

HB 1371

2012

1 A bill to be entitled
2 An act relating to developmental disabilities;
3 creating s. 383.141, F.S.; providing legislative
4 findings; providing definitions; requiring that health
5 care providers provide pregnant women with current
6 information about the conditions that are tested for
7 in a prenatal test, the accuracy of such tests, and
8 resources for obtaining support services for such
9 conditions, including information and support services
10 regarding Down syndrome and other prenatally diagnosed
11 conditions; establishing a prenatal advocacy council
12 within the Department of Health; providing membership
13 for the council; providing duties of the council;
14 providing meeting times for the council; requiring the
15 members to serve without compensation, but be
16 reimbursed for per diem and travel expenses; requiring
17 the department to provide administrative support;
18 amending s. 383.14, F.S.; conforming provisions to
19 changes made by the act; amending s. 1002.39, F.S.;
20 requiring that each school provide information
21 regarding the John M. McKay Scholarship Program upon
22 the enrollment of a dependent child of a member of the
23 United States Armed Forces; amending s. 1004.55, F.S.;
24 requiring each regional autism center in this state to
25 provide coordination and dissemination of local and
26 regional information regarding available resources for
27 services for children who have developmental
28 disabilities, not just autism or autistic-like

HB 1371

2012

29 disabilities; revising the requirements for the
30 centers with respect to supporting state agencies in
31 development training; providing an effective date.
32

33 Be It Enacted by the Legislature of the State of Florida:
34

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

37 383.141 Prenatally diagnosed conditions; patient to be
38 provided information; definitions; clearinghouse of
39 information.-

40 (1) The Legislature finds that pregnant women who choose
41 to undergo prenatal screening should have access to timely and
42 informative counseling about the conditions being tested for,
43 the accuracy of such tests, and resources for obtaining support
44 services for such conditions. Informed consent is a critical
45 component for all genetic testing and prenatal screening,
46 particularly as the results of such testing or screening and the
47 counseling that follows may lead to the unnecessary abortion of
48 unborn humans who have Down syndrome or other prenatally
49 diagnosed conditions.

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

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

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

HB 1371

2012

57 (c) "Prenatally diagnosed condition" means an adverse
58 fetal health condition identified by prenatal genetic testing or
59 indicated by prenatal screening procedures.

60 (d) "Prenatal test" means a diagnostic procedure or
61 screening procedure performed on a pregnant woman or her unborn
62 offspring to obtain information about her offspring's health or
63 development.

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

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

81 1. Three members appointed by the Governor;

82 2. Three members appointed by the President of the Senate;

83 and

84 3. Three members appointed by the Speaker of the House of

85 Representatives.

86 (b) The prenatal advocacy council shall establish a
 87 clearinghouse of information concerning providers of supportive
 88 services, information hotlines specific to Down syndrome and
 89 other prenataally diagnosed conditions, resource centers,
 90 educational programs, other support programs for parents and
 91 families, and developmental evaluation and intervention services
 92 under s. 391.303. The prenatal advocacy council shall meet
 93 quarterly to review this clearinghouse of information.

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

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

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

101 383.14 Screening for metabolic disorders, other hereditary
 102 and congenital disorders, and environmental risk factors.—

103 (1) SCREENING REQUIREMENTS.—To help ensure access to the
 104 maternal and child health care system, the Department of Health
 105 shall promote the screening of all newborns born in this state
 106 ~~Florida~~ for metabolic, hereditary, and congenital disorders
 107 known to result in significant impairment of health or
 108 intellect, as screening programs accepted by current medical
 109 practice become available and practical in the judgment of the
 110 department. The department shall also promote the identification
 111 and screening of all newborns in this state and their families
 112 for environmental risk factors such as low income, poor

HB 1371

2012

113 education, maternal and family stress, emotional instability,
114 substance abuse, and other high-risk conditions associated with
115 increased risk of infant mortality and morbidity to provide
116 early intervention, remediation, and prevention services,
117 including, but not limited to, parent support and training
118 programs, home visitation, and case management. Identification,
119 perinatal screening, and intervention efforts shall begin before
120 ~~prior to~~ and immediately following the birth of the child by the
121 attending health care provider. Such efforts shall be conducted
122 in hospitals, perinatal centers, county health departments,
123 school health programs that provide prenatal care, and birthing
124 centers, and reported to the Office of Vital Statistics.

