

Representative Ronda Rudd Menlove proposes the following substitute bill:

PILOT PROGRAM FOR AUTISM SPECTRUM

DISORDERS SERVICES

2012 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Ronda Rudd Menlove

Senate Sponsor: Curtis S. Bramble

LONG TITLE

General Description:

This bill creates a pilot program for autism spectrum disorders services in the Medicaid program; for the private sector, non-Medicaid population through the Autism Treatment Account; and for certain children of state employees administered by Public Employees' Benefit and Insurance Program Act.

Highlighted Provisions:

This bill:

- ▶ provides a funding mechanism for the autism Medicaid waiver;
- ▶ directs the state Medicaid program to develop a Medicaid waiver to provide proven effective services for children between the ages of two to six with autism spectrum disorder;
- ▶ requires the department to convene a public process to develop the Medicaid waiver;
- ▶ requires the department to include services for children located in rural and underserved areas of the state;
- ▶ requires the department to measure the cost and the effectiveness of the treatments and services for autism spectrum disorders;



- 26 ▶ requires the department to report to the Legislative Health and Human Services
- 27 Interim Committee by November 30, 2013;
- 28 ▶ amends provisions of the Autism Treatment Account to:
- 29 • update terminology used for autism treatment options;
- 30 • amend the uses of the account to focus on evaluation and treatment of children
- 31 between the ages of two to six years old with autism spectrum disorders;
- 32 • work with telehealth services to reach children in rural and underserved areas of
- 33 the state; and
- 34 • create a mechanism to identify children qualified for services, provide and pay
- 35 for services for children, and to evaluate effectiveness of treatments; and
- 36 ▶ establishes a pilot program for autism services for certain children of state
- 37 employees administered by the Public Employees' Benefit and Insurance Program.

38 Money Appropriated in this Bill:

39 This bill appropriates in fiscal year 2011-12:

- 40 ▶ to Department of Health - Medicaid Optional Services
- 41 • from General Fund, One-time \$1,500,000 to fund autism treatment; and
- 42 ▶ to Department of Human Services - Child and Family Services
- 43 • from General Fund, One-time (\$1,500,000) to fund autism treatment.

44 This bill provides intent language making certain fiscal year 2012 appropriations in the

45 Department of Health nonlapsing for purposes of studying children with autism

46 spectrum disorders.

47 Other Special Clauses:

48 None

49 Utah Code Sections Affected:

50 AMENDS:

- 51 **26-18-402**, as last amended by Laws of Utah 2010, Chapter 340
- 52 **26-52-102**, as enacted by Laws of Utah 2010, Chapter 69
- 53 **26-52-201**, as enacted by Laws of Utah 2010, Chapter 69
- 54 **26-52-202**, as last amended by Laws of Utah 2011, Chapter 340

55 ENACTS:

- 56 **26-18-407**, Utah Code Annotated 1953

57 26-52-203, Utah Code Annotated 1953

58 49-20-411, Utah Code Annotated 1953

59

60 *Be it enacted by the Legislature of the state of Utah:*

61 Section 1. Section **26-18-402** is amended to read:

62 **26-18-402. Medicaid Restricted Account.**

63 (1) There is created a restricted account in the General Fund known as the Medicaid
64 Restricted Account.

65 (2) (a) Except as provided in Subsection (3), the following shall be deposited into the
66 Medicaid Restricted Account:

67 (i) any general funds appropriated to the department for the state plan for medical
68 assistance or for the Division of Health Care Financing that are not expended by the
69 department in the fiscal year for which the general funds were appropriated and which are not
70 otherwise designated as nonlapsing shall lapse into the Medicaid Restricted Account;

71 (ii) any unused state funds that are associated with the Medicaid program, as defined in
72 Section 26-18-2, from the Department of Workforce Services and the Department of Human
73 Services; and

74 (iii) any penalties imposed and collected under:

75 (A) Section 17B-2a-818.5;

76 (B) Section 19-1-206;

77 (C) Section 79-2-404;

78 (D) Section 63A-5-205;

79 (E) Section 63C-9-403; or

80 (F) Section 72-6-107.5.

81 (b) The account shall earn interest and all interest earned shall be deposited into the
82 account.

83 (c) The Legislature may appropriate money in the restricted account to fund programs
84 that expand medical assistance coverage and private health insurance plans to low income
85 persons who have not traditionally been served by Medicaid, including the Utah Children's
86 Health Insurance Program created in Chapter 40.

