuria (PKU).

More than 800 prenatal tests are available evaluate a wide range of diseases. Genetic counseling is an essential part of the testing process to keep families informed about the diagnosis, severity, and prognosis of any discovered disorder as well as available options for treatment.

Prenatal Screening in Statute

The Florida Healthy Start Program[2] provides for universal risk screening of all Florida's pregnant women and newborn infants to identify those at risk of poor birth, health, and developmental outcomes. Healthy Start also includes targeted support services to address identified risks, including information and referral, comprehensive assessment of service needs in light of family and community resources, ongoing care coordination and support to assure access to needed services, psychosocial, nutritional, and smoking cessation counseling, and childbirth, breastfeeding, and parenting support and education.[3]

Healthy Start prenatal screening focuses on improving mothers' medical or socioeconomic risk factors to create a healthier pregnancy. Factors considered in pregnant women include level of education, presence of other special needs children, marital status, mental health screening, financial hardship, drug and tobacco use, feelings about the pregnancy, and any medical problems. Healthy Start does not place any emphasis on support for those babies who have been

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[1] Medscape Reference, *Prenatal Diagnosis and Fetal Therapy*, available at: http://emedicine.medscape.com/article/936318-overview#aw2aab6b3 (last visited on January 27, 2012).

[2] Provisions for this program are located in s. 383.14, F.S., and related rules.

[3] Department of Health, *Florida's Healthy Start*, available at: http://www.doh.state.fl.us/Family/mch/hs/hs.html (last visited on January 27, 2012).

given a medical diagnosis via medical prenatal screening or genetic testing.[4] Physicians are required to administer such screening on the patient's initial pregnancy visit and report the results to the Office of Vital Statistics for further care coordination.[5]

Department screening for medical diseases occurs after the birth of the child. Specific diseases which are screened for and procedures for reporting are specified in rule. Newborns who receive a positive result on any of the disease screens are referred to appropriate healthcare professionals and support and counseling services.[6]

The department is also required to educate the public about the prevention and management of metabolic, hereditary, and congenital disorders associated with environmental risk factors; and promote the availability of genetic studies and counseling in order that the parents, siblings, and affected newborns may benefit from available knowledge of the condition.[7] Healthy Start provides information and support concerning environmental risk factors during pregnancy, and Children's Medical Services coordinates counseling for any disorders identified during post-natal screening, but currently no programs focus on prenatally-diagnosed medical conditions.[8]

Informed Consent

Before performing any medical testing or treatments, a patient must give voluntary, informed consent to the practitioner performing the procedure. The nature of the procedure, risks, benefits, potential results, and other available options must be explained to the patient in terms that he or she can understand. The patient must also be deemed mentally competent, meaning that he or she can understand the options and their implications and be able to make his or her own decisions. If a patient is not deemed mentally competent, the person appointed to make decisions for the patient must give informed consent.

Consent is often implied for routine tests such as blood draws or X-rays but must always be explicitly given for more invasive procedures such as surgery.[9,10]

Genetics and Newborn Screening Advisory Council

The Genetics and Newborn Screening Advisory Council (the council) was created within the department in 1980[11] to recommend the conditions that should be tested through newborn screening or genetic testing, the appropriate modalities to use, and how to make current testing services more coordinated and efficient. The council consists of:

- Two consumer members;
- Three pediatricians, including at least one pediatric hematologist;

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[4] Department of Health, Healthy Start Program, *Prenatal Risk Screening Form*, available at: http://www.doh.state.fl.us/Family/mch/hs/english_prenatal_screen.pdf (last visited on January 27, 2012).

[5] Section 383.14(1)(a), F.S.

[6] Rule 64C-7, F.A.C.

[7] Section 383.14(3)(c) and (f), F.S.

[8] Telephone conversations with Healthy Start, Children's Medical Services, and department legislative staff.

[9] EMedicine Health, *Informed Consent*, available at: http://www.emedicinehealth.com/informed_consent/article_em.htm (last visited on January 27, 2012).

