By Senator Gardiner

9-00771D-12 20121826__

A bill to be entitled

An act relating to developmental disabilities; creating s. 383.141, F.S.; providing legislative findings; providing definitions; requiring that health care providers provide pregnant women with current information about the conditions that are tested for in a prenatal test, the accuracy of such tests, and resources for obtaining support services for such conditions, including information and support services regarding Down syndrome and other prenatally diagnosed conditions; establishing a prenatal advocacy council within the Department of Health; providing membership for the council; providing duties of the council; providing meeting times for the council; requiring the members to serve without compensation, but be reimbursed for per diem and travel expenses; requiring the department to provide administrative support; amending s. 383.14, F.S.; conforming provisions to changes made by the act; amending s. 1002.39, F.S.; requiring that each school provide information regarding the John M. McKay Scholarship Program upon the enrollment of a dependent child of a member of the United States Armed Forces; amending s. 1004.55, F.S.; requiring each regional autism center in this state to provide coordination and dissemination of local and regional information regarding available resources for services for children who have developmental disabilities, not just autism or autistic-like disabilities; revising the requirements for the centers with respect to supporting state agencies in development training; providing an effective date.

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

Section 1. Section 383.141, Florida Statutes, is created to read:

383.141 Prenatally diagnosed conditions; patient to be provided information; definitions; clearinghouse of information.—

(1) The Legislature finds that pregnant women who choose to undergo prenatal screening 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. Informed consent is a critical component for all genetic testing and prenatal screening, particularly as the results of such testing or screening and the counseling that follows may lead to the unnecessary abortion of unborn humans who have Down syndrome or other prenatally diagnosed conditions.

(2) As used in this section, the term:

(a) "Down syndrome" means a chromosomal disorder caused by an error in cell division which results in the presence of an extra whole or partial copy of chromosome 21.

(b) "Health care provider" means a person or entity licensed, accredited, or certified by the Department of Health to perform specified health services.

(c) "Prenatally diagnosed condition" means an adverse fetal health condition identified by prenatal genetic testing or

<u>indicated by prenatal screening procedures.</u>

<u>(d) “Prenatal test” means a diagnostic procedure or screening procedure performed on a pregnant woman or her unborn offspring to obtain information about her offspring’s health or development.</u>

<u>(3) When a prenatally diagnosed condition, including, but not limited to, Down syndrome, becomes prenatally diagnosed as a result of one or more prenatal tests, the health care provider who requested or ordered prenatal tests, or his or her designee, shall provide the patient with current information about the conditions that were tested for, the accuracy of such tests, and resources for obtaining support services for such conditions, including information hotlines specific to Down syndrome or other prenatally diagnosed conditions, resource centers, and clearinghouses for such conditions, support programs for parents and families, and developmental evaluation and intervention services under s. 391.303.</u>

<u>(4)(a) There is established a prenatal advocacy council within the Department of Health which consists of health care providers and caregivers who perform health care services for persons who have developmental disabilities, including Down syndrome and autism. This group shall consist of nine members:</u>

<u>1. Three members appointed by the Governor;</u>

<u>2. Three members appointed by the President of the Senate; and</u>

<u>3. Three members appointed by the Speaker of the House of Representatives.</u>

<u>(b) The prenatal advocacy council shall establish a clearinghouse of information concerning providers of supportive</u>

services, information hotlines specific to Down syndrome and other prenatally diagnosed conditions, resource centers, educational programs, other support programs for parents and families, and developmental evaluation and intervention services under s. 391.303. The prenatal advocacy council shall meet quarterly to review this clearinghouse of information.

(c) Members of the council shall serve without compensation, but are entitled to reimbursement for per diem and travel expenses as provided in s. 112.061.

(d) The Department of Health shall provide administrative support for the prenatal advocacy council.

Section 2. Subsection (1) of section 383.14, Florida Statutes, is amended to read:

383.14 Screening for metabolic disorders, other hereditary and congenital disorders, and environmental risk factors.—

(1) SCREENING REQUIREMENTS.—To help ensure access to the maternal and child health care system, the Department of Health shall promote the screening of all newborns born in this state ~~Florida~~ for metabolic, hereditary, and congenital disorders known to result in significant impairment of health or intellect, as screening programs accepted by current medical practice become available and practical in the judgment of the department. The department shall also promote the identification and screening of all newborns in this state and their families for environmental risk factors such as low income, poor education, maternal and family stress, emotional instability, substance abuse, and other high-risk conditions associated with increased risk of infant mortality and morbidity to provide early intervention, remediation, and prevention services,

including, but not limited to, parent support and training programs, home visitation, and case management. Identification, perinatal screening, and intervention efforts shall begin before ~~prior to~~ and immediately following the birth of the child by the attending health care provider. Such efforts shall be conducted in hospitals, perinatal centers, county health departments, school health programs that provide prenatal care, and birthing centers, and reported to the Office of Vital Statistics.