87 (3) For fiscal years 2008-09, 2009-10, ~~and~~ 2010-11, 2011-12, and 2012-13 the

88 following funds are nonlapsing:

89 (a) any general funds appropriated to the department for the state plan for medical
90 assistance, or for the Division of Health Care Financing that are not expended by the
91 department in the fiscal year in which the general funds were appropriated; and

92 (b) funds described in Subsection (2)(a)(ii).

93 Section 2. Section **26-18-407** is enacted to read:

94 **26-18-407. Medicaid waiver for autism spectrum disorder.**

95 (1) For purposes of this section "autism spectrum disorder" means a pervasive
96 developmental disorder as defined by the most recent edition of the Diagnostic and Statistical
97 Manual on Mental Disorders, including:

98 (a) Autistic disorder;

99 (b) Asperger's disorder; and

100 (c) pervasive developmental disorder not otherwise specified.

101 (2) The department shall, by July 1, 2012, apply for a Medicaid waiver with the
102 Centers for Medicare and Medicaid Services within the United States Department of Health
103 and Human Services to implement an autism spectrum disorders program within the state
104 Medicaid program.

105 (3) The autism spectrum disorders waiver program shall:

106 (a) provide services to children between the ages of two years and six years with
107 autism spectrum disorders;

108 (b) accept applications for the program during periods of open enrollment;

109 (c) initially provide services for up to 500 children, as funding permits;

110 (d) convene a public process with the Department of Human Services to develop the
111 benefits and services to include in the autism waiver program, including:

112 (i) demonstrated effective treatments;

113 (ii) methods to engage family members in the treatment process; and

114 (iii) outreach to children in rural and underserved areas of the state; and

115 (e) include a mechanism to evaluate the cost, effectiveness, and outcomes of the
116 different services provided as part of the autism waiver program.

117 (4) The department shall report to the Legislature's Health and Human Services Interim
118 Committee by November 30, 2013, and prior to each November 30 thereafter while the waiver

119 is in effect regarding:

120 (a) the number of children diagnosed with autism spectrum disorder and the number of

121 children served under the waiver;

122 (b) success involving families in supporting treatment plans for autistic children;

123 (c) the cost of the autism waiver program; and

124 (d) the outcomes and effectiveness of the services offered by the autism waiver

125 program.

126 Section 3. Section **26-52-102** is amended to read:

127 **26-52-102. Definitions.**

128 As used in this chapter:

129 (1) "Account" means the Autism Treatment Account created in Section 26-52-201.

130 (2) "Applied behavior analysis" means the design, implementation, and evaluation of

131 environmental modifications using behavioral stimuli and consequences to produce socially

132 significant improvement in human behavior, including the use of direct observation,

133 measurement, and functional analysis of the relationship between environment and behavior

134 that are:

135 (a) necessary to develop, maintain, or restore, to the maximum extent practicable, the

136 functioning of an individual; and

137 (b) provided or supervised by a:

138 (i) board certified behavior analyst; or

139 (ii) a licensed psychologist with equivalent university training and supervised

140 experience who is working toward board certification in applied behavior analysis.

141 ~~[(2)]~~ (3) "Autism spectrum disorder" means a pervasive developmental disorder as

142 defined by the most recent edition of the Diagnostic and Statistical Manual on Mental

143 Disorders, including:

144 (a) Autistic disorder;

145 (b) Asperger's disorder; and

146 (c) pervasive developmental disorder not otherwise specified.

147 ~~[(3)]~~ (4) "Committee" means the Autism Treatment Account Advisory Committee

148 created under Section 26-52-202.

149 ~~[(4)]~~ "Early intensive behavior therapy" means therapy that:]

150 ~~[(a) involves intensive behavioral intervention over an extended period of time;]~~
151 ~~[(b) is evidence-based; and]~~
152 ~~[(c) is generally accepted by the medical community or the American Academy of~~
153 ~~Pediatrics as an effective treatment for young children with an autism spectrum disorder.]~~

154 Section 4. Section **26-52-201** is amended to read:

155 **26-52-201. Autism Treatment Account.**

156 (1) There is created within the General Fund a restricted account known as the Autism
157 Treatment Account.

158 (2) (a) The account shall consist of:

159 ~~[(a)]~~ (i) gifts, grants, devises, donations, and bequests of real property, personal
160 property, or services, from any source, or any other conveyance that may be made to the
161 account from private sources;

162 ~~[(b)]~~ (ii) interest and other earnings derived from the account money; and

163 ~~[(c)]~~ (iii) any additional amounts as appropriated by the Legislature.

