



General Assembly

Substitute Bill No. 1324

January Session, 2007

* _____SB01324PH_APP032307_____*

AN ACT CONCERNING HEALTH CARE ACCESS, QUALITY AND FAMILY SUPPORT FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. Section 17a-219a of the general statutes is repealed and
2 the following is substituted in lieu thereof (*Effective July 1, 2007*):

3 As used in this section and sections 17a-219b and 17a-219c:

4 (1) ["Children with disabilities"] "Children with special health care
5 needs" means any child with a physical, emotional or mental
6 impairment under the age of eighteen years who (A) if under the age
7 of five, has a severe disability and substantial developmental delay, or
8 a specific diagnosed condition with a high probability of resulting in a
9 developmental delay, (B) has a moderate, severe or profound
10 educational disability, or (C) otherwise meets the definition of
11 developmental disabilities in the federal Developmental Disabilities
12 Act, Section 102(5), as codified in 42 USC 6001(8).

13 (2) "Family" means a child with [a disability] special health care
14 needs and (A) one or more biological or adoptive parents, (B) one or
15 more persons to whom legal custody has been given and in whose
16 home the child resides, or (C) other adult family members who reside
17 with and have a primary responsibility for providing continuous care
18 to a child with [a disability] special health care needs.

19 (3) "Family support services" means services, cash subsidies, and
20 goods which enhance the ability of all children with [disabilities]
21 special health care needs to grow within their families, to reduce the
22 emotional and financial costs to families who care at home for children
23 with [disabilities] special health care needs, and to assist families of
24 children with [disabilities] special health care needs to find the
25 supports, services and assistance to lead lives in their communities.

26 Sec. 2. Section 17a-219b of the general statutes is repealed and the
27 following is substituted in lieu thereof (*Effective July 1, 2007*):

28 (a) The [Department] Commissioners of Public Health, Mental
29 Retardation, Children and Families, Education and Social Services
30 shall [be responsible for the coordination of family support services for
31 children with disabilities. The department shall, within available
32 appropriations, promote state-wide availability of family support
33 services] develop and implement a comprehensive, coordinated health
34 service system for children with special health care needs, which shall
35 be known as the Children with Special Health Care Needs Partnership.

36 (b) The Children with Special Health Care Needs Partnership shall
37 seek to improve health care access, quality and family support for
38 children with special health care needs through (1) improved family
39 access to needed health services, advocacy and assistance, including,
40 but not limited to, addressing reimbursement wherever services are
41 obtained, in-home services and continuous coverage issues; (2)
42 expansion of individualized, family-centered, community-based
43 services that reduce barriers to community living for families; (3)
44 reduction in reliance on, and in average length of stays in, institutional
45 and residential services, hospitals and congregate care for children; (4)
46 capture and investment of enhanced federal revenue and savings
47 derived from reduced residential services and increased community-
48 based services; (5) usage and promotion of effective health delivery
49 models and health insurance strategies; (6) improved administrative
50 oversight and efficiencies, including results-based accountability to
51 improve the health and well-being of children with special health care

52 needs and their families, including, but not limited to, reducing the
53 number of children with special health care needs who are placed out
54 of home; (7) monitoring of individual outcomes, provider performance
55 and overall program performance; (8) improved workforce supply,
56 quality, training, compensation and career ladders; (9) improved
57 collaboration between families and health professionals through the
58 medical home or other model approaches that enable families to
59 partner in decision-making at all levels; (10) efficient and effective use
60 of existing state resources and other resources for such services; (11)
61 maximization of federal funds for health care services, including, but
62 not limited to, the Katie Beckett waiver and other federal waivers; (12)
63 promotion of state-wide availability of such services; (13) family
64 support services; and (14) improved coordination between
65 departments, other state agencies and providers.

66 [(b)] (c) The [Department] Departments of Public Health, Mental
67 Retardation, Children and Families, Education and Social Services, in
68 coordination with the Children with Special Health Care Needs
69 Partnership Oversight Council, established pursuant to section 17a-
70 219c, as amended by this act, and other state, regional and local
71 agencies that operate family support services or administer programs,
72 shall assist families in accessing all other sources of government funds
73 before using existing family support funds appropriated by the
74 General Assembly pursuant to sections 17a-219a to 17a-219c, inclusive,
75 as amended by this act, or any other provision of the general statutes
76 or public or special act.