[10] Standards of practice for informed consent are also found in Rule 64B8-9.007, F.A.C.

[11] Phone conversation with Florida Newborn Screening Program staff.

- One representative from each of the four medical schools in the state;
- The State Surgeon General or his or her designee;
- One representative from Children's Medical Services;
- One representative from the Florida Hospital Association;
- One individual with experience in newborn screening programs;
- One individual representing audiologists; and
- One representative from the Agency for Persons with Disabilities.

Ad hoc or temporary technical advisory groups may be formed to assist the council with specific topics. Council members serve without pay but may be reimbursed for travel expenses.[12]

Statutory Creation of Advisory Bodies, Commissions, or Boards

The statutory creation of any collegial body to serve as an adjunct to an executive agency is subject to certain provisions in s. 20.052, F.S. Such a body may only be created when it is found to be necessary and beneficial to the furtherance of a public purpose, and it must be terminated by the Legislature when it no longer fulfills such a purpose. The Legislature and the public must be kept informed of the numbers, purposes, memberships, activities, and expenses of any collegial or advisory bodies.

A committee or task force is defined in statute to mean "an advisory body created without specific statutory enactment for a time not to exceed 1 year or created by specific statutory enactment for a time not to exceed 3 years and appointed to study a problem and recommend a solution or policy alternative with respect to that problem. Its existence terminates upon the completion of its assignment."[13]

Private citizen members of any advisory body (with exceptions for members of commissions or boards of trustees) may only be appointed by the Governor, the head of the executive agency to which the advisory body is adjunct, the executive director of the agency, or a Cabinet officer. Private citizen members of a commission or a board of trustees may only be appointed by the Governor, must be confirmed by the Senate, and are subject to the dual-office-holding prohibition of s. 5(a), Art. II of the State Constitution.

Members of agency advisory bodies serve for 4-year staggered terms and are ineligible for any compensation other than travel expenses, unless expressly provided otherwise in the State Constitution. Unless an exemption is specified by law, all meetings are public, and records of minutes and votes must be maintained.[14]

John M. McKay Scholarship for Students with Disabilities Program

The John M. McKay Scholarship for Students with Disabilities Program is established to provide the option to attend a public school other than the one to which assigned or to provide a

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[12] Section 383.14(5)

[13] Section 20.03(8), F.S.

[14] Section 20.052, F.S.

scholarship to a private school of choice for certain students with disabilities.[15] To receive such a scholarship for enrollment in a private school, a student must have been accepted to a school which is eligible to participate in the program and have:

- Received specialized instructional services as part of a public pre-kindergarten program during the previous school year and has a current individual educational plan developed by the local school board fulfilling certain criteria;
- Attended a Florida public school or the Florida School for the Deaf and Blind during the previous school year; or
- Was enrolled in a public school during any of the 5 years prior to the 2010-2011 fiscal year, has a current individual educational plan developed by the local school board fulfilling certain criteria, and receives a first-time John M. McKay scholarship for the 2011-2012 school year.

A dependent child of a member of the military who transfers to a school in this state from another jurisdiction due to a parent's permanent change of station orders is exempt from these requirements.[16]

The scholarship will remain in force until the student returns to a public school, graduates from high school, or reaches the age of 22, whichever comes first. If a student enters a Department of Juvenile Justice detention center for more than 21 days, this is considered as a return to public school.[17]

Regional Autism Centers

Seven regional autism centers exist in Florida to provide nonresidential resource and training services to people with autism, pervasive developmental disorders not otherwise specified, autistic-like disabilities, dual sensory impairments (both permanent visual and hearing impairments[18]), or who have a sensory impairment with other handicapping conditions. The centers are located in Tallahassee, Gainesville, Jacksonville, Tampa, Miami, Orlando, and Boca Raton and operate independently of one another to coordinate services for residents in their regions. Centers coordinate services within and between state and local agencies and school districts but may not duplicate services provided by those agencies or school districts.