164 (b) (i) For purposes of this subsection, the Affordable Care Act is as defined in Section
165 31A-2-212.

166 (ii) If an insurer contributes to the Autism Treatment Account, for purposes of
167 calculating an insurer's medical loss ratio under the Affordable Care Act, the insurance
168 commissioner shall consider the contribution to the Autism Treatment Account as a claims
169 payment by the insurer.

170 (3) (a) Except as provided under Subsection (3)(b), the executive director of the
171 department shall be responsible for administering the account.

172 (b) The committee shall be responsible for the following actions in relation to the
173 account, consistent with the requirements of this title:

174 (i) prioritizing and allocating uses for account money, as permitted under Subsection
175 (4);

176 (ii) determining ~~[what]~~ which providers ~~[or organizations]~~ of services for the treatment
177 of autism spectrum disorder qualify for disbursements from the account for services rendered;
178 and

179 (iii) authorization of all other distributions from the account, except that disbursements
180 for expenses authorized under ~~[Subsection]~~ Subsections (6) and (7) shall also require the

181 approval of the executive director.

182 (4) Account money may be used to:

183 (a) assist with the cost of evaluating and treating [~~persons~~] a child between the age of
184 two and six years with an autism spectrum disorder; and

185 (b) provide [~~persons~~] a child between the age of two and six years with an autism
186 spectrum disorder with treatments that utilize [~~early intensive behavior therapy; and~~] applied
187 behavior analysis and other proven effective treatments included under Subsection
188 26-52-202(4)(b)(ii).

189 [~~(c) provide grants to persons or organizations for providing the services described in~~
190 ~~Subsection (4)(a) or (b).]~~

191 (5) An individual who receives services that are paid for from the account [~~or who~~
192 ~~receives services through an organization or provider that receives payment from the account]~~
193 shall:

194 (a) be a resident of Utah;

195 (b) have been diagnosed by a qualified professional as having an autism spectrum
196 disorder;

197 (c) be [~~younger than eight~~] between the age of two and six years [~~of age~~]; and

198 (d) have a need that can be met within the requirements of this [~~title~~] chapter.

199 (6) All actual and necessary operating expenses for the committee and staff shall be
200 paid by the account.

201 (7) [~~Account~~] No more than 9% of the account money may [~~not~~] be used for
202 administrative or other expenses of the Department of Health [~~that are not normally provided~~
203 ~~for by legislative appropriation~~].

204 (8) All interest and other earnings derived from the account money shall be deposited
205 into the account.

206 (9) The state treasurer shall invest the money in the account under Title 51, Chapter 7,
207 State Money Management Act.

208 Section 5. Section **26-52-202** is amended to read:

209 **26-52-202. Autism Treatment Account Advisory Committee -- Membership --**
210 **Time limit.**

211 (1) (a) There is created an Autism Treatment Account Advisory Committee consisting

212 of ~~five~~ six members appointed by the governor to two-year terms of office as follows:

213 (i) one person holding a doctorate degree who has experience in treating persons with
214 an autism spectrum disorder;

215 (ii) one person who is a Board Certified Behavior Analyst;

216 ~~[(ii)]~~ (iii) one person who is a physician licensed under Title 58, Chapter 67, Utah
217 Medical Practice Act, or Title 58, Chapter 68, Utah Osteopathic Medical Practice Act, who has
218 completed a residency program in pediatrics;

219 ~~[(iii)]~~ (iv) one person who is employed in the Department of Health; and

220 ~~[(iv)]~~ (v) two persons from the community who are familiar with autism spectrum
221 disorders and their effects, diagnosis, treatment, rehabilitation, and support needs, including:

222 (A) family members of a person with an autism spectrum disorder;

223 (B) representatives of an association which advocates for persons with an autism
224 spectrum disorder; and

225 (C) specialists or professionals who work with persons with autism spectrum disorders.

226 (b) Notwithstanding the requirements of Subsection (1)(a), the governor shall, at the
227 time of appointment or reappointment, adjust the length of terms to ensure that the terms of
228 committee members are staggered so that approximately half of the committee is appointed
229 every year.

230 (c) If a vacancy occurs in the committee membership for any reason, a replacement
231 may be appointed for the unexpired term.

232 (2) The department shall provide staff support to the committee.

233 (3) (a) The committee shall elect a chair from the membership on an annual basis.

234 (b) A majority of the committee constitutes a quorum at any meeting, and, if a quorum
235 exists, the action of the majority of members present shall be the action of the committee.