77 (d) The Commissioners of Public Health, Mental Retardation,
78 Children and Families, Education and Social Services shall each
79 designate a director for the Children with Special Health Care Needs
80 Partnership. Each director shall coordinate the responsibilities of his or
81 her department, within the statutory authority of the department, for
82 the planning, development, administration and evaluation of the
83 activities specified under this section, and shall report regularly on
84 such activities to the Children with Special Health Care Needs

85 Partnership Oversight Council.

86 Sec. 3. Section 17a-219c of the general statutes is repealed and the
87 following is substituted in lieu thereof (*Effective July 1, 2007*):

88 (a) There is established a [Family Support] Children with Special
89 Health Care Needs Partnership Oversight Council [to assist the
90 Department of Mental Retardation and other state agencies that
91 administer or fund family support services to act in concert and,
92 within available appropriations, to (1) establish a comprehensive,
93 coordinated system of family support services, (2) use existing state
94 and other resources efficiently and effectively as appropriate for such
95 services, (3) identify and address services that are needed for families
96 of children with disabilities, and (4) promote state-wide availability of
97 such services. The council shall consist of twenty-seven voting
98 members including the Commissioners of Public Health, Mental
99 Retardation, Children and Families, Education and Social Services, or
100 their designees, the Child Advocate, the executive director of the
101 Office of Protection and Advocacy for Persons with Disabilities, the
102 chairperson of the State Interagency Birth-to-Three Coordinating
103 Council, as established pursuant to section 17a-248b, the executive
104 director of the Commission on Children, and family members of, or
105 individuals who advocate for, children with disabilities. The family
106 members or individuals who advocate for children with disabilities
107 shall comprise two-thirds of the council and shall be appointed as
108 follows: Six by the Governor, three by the president pro tempore of the
109 Senate, two by the majority leader of the Senate, one by the minority
110 leader of the Senate, three by the speaker of the House of
111 Representatives, two by the majority leader of the House of
112 Representatives and one by the minority leader of the House of
113 Representatives. Members shall be appointed for a term of four years.
114 Members shall be limited to two consecutive terms. The council shall
115 meet at least quarterly and shall select its own chairperson. Council
116 members shall serve without compensation but shall be reimbursed for
117 necessary expenses incurred. The costs of administering the council

118 shall be within available appropriations in accordance with sections
119 17a-219a to 17a-219c, inclusive] which shall (1) advise the
120 Commissioners of Public Health, Mental Retardation, Children and
121 Families, Education and Social Services on the planning and
122 implementation of the Children with Special Health Care Needs
123 Partnership, and (2) engage in other activities related to family support
124 pursuant to this section.

125 [(b) The council shall: (1) Gather input and develop a vision and
126 guidelines for family support services in Connecticut; (2) review
127 existing program policies, procedures and funding mechanisms for
128 conformity to the guidelines and make appropriate recommendations;
129 (3) monitor the implementation of the guidelines and
130 recommendations; (4) report to the Governor and the General
131 Assembly on an annual basis regarding the status of family support
132 services, including the implementation of the guidelines and
133 recommendations; (5) advocate for family support services in
134 accordance with the guidelines; (6) compile and distribute information
135 on family support services within public and private agencies; and (7)
136 perform such other duties as are related to the advancement of family
137 centered supports, policies and services.]

138 (b) The council shall consist of the following members:

139 (1) The chairpersons and ranking members of the joint standing
140 committees of the General Assembly having cognizance of matters
141 relating to education, human services, public health and
142 appropriations, and the select committee of the General Assembly
143 having cognizance of matters relating to children;

144 (2) The Child Advocate, or a designee;

145 (3) The executive director of the Office of Protection and Advocacy
146 for Persons with Disabilities, or a designee;

147 (4) The chairperson of the State Interagency Birth-to-Three
148 Coordinating Council, as established pursuant to section 17a-248b, or a

149 designee;

150 (5) The executive director of the Commission on Children, or a
151 designee;

152 (6) Family members of, or individuals who advocate for, children
153 with special health care needs. The family members or individuals
154 who advocate for children with special health care needs shall be
155 appointed as follows: Six by the Governor, three by the president pro
156 tempore of the Senate, three by the speaker of the House of
157 Representatives, two by the majority leader of the Senate, two by the
158 majority leader of the House of Representatives, one by the minority
159 leader of the Senate and one by the minority leader of the House of
160 Representatives. Family members shall be appointed for a term of four
161 years;

162 (7) Two members of the General Assembly, one of whom shall be
163 appointed by the president pro tempore of the Senate and one of
164 whom shall be appointed by the Speaker of the House of
165 Representatives;

166 (8) The Healthcare Advocate, or a designee;

167 (9) The director of the Commission on the Deaf and Hearing
168 Impaired, or a designee;

169 (10) A pediatrician with expertise regarding children with special
170 health care needs, appointed by the speaker of the House of
171 Representatives;