Each center provides:

- Staff with expertise in autism, autistic-like behaviors, and sensory impairments;
- Individual and direct family assistance in the home, community, and school;
- Technical assistance and consultation services for a client of the center, the client's family, and the school district;
- Professional training programs for personnel who work with the populations served by the centers;

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[15] Students with disabilities eligible for this scholarship include K-12 students with documented intellectual disabilities, speech or language impairments, visual or hearing impairments, orthopedic impairments, other health impairments, emotional or behavioral disabilities, learning disabilities, traumatic brain injuries, developmental delay, or autism spectrum disorders. See s. 1002.39, F.S.

[16] Section 1002.39(1) and (2), F.S.

[17] Section 1002.39(4), F.S.

[18] Section 427.703(4), F.S.

- Public education programs to increase awareness of the public about autism, autistic-related disabilities of communication and behavior, dual sensory impairments, and sensory impairments with other handicapping conditions;
- Coordination and dissemination of information regarding available resources for children with the developmental disabilities served by regional autism centers;
- Support to state agencies in the development of training for early child care providers and educators with respect to the developmental disabilities served by regional autism centers.[19]

III. Effect of Proposed Changes:

Section 1 creates s. 383.141, F.S. This section provides legislative intent that pregnant women who choose to undergo prenatal screening for developmental disabilities should have access to timely and informative counseling about the conditions being tested for, the accuracy of such tests, and resources for obtaining support services for such conditions. Definitions for various terms are provided.

The bill requires a healthcare provider who diagnoses a developmental disability in a fetus based on a prenatal test to provide the pregnant mother with current information about the nature of the developmental disability, the accuracy of the prenatal test, and resources for support services for the diagnosed disorder. Such services include hotlines, resource centers, and information clearinghouses related to Down syndrome or other prenatally diagnosed developmental disabilities; support programs for parents and families; and developmental evaluation and intervention services under s. 391.303, F.S.

The bill authorizes the department to establish a clearinghouse of information relating to support services for people and the families of people with developmental disabilities. Such information will be made available to health care providers for use in counseling pregnant women whose unborn children have been prenatally diagnosed with developmental disabilities.

An advisory board is also established within the department to provide technical assistance and expertise to the department in the creation of this clearinghouse. The council will consist of nine members who are health care providers or caregivers who perform health care services for persons who have developmental disabilities, including Down syndrome and autism. Three members each are appointed by the Governor, the President of the Senate, and the Speaker of the House of Representatives. Details concerning the terms and duties of the council are specified. The department will provide administrative support to the council.

Section 2 amends s. 1002.39, F.S., concerning the John M. McKay Scholarship Program. Students who were enrolled in public school during any of the 5 years prior to the 2010-2011 fiscal year, have current individualized educational plans developed by the district school board following certain conditions, and receive a John M. McKay scholarship for the 2011-2012 school year— regardless of whether it was a first-time scholarship—will be able to enroll in an eligible private school. Dependent children of military personnel who transfer to a school in Florida from another jurisdiction pursuant to a parent’s permanent change of station orders must be provided information on the John M. McKay Scholarship Program by the school.

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[19] Section 1004.55, F.S.

This section also creates the John M. McKay Scholarship Pilot Program, which will operate for 2 years in the Charlotte, DeSoto, Manatee, and Sarasota school districts. Students with in these school districts will be eligible to receive a scholarship for instruction at private schools (sectarian or nonsectarian) if they:

- Have one of the disabilities which would make them eligible for the John M. McKay Scholarship Program in general;
- Are 22 years old;
- Are receiving instruction from an instructor in a private school to meet the high school graduation requirements in s. 1103.428, F.S.;
- Do not have a high school diploma;
- Receive supported employment services, defined as employment that is located or provided in an integrated work setting, with earnings paid on a commensurate wage basis, and for which continued support is needed for job maintenance.

Students in the pilot program may continue to participate in the program until they receive a high school diploma or turn 23, whichever occurs first. Specific criteria are set forth for employment service producers and private schools. Specific provisions are also made for the transfer of scholarship payments between the state, the student or parent of the student receiving the scholarship, and the provider of supported employment services. The bill identifies the funding source and the calculation methodology for the amount of the scholarship.