236 (c) The executive director may remove a committee member:

237 (i) if the member is unable or unwilling to carry out the member's assigned
238 responsibilities; or

239 (ii) for good cause.

240 (4) The committee may, in accordance with Title 63G, Chapter 3, Utah Administrative
241 Rulemaking Act, make rules governing the committee's activities, which rules shall:

242 (a) comply with the requirements of this title; and

243 (b) include:

244 (i) qualification criteria and procedures for selecting ~~[service and treatment providers~~
245 ~~that receive disbursements from the account, which criteria shall give additional consideration~~
246 ~~to providers that are willing to use low interest loans when providing services to individuals;~~
247 ~~and] children who may qualify for assistance from the account;~~

248 (ii) qualifications, criteria, and procedures for evaluating the services and providers to
249 include in the program, which shall include at least:

250 (A) applied behavior analysis provided by or supervised by a Board Certified Behavior
251 Analyst;

252 (B) collaboration with existing tele-health networks to reach children in rural and
253 under-served areas of the state; and

254 (C) methods to engage family members in the treatment process; and

255 ~~[(ii)] (iii) provisions to address and avoid conflicts of interest that may arise in relation~~
256 ~~to[:]~~ the committee's work.

257 ~~[(A) the committee's selection of providers and persons that receive referrals,~~
258 ~~disbursements, or assistance from the account; and]~~

259 ~~[(B) other matters that may constitute a conflict of interest.]~~

260 (5) The committee shall meet as necessary to carry out its duties and shall meet upon a
261 call of the committee chair or a call of a majority of the committee members~~[-but no more than~~
262 ~~four times per year].~~

263 (6) The committee shall comply with the procedures and requirements of:

264 (a) Title 52, Chapter 4, Open and Public Meetings Act; and

265 (b) Title 63G, Chapter 2, Government Records Access and Management Act.

266 (7) Committee members shall receive no compensation or per diem allowance for their
267 services.

268 (8) (a) Not later than November 30 of each year, the committee shall provide a written
269 report summarizing the activities of the committee to:

270 ~~[(a)]~~ (i) the executive director of the department;

271 ~~[(b)]~~ (ii) the Legislature's Health and Human Services Interim Committee; and

272 ~~[(c)]~~ (iii) the Legislature's Health and Human Services Appropriations Subcommittee.

273 (b) The report under Subsection (8)(a) shall include:

274 (i) the number of children diagnosed with autism spectrum disorder who are receiving
275 services under this chapter;

276 (ii) the types of services provided to children under this chapter; and

277 (iii) results of any evaluations on the effectiveness of treatments and services provided
278 under this chapter.

279 Section 6. Section **26-52-203** is enacted to read:

280 **26-52-203. Administration of services for eligible individuals.**

281 (1) (a) The department shall establish a mechanism to:

282 (i) identify the children who are eligible to receive services from the account in
283 accordance with the standards for eligibility established in rules adopted by the committee
284 under Subsection 26-52-202(4); and

285 (ii) review and pay for services provided to a child under this chapter.

286 (b) The department may contract with another state agency or a private entity to assist
287 with the mechanism to identify eligible children, provide for services, and pay for services.

288 (2) The department, or the entity selected to assist the department under Subsection (1)
289 may negotiate with providers of the services that are eligible under this chapter to maximize
290 efficiencies and quality of services to children.

291 Section 7. Section **49-20-411** is enacted to read:

292 **49-20-411. Autism Pilot Program.**

293 (1) As used in this section:

294 (a) "Applied behavior analysis" means the design, implementation, and evaluation of
295 environmental modifications using behavioral stimuli and consequences to produce socially
296 significant improvement in human behavior, including the use of direct observation,
297 measurement, and functional analysis of the relationship between environment and behavior
298 that are:

299 (i) necessary to develop, maintain, or restore, to the maximum extent practicable, the
300 functioning of an individual; and

301 (ii) provided or supervised by a board certified behavior analyst or a licensed
302 psychologist with equivalent university training and supervised experience.

303 (b) "Autism spectrum disorder" means a pervasive developmental disorder, as defined
304 by the most recent edition of the Diagnostic and Statistical Manual on Mental Disorders,

305 including:

306 (i) autistic disorder;

307 (ii) asperger's disorder; and

308 (iii) a pervasive developmental disorder not otherwise specified.

309 (c) "Treatment of autism spectrum disorders" means any treatment generally accepted

310 by the medical community or the American Academy of Pediatrics as an effective treatment for

311 an individual with an autism spectrum disorder, including applied behavior analysis.