(a) *Prenatal screening.*—The department shall develop a multilevel screening process that includes a risk assessment instrument to identify women at risk for a preterm birth or other high-risk condition. The primary health care provider shall complete the risk assessment instrument and report the results to the Office of Vital Statistics so that the woman may immediately be notified and referred to appropriate health, education, and social services and other support services in accordance with s. 383.141.

(b) *Postnatal screening.*—A risk factor analysis using the department's designated risk assessment instrument shall also be conducted as part of the medical screening process upon the birth of a child and submitted to the department's Office of Vital Statistics for recording and other purposes provided for in this chapter. The department's screening process for risk assessment shall include a scoring mechanism and procedures that establish thresholds for notification, further assessment, referral, and eligibility for services by professionals or paraprofessionals consistent with the level of risk. Procedures for developing and using the screening instrument, notification, referral, and care coordination services, reporting requirements, management information, and maintenance of a computer-driven registry in the Office of Vital Statistics which ensures privacy safeguards must be consistent with the provisions and plans established under chapter 411, Pub. L. No. 99-457, and this chapter. Procedures established for reporting information and maintaining a confidential registry must include a mechanism for a centralized information depository at the state and county levels. The department shall coordinate with existing risk assessment systems and information registries. The department must ensure, to the maximum extent possible, that the screening information registry is integrated with the department's automated data systems, including the Florida On-line Recipient Integrated Data Access (FLORIDA) system. Tests and screenings must be performed by the State Public Health Laboratory, in coordination with Children's Medical Services, at such times and in such manner as is prescribed by the department after consultation with the Genetics and Newborn Screening Advisory Council and the Office of Early Learning.

(c) *Release of screening results.*—Notwithstanding any other law to the contrary, the State Public Health Laboratory may release, directly or through the Children's Medical Services program, the results of a newborn's hearing and metabolic tests or screening to the newborn's primary care physician.

Section 3. Paragraph (a) of subsection (2) of section 1002.39, Florida Statutes, is amended to read:

1002.39 The John M. McKay Scholarships for Students with Disabilities Program.—There is established a program that is separate and distinct from the Opportunity Scholarship Program and is named the John M. McKay Scholarships for Students with

Disabilities Program.

(2) JOHN M. MCKAY SCHOLARSHIP ELIGIBILITY.—The parent of a student with a disability may request and receive from the state a John M. McKay Scholarship for the child to enroll in and attend a private school in accordance with this section if:

(a) The student has:

1. Received specialized instructional services under the Voluntary Prekindergarten Education Program pursuant to s. 1002.66 during the previous school year and the student has a current individual educational plan developed by the local school board in accordance with rules of the State Board of Education for the John M. McKay Scholarships for Students with Disabilities Program or a 504 accommodation plan has been issued under s. 504 of the Rehabilitation Act of 1973;

2. Spent the prior school year in attendance at a Florida public school or the Florida School for the Deaf and the Blind. For purposes of this subparagraph, prior school year in attendance means that the student was enrolled and reported by:

a. A school district for funding during the preceding October and February Florida Education Finance Program surveys in kindergarten through grade 12, which includes time spent in a Department of Juvenile Justice commitment program if funded under the Florida Education Finance Program;

b. The Florida School for the Deaf and the Blind during the preceding October and February student membership surveys in kindergarten through grade 12; or

c. A school district for funding during the preceding October and February Florida Education Finance Program surveys, was at least 4 years of age when so enrolled and reported, and was eligible for services under s. 1003.21(1)(e); or

3. Been enrolled and reported by a school district for funding, during the October and February Florida Education Finance Program surveys, in any of the 5 years prior to the 2010-2011 fiscal year; has a current individualized educational plan developed by the district school board in accordance with rules of the State Board of Education for the John M. McKay Scholarship Program no later than June 30, 2011; and receives a ~~first-time~~ John M. McKay scholarship for the 2011-2012 school year. Upon request of the parent, the local school district shall complete a matrix of services as required in subparagraph (5)(b)1. for a student requesting a current individualized educational plan in accordance with the provisions of this subparagraph.

However, a dependent child of a member of the United States Armed Forces who transfers to a school in this state from out of state or from a foreign country due to a parent's permanent change of station orders is exempt from this paragraph but must meet all other eligibility requirements to participate in the program. Upon the enrollment of the dependent child of a member of the United States Armed Forces, the school shall provide information regarding this program.

Section 4. Paragraphs (f) and (g) of subsection (4) of section 1004.55, Florida Statutes, are amended to read:

1004.55 Regional autism centers; public record exemptions.—

(4) Each center shall provide:

(f) Coordination and dissemination of local and regional information regarding available resources for services for children <u>who have</u> ~~with the~~ developmental disabilities ~~described in subsection (1)~~.

(g) Support to state agencies in the development of training for early child care providers and educators with respect to ~~the~~ developmental disabilities ~~described in subsection (1)~~.

Section 5. This act shall take effect July 1, 2012.