Section 3 amends s. 1004.55, F.S., to require regional autism centers to provide information on local resources for children who have developmental disabilities as defined by s. 393.063(9) and (13), F.S. Section 1004.55, F.S., pertains to services for persons of all ages and of all levels of intellectual functioning who have autism, pervasive developmental disorders that are not otherwise specified, autistic-like disabilities, dual sensory impairments, or sensory impairments with other handicapping conditions. Regional autism centers must also support state agencies in the development of training for early child care providers and educators with respect to all developmental disabilities as defined by s. 393.063(9) and (13), F.S.

Section 4 provides an effective date of July 1, 2012.

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 Article VII, Section 18 of the Florida Constitution.

B. Public Records/Open Meetings Issues:

The provisions of this bill have no impact on public records or open meetings issues under the requirements of Article I, Section 24(a) and (b) of the Florida Constitution.

C. Trust Funds Restrictions:

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

V. Fiscal Impact Statement:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

Pregnant mothers of children prenatally-diagnosed with medical conditions will be better informed about the nature of the disease, treatment options, and support services. Additional children may qualify for the John M. McKay Scholarship Program, and military personnel who were reassigned to Florida will have greater awareness of the program. Families of children with all types of developmental disabilities will receive better support from regional autism centers.

C. Government Sector Impact:

Additional children may apply for the John M. McKay Scholarship Program due to increased eligibility criteria and increased awareness. Creation of the John M. McKay Scholarship Pilot Program will have a negative fiscal impact on the Florida Education Finance Program as additional funds must be appropriated to support this program. The exact fiscal impact is indeterminate as the number of people who will meet the eligibility requirements and apply for the program is unknown.

Workload and costs for the department will increase related to administrative support of the prenatal advocacy council.

Regional autism centers will experience an increase in workload and a negative fiscal impact related to compiling resources and creating educational programs related to additional types of developmental disabilities.

VI. Technical Deficiencies:

Lines 327 and 331 refer to developmental disabilities as defined in s. 393.063(9) and (13), F.S. However, “developmental disability” is defined in s. 393.063(9), F.S. The term “Down syndrome” is defined in s. 393.063(13), F.S.

VII. Related Issues:

The bill requires a private school participating in the John M. McKay Scholarship Pilot Program to fulfill certain conditions, including submitting documentation of the private school’s and student’s fee schedules to the provider of employment services at least 30 days before any quarterly scholarship payment is made for the student. If the private school does not fulfill these and other conditions, the student is ineligible to receive scholarship payments and the school is ineligible to participate in the scholarship program. It is unclear what happens to the student at this point, in which his or her scholarship has apparently been terminated due to no fault of his or her own.

The bill's language concerning the John M. McKay Scholarship Pilot Program provides many specifications for transferring funds between the Florida Education Finance Program and the student or his or her parents and between the student or parent and the provider of employment services. However, there are no specifications for the transfer of any scholarship funds to the private school.

Section 1004.55(1), F.S., states that regional autism centers may coordinate services within and between state and local agencies and school districts but may not duplicate services provided by those agencies or districts. The bill's expansion of the types of developmental disabilities for which regional autism centers must provide support could go against this provision.

VIII. Additional Information:

A. Committee Substitute – Statement of Substantial Changes:

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

CS by Health Regulation on January 31, 2012:
The CS provides a definition for "developmental disability" and clarifies other definitions. It restricts provisions concerning dissemination of information about prenatally-diagnosed conditions to only prenatally-diagnosed developmental disabilities. It requires the department to create a developmental disability information clearinghouse with help from an advisory council and clarifies duties and terms relating to the advisory council. The CS also creates a John M. McKay Scholarship Pilot Program in certain counties and provides eligibility criteria and other conditions for participation. It also clarifies that regional autism centers must provide information on local resources for children who have developmental disabilities as defined by s. 393.063(9) and (13), F.S., as well as support state agencies in the development of training for early child care providers and educators with respect to these developmental disabilities.

B. Amendments:

None.