172 (11) A representative of the health care insurance industry,
173 appointed by the president pro tempore of the Senate;

174 (12) A mental health provider, appointed by the Governor;

175 (13) A representative of a nursing association, appointed by the
176 Governor;

177 (14) A business leader who has demonstrated interest in the well-
178 being of children with special health care needs, appointed by the
179 Governor; and

180 (15) Five nonvoting ex-officio members, consisting of the
181 Commissioners of Public Health, Mental Retardation, Children and
182 Families, Education and Social Services, or their designees;

183 (c) The council shall meet at least quarterly and shall select
184 cochairpersons from among its members, one of whom shall be a
185 family member and one of whom shall be a member of the General
186 Assembly. Council members shall serve without compensation but
187 shall be reimbursed for necessary expenses incurred.

188 (d) The council shall make specific recommendations on matters
189 related to the planning and implementation of the Children with
190 Special Health Care Needs Partnership which shall include, but not be
191 limited to, review of any relevant contracts related to the partnership
192 and related activities, to assure that the contracting outside agency's
193 decisions are consistent with the partnership's goals pursuant to
194 section 17a-219b, as amended by this act. The council may conduct or
195 cause to be conducted an external, independent evaluation of the
196 partnership.

197 (e) In addition to the activities described in subsection (d) of this
198 section, the council shall: (1) Gather input and develop a vision and
199 guidelines for family support services in Connecticut; (2) review
200 existing program policies, procedures and funding mechanisms for
201 conformity to the guidelines and make appropriate recommendations
202 to the Governor and the General Assembly; (3) monitor the
203 implementation of the guidelines and recommendations; (4) report to
204 the Governor and the General Assembly on an annual basis regarding
205 the status of family support services, including the implementation of
206 the guidelines and recommendations; (5) advocate for family support
207 services in accordance with the guidelines; (6) compile and distribute
208 information on family support services within public and private

209 agencies; and (7) perform such other duties as are related to the
210 advancement of family centered supports, policies and services.

211 (f) There is established a Family Support Network, which shall be
212 administered by the council. The Family Support Network shall
213 conduct educational outreach to families of children with special
214 health care needs throughout the state, and may conduct other
215 functions deemed appropriate by the council from time to time.

216 (g) On or before January 1, 2008, and annually thereafter, the council
217 shall submit a report, in accordance with section 11-4a, to the Governor
218 and the joint standing committees of the General Assembly having
219 cognizance of matters relating to education, human services, public
220 health, appropriations and social services, and to the select committee
221 of the General Assembly having cognizance of matters relating to
222 children.

223 (h) The Joint Committee on Legislative Management shall provide
224 administrative support to the chairpersons and assistance in convening
225 the council's meetings.

226 Sec. 4. Section 17a-217a of the general statutes is repealed and the
227 following is substituted in lieu thereof (*Effective July 1, 2007*):

228 (a) There shall be a Camp Harkness Advisory Committee to advise
229 the Commissioner of Mental Retardation with respect to issues
230 concerning the health and safety of persons who attend and utilize the
231 facilities at Camp Harkness. The advisory committee shall be
232 composed of twelve members as follows: (1) The director of Camp
233 Harkness, who shall serve ex officio, one member representing the
234 Southeastern Connecticut Association for the Retarded, one member
235 representing the Southbury Training School, one member representing
236 the Association for Retarded Citizens of New London County, one
237 consumer representing persons who use the camp on a residential
238 basis and one member representing parents or guardians of persons
239 who use the camp, all of whom shall be appointed by the Governor; (2)

240 one member representing parents or guardians of persons who use the
241 camp, who shall be appointed by the president pro tempore of the
242 Senate; (3) one consumer from the [Family Support] Children with
243 Special Health Care Needs Partnership Oversight Council established
244 pursuant to section 17a-219c, as amended by this act, representing
245 persons who use the camp on a day basis, who shall be appointed by
246 the speaker of the House of Representatives; (4) one member
247 representing the board of selectmen of the town of Waterford, who
248 shall be appointed by the majority leader of the House of
249 Representatives; (5) one member representing the Camp Harkness
250 Booster Club, who shall be appointed by the majority leader of the
251 Senate; (6) one member representing the Connecticut Institute for the
252 Blind and the Oak Hill School, who shall be appointed by the minority
253 leader of the House of Representatives; and (7) one member
254 representing the United Cerebral Palsy Association, who shall be
255 appointed by the minority leader of the Senate.

256 (b) The advisory committee shall promote communication
257 regarding camp services and develop recommendations for the
258 commissioner regarding the use of Camp Harkness.