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

134 (b) Postnatal screening.—A risk factor analysis using the
135 department's designated risk assessment instrument shall also be
136 conducted as part of the medical screening process upon the
137 birth of a child and submitted to the department's Office of
138 Vital Statistics for recording and other purposes provided for
139 in this chapter. The department's screening process for risk
140 assessment shall include a scoring mechanism and procedures that

HB 1371

2012

141 establish thresholds for notification, further assessment,
142 referral, and eligibility for services by professionals or
143 paraprofessionals consistent with the level of risk. Procedures
144 for developing and using the screening instrument, notification,
145 referral, and care coordination services, reporting
146 requirements, management information, and maintenance of a
147 computer-driven registry in the Office of Vital Statistics which
148 ensures privacy safeguards must be consistent with the
149 provisions and plans established under chapter 411, Pub. L. No.
150 99-457, and this chapter. Procedures established for reporting
151 information and maintaining a confidential registry must include
152 a mechanism for a centralized information depository at the
153 state and county levels. The department shall coordinate with
154 existing risk assessment systems and information registries. The
155 department must ensure, to the maximum extent possible, that the
156 screening information registry is integrated with the
157 department's automated data systems, including the Florida On-
158 line Recipient Integrated Data Access (FLORIDA) system. Tests
159 and screenings must be performed by the State Public Health
160 Laboratory, in coordination with Children's Medical Services, at
161 such times and in such manner as is prescribed by the department
162 after consultation with the Genetics and Newborn Screening
163 Advisory Council and the Office of Early Learning.

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

HB 1371

2012

169 Section 3. Paragraph (a) of subsection (2) of section
170 1002.39, Florida Statutes, is amended to read:

171 1002.39 The John M. McKay Scholarships for Students with
172 Disabilities Program.—There is established a program that is
173 separate and distinct from the Opportunity Scholarship Program
174 and is named the John M. McKay Scholarships for Students with
175 Disabilities Program.

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

180 (a) The student has:

181 1. Received specialized instructional services under the
182 Voluntary Prekindergarten Education Program pursuant to s.
183 1002.66 during the previous school year and the student has a
184 current individual educational plan developed by the local
185 school board in accordance with rules of the State Board of
186 Education for the John M. McKay Scholarships for Students with
187 Disabilities Program or a 504 accommodation plan has been issued
188 under s. 504 of the Rehabilitation Act of 1973;

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

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

HB 1371

2012

197 | under the Florida Education Finance Program;

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

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

205 | 3. Been enrolled and reported by a school district for
206 | funding, during the October and February Florida Education
207 | Finance Program surveys, in any of the 5 years prior to the
208 | 2010-2011 fiscal year; has a current individualized educational
209 | plan developed by the district school board in accordance with
210 | rules of the State Board of Education for the John M. McKay
211 | Scholarship Program no later than June 30, 2011; and receives a
212 | ~~first-time~~ John M. McKay scholarship for the 2011-2012 school
213 | year. Upon request of the parent, the local school district
214 | shall complete a matrix of services as required in subparagraph
215 | (5)(b)1. for a student requesting a current individualized
216 | educational plan in accordance with the provisions of this
217 | subparagraph.

218 |
219 | However, a dependent child of a member of the United States
220 | Armed Forces who transfers to a school in this state from out of
221 | state or from a foreign country due to a parent's permanent
222 | change of station orders is exempt from this paragraph but must
223 | meet all other eligibility requirements to participate in the
224 | program. Upon the enrollment of the dependent child of a member

HB 1371

2012

225 of the United States Armed Forces, the school shall provide
 226 information regarding this program.

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

229 1004.55 Regional autism centers; public record
 230 exemptions.-

231 (4) Each center shall provide:

232 (f) Coordination and dissemination of local and regional
 233 information regarding available resources for services for
 234 children who have ~~with the~~ developmental disabilities ~~described~~
 235 ~~in subsection (1).~~

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

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