312 (2) (a) Beginning July 1, 2012 and ending July 1, 2014, the Public Employees' Benefit

313 and Insurance Program shall provide a pilot program for the treatment of autism spectrum

314 disorders in accordance with Subsection (2)(b) for up to 50 children who:

315 (i) are between the age of two and six years old by July 1, 2012;

316 (ii) enroll in the pilot program on or before July 1, 2012; and

317 (iii) have a parent who is enrolled in a health plan that was offered under this chapter

318 on or before January 1, 2012.

319 (b) The autism services provided in this pilot program shall include:

320 (i) diagnosis of autism spectrum disorder by a physician or qualified mental health

321 professional, and the development of a treatment plan;

322 (ii) applied behavior analysis provided by a certified behavior analyst or someone with

323 equivalent training for a child with an autism spectrum disorder; and

324 (iii) an annual maximum benefit of \$30,000 for autism spectrum disorder treatments

325 with the following cost sharing from the parents of the child with autism spectrum disorder:

326 (A) the parents will pay the first \$250 of expenses for autism treatments provided by

327 the pilot program;

328 (B) the pilot program will pay 80% of the cost of the treatment after the first \$250, and

329 the parents will pay 20% of the cost of treatment; and

330 (C) the pilot program will pay a maximum of a \$150 per day for treatment of autism

331 spectrum disorder under Subsection (1)(c).

332 (3) The autism pilot program is a limited pilot to study the efficacy of providing autism

333 treatment and is not a mandate for coverage of autism treatment within the health plans offered

334 by the Public Employees' Benefit and Insurance Program.

335 **Section 8. Appropriation.**

336 Under the terms and conditions of Title 63J, Chapter 1, Budgetary Procedures Act, the
337 following sums of money are appropriated from resources not otherwise appropriated, or
338 reduced from amounts previously appropriated, out of the funds or accounts indicated for the
339 fiscal year beginning July 1, 2011 and ending June 30, 2012. These are additions to any
340 amounts previously appropriated for fiscal year 2012.

341 To Department of Human Services - Child and Family Services
342 From General Fund, One-time (\$1,500,000)

343 Schedule of Programs:
344 Service Delivery (\$1,500,000)

345 To Department of Health - Medicaid Optional Services
346 From General Fund, One-time \$1,500,000

347 Schedule of Programs:
348 Other Optional Services \$1,500,000

349 The Legislature intends that the Department of Health use the appropriation of
350 \$1,500,000 to provide services and treatment for children with autism spectrum disorder
351 between the age of two to six years within Medicaid.

352 Under Section 63J-1-603 of the Utah Code, the Legislature intends that up to
353 \$3,000,000 of appropriations provided for the Department of Health - Medicaid Mandatory
354 Services line item not lapse at the close of Fiscal Year 2012. The use of any nonlapsing funds
355 is limited to a pilot project to provide services and treatment for children with autism spectrum
356 disorder between the age of two to six years.

357 Under Section 63J-1-603 of the Utah Code, the Legislature intends that up to
358 \$6,000,000 of appropriations provided for the Department of Health - Medicaid Optional
359 Services line item not lapse at the close of Fiscal Year 2012. The use of any nonlapsing funds
360 is limited to a pilot project to provide services and treatment for children with autism spectrum
361 disorder between the age of two to six years.

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363 \$3,000,000 of appropriations provided for the Department of Health - Medicaid Mandatory
364 Services line item not lapse at the close of Fiscal Year 2013. The use of any nonlapsing funds
365 is limited to a pilot project to provide services and treatment for children with autism spectrum
366 disorder between the age of two to six years.

367 Under Section 63J-1-603 of the Utah Code, the Legislature intends that up to
368 \$6,000,000 of appropriations provided for the Department of Health - Medicaid Optional
369 Services line item not lapse at the close of Fiscal Year 2013. The use of any nonlapsing funds
370 is limited to a pilot project to provide services and treatment for children with autism spectrum
371 disorder between the age of two to six years.

372 The Legislature intends that the Department of Health provide services and treatment
373 for children with autism spectrum disorder between the age of two to six years within Medicaid
374 from nonlapsing funds provided for this purpose up to a maximum of \$6,000,000 in state
375 funds. The department shall inform the Legislature if expenditures by line item for these
376 services require a subsequent transfer of nonlapsing funds.

377 Under Section 63J-1-603 of the Utah Code, the Legislature intends that the cost of
378 services for the autism treatment pilot program in Section 49-20-411 shall be paid for from the
379 surplus in the public employees' state risk pool contingency reserve.