259 (c) Not later than October 1, 2002, and annually thereafter, the
260 advisory committee shall submit a report to the commissioner and to
261 the joint standing committee of the General Assembly having
262 cognizance of matters relating to public health concerning the status of
263 Camp Harkness. Such report shall be submitted in accordance with
264 section 11-4a.

265 Sec. 5. Subsection (g) of section 17a-248g of the general statutes is
266 repealed and the following is substituted in lieu thereof (*Effective July*
267 *1, 2007*):

268 (g) Notwithstanding any provision of title 38a relating to the
269 permissible exclusion of payments for services under governmental
270 programs, no such exclusion shall apply with respect to payments
271 made pursuant to section 17a-248, sections 17a-248b to 17a-248f,

272 inclusive, this section and sections 38a-490a and 38a-516a. Except as
273 provided in this subsection, nothing in this section shall increase or
274 enhance coverages provided for within an insurance contract subject to
275 the provisions of section 10-94f, subsection (a) of section 10-94g,
276 subsection [(a)] (b) of section 17a-219b, as amended by this act,
277 [subsection (a) of] section 17a-219c, as amended by this act, sections
278 17a-248, 17a-248b to 17a-248f, inclusive, this section, and sections 38a-
279 490a and 38a-516a.

280 Sec. 6. Section 17b-338 of the general statutes is repealed and the
281 following is substituted in lieu thereof (*Effective July 1, 2007*):

282 (a) There is established a Long-Term Care Advisory Council which
283 shall consist of the following: (1) The executive director of the
284 Commission on Aging, or the executive director's designee; (2) the
285 State Nursing Home Ombudsman, or the ombudsman's designee; (3)
286 the president of the Coalition of Presidents of Resident Councils, or the
287 president's designee; (4) the executive director of the Legal Assistance
288 Resource Center of Connecticut, or the executive director's designee;
289 (5) the state president of AARP, or the president's designee; (6) one
290 representative of a bargaining unit for health care employees,
291 appointed by the president of the bargaining unit; (7) the president of
292 the Connecticut Association of Not-For-Profit Providers for the Aging,
293 or the president's designee; (8) the president of the Connecticut
294 Association of Health Care Facilities, or the president's designee; (9)
295 the president of the Connecticut Association of Residential Care
296 Homes, or the president's designee; (10) the president of the
297 Connecticut Hospital Association or the president's designee; (11) the
298 executive director of the Connecticut Assisted Living Association or
299 the executive director's designee; (12) the executive director of the
300 Connecticut Association for Homecare or the executive director's
301 designee; (13) the president of Connecticut Community Care, Inc. or
302 the president's designee; (14) one member of the Connecticut
303 Association of Area Agencies on Aging appointed by the agency; (15)
304 the president of the Connecticut chapter of the Connecticut

305 Alzheimer's Association; (16) one member of the Connecticut
306 Association of Adult Day Centers appointed by the association; (17)
307 the president of the Connecticut Chapter of the American College of
308 Health Care Administrators, or the president's designee; (18) the
309 president of the Connecticut Council for Persons with Disabilities, or
310 the president's designee; (19) the president of the Connecticut
311 Association of Community Action Agencies, or the president's
312 designee; (20) a personal care attendant appointed by the speaker of
313 the House of Representatives; (21) the [president of the Family Support
314 Council] cochairpersons of the Children with Special Health Care
315 Needs Partnership, or the [president's designee] cochairpersons'
316 designees; (22) a person who, in a home setting, cares for a person with
317 a disability and is appointed by the president pro tempore of the
318 Senate; (23) three persons with a disability appointed one each by the
319 majority leader of the House of Representatives, the majority leader of
320 the Senate and the minority leader of the House of Representatives;
321 (24) a legislator who is a member of the Long-Term Care Planning
322 Committee; and (25) one member who is a nonunion home health aide
323 appointed by the minority leader of the Senate.

324 (b) The council shall advise and make recommendations to the
325 Long-Term Care Planning Committee established under section 17b-
326 337.

327 (c) The Long-Term Care Advisory Council shall seek
328 recommendations from persons with disabilities or persons receiving
329 long-term care services who reflect the socio-economic diversity of the
330 state.

331 Sec. 7. Section 17b-283 of the general statutes is repealed and the
332 following is substituted in lieu thereof (*Effective July 1, 2007*):

333 The Commissioner of Social Services shall amend the state's model
334 2176 Medicaid waiver to allow one hundred twenty-five disabled
335 persons to participate under the waiver. The commissioner may,
336 within available appropriations, amend such waiver to increase the

