

**AUTISM PROGRAM AMENDMENTS**

2014 GENERAL SESSION

STATE OF UTAH

**Chief Sponsor: Ronda Rudd Menlove**

Senate Sponsor: Curtis S. Bramble

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**LONG TITLE**

**General Description:**

This bill amends provisions of the Utah Health Code and the Utah State Retirement and Insurance Benefit Act related to programs for the treatment of autism spectrum disorder.

**Highlighted Provisions:**

This bill:

- ▶ requires the Department of Health to establish, through a Medicaid waiver, an ongoing program for the treatment of qualified children with autism spectrum disorder;
- ▶ requires the Public Employee Insurance and Benefit Program to establish an ongoing program for the treatment of qualified children with autism spectrum disorder; and
- ▶ makes technical and conforming amendments.

**Money Appropriated in this Bill:**

None

**Other Special Clauses:**

None

**Utah Code Sections Affected:**

AMENDS:

**26-18-407**, as enacted by Laws of Utah 2012, Chapter 402

**26-52-102**, as last amended by Laws of Utah 2012, Chapter 402

**26-52-201**, as last amended by Laws of Utah 2012, Chapter 402

30 26-52-202, as last amended by Laws of Utah 2012, Chapters 242 and 402

31 26-52-203, as enacted by Laws of Utah 2012, Chapter 402

32 49-20-411, as enacted by Laws of Utah 2012, Chapter 402

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

35 Section 1. Section 26-18-407 is amended to read:

36 **26-18-407. Medicaid waiver for autism spectrum disorder.**

37 (1) ~~[For purposes of]~~ As used in this section ["autism]:

38 (a) "Autism spectrum disorder" ~~[means a pervasive developmental disorder]~~ is as

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

40 Disorders~~[, including:]~~ or a recent edition of a professionally accepted diagnostic manual.

41 ~~[(a) autistic disorder;]~~

42 ~~[(b) asperger's disorder; and]~~

43 ~~[(c) pervasive developmental disorder not otherwise specified.]~~

44 (b) "Program" means the autism spectrum disorder program created in Subsection (3).

45 (c) "Qualified child" means a child who is:

46 (i) at least two years of age but less than seven years of age; and

47 (ii) diagnosed with an autism spectrum disorder by a qualified professional.

48 (2) The department shall~~[, by July 1, 2012,]~~ apply for a Medicaid waiver with the  
49 Centers for Medicare and Medicaid Services within the United States Department of Health  
50 and Human Services to implement ~~[an autism spectrum disorders program]~~, within the state  
51 Medicaid program, the program described in Subsection (3).

52 ~~[(3) The autism spectrum disorders waiver program shall:]~~

53 ~~[(a) provide services to children between the ages of two years and six years with~~  
54 ~~autism spectrum disorders;]~~

55 (3) The department shall offer an autism spectrum disorder program that:

56 (a) as funding permits, provides treatment for autism spectrum disorders to qualified  
57 children; and

58 (b) [~~accept~~] accepts applications for the program during periods of open enrollment[;].  
59 [~~(c) initially provide services for up to 500 children, as funding permits;~~]

60 (4) The department shall:

61 [~~(4)~~] (a) convene a public process with the Department of Human Services to [~~develop~~]  
62 determine the benefits and services [to include in the autism waiver program, including] the  
63 program shall offer qualified children that considers, in addition to any other relevant factor:

- 64 (i) demonstrated effective treatments;
- 65 (ii) methods to engage family members in the treatment process; and
- 66 (iii) outreach to qualified children in rural and underserved areas of the state; and
- 67 [~~(c) include a mechanism to~~]

68 (b) evaluate the [~~cost, effectiveness, and outcomes of the different services provided as~~  
69 ~~part of the autism waiver~~] ongoing results, cost, and effectiveness of the program.

70 [~~(4)~~] (5) The department shall annually report to the Legislature's Health and Human  
71 Services Interim Committee [~~by November 30, 2013, and prior to~~] before each November 30  
72 [~~thereafter~~] while the waiver is in effect regarding:

- 73 (a) the number of [~~children diagnosed with autism spectrum disorder and the number~~  
74 ~~of~~] qualified children served under the waiver;
- 75 (b) success involving families in supporting treatment plans for autistic children;
- 76 (c) the cost of the [~~autism waiver~~] program; and
- 77 (d) the [~~outcomes~~] results and effectiveness of the [~~services offered by the autism~~  
78 ~~waiver~~] program.

79 Section 2. Section **26-52-102** is amended to read:

80 **26-52-102. Definitions.**

81 As used in this chapter:

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

83 (2) "Applied behavior analysis" means the design, implementation, and evaluation of  
84 environmental modifications using behavioral stimuli and consequences to produce socially  
85 significant improvement in human behavior, including the use of direct observation,

86 measurement, and functional analysis of the relationship between environment and behavior  
87 that are:

88 (a) necessary to develop, maintain, or restore, to the maximum extent practicable, the  
89 functioning of an individual; and

90 (b) provided or supervised by, for the purposes of the program, a:

91 (i) board certified behavior analyst; or

92 (ii) [a] licensed psychologist with equivalent university training and supervised  
93 experience who is working toward board certification in applied behavior analysis.

94 (3) "Autism spectrum disorder" [~~means a pervasive developmental disorder~~] is as  
95 defined by the most recent edition of the Diagnostic and Statistical Manual on Mental  
96 Disorders[~~, including:~~] or a recent edition of a professionally accepted diagnostic manual.

97 [~~(a) autistic disorder;~~]

98 [~~(b) asperger's disorder; and~~]

99 [~~(c) pervasive developmental disorder not otherwise specified.~~]

100 (4) "Committee" means the Autism Treatment Account Advisory Committee created  
101 under Section [26-52-202](#).

102 (5) "Program" means the services offered by the committee using funds from the  
103 account.

104 (6) "Qualified child" means a child who:

105 (a) is at least two years of age but less than seven years of age;

106 (b) is diagnosed with an autism spectrum disorder; and

107 (c) meets the other qualification criteria established by the committee under Subsection  
108 [26-52-202\(4\)](#).

109 (7) "Treatment" means the treatment of autism spectrum disorder.

110 Section 3. Section **26-52-201** is amended to read:

111 **26-52-201. Autism Treatment Account -- Medical loss ratio calculation -- Use of**  
112 **account.**

113 (1) There is created within the General Fund a restricted account known as the Autism

114 Treatment Account.

115 (2) ~~[(a)]~~ The account shall consist of:

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

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

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

121 ~~[(b) (i) For purposes of this subsection, the Affordable Care Act is as defined in~~  
122 ~~Section [31A-2-212](#).]~~

123 ~~[(ii)]~~ (3) If an insurer contributes to the ~~[Autism Treatment Account]~~ account, for  
124 purposes of calculating an insurer's medical loss ratio under the ~~[Affordable Care Act,]~~  
125 PPACA, as defined in Section [31A-1-301](#), the insurance commissioner shall consider the  
126 contribution to the ~~[Autism Treatment Account as]~~ account to be a claims payment by the  
127 insurer.

128 ~~[(3)(a)]~~ (4) Except as provided ~~[under]~~ in Subsection ~~[(3)(b)]~~ (5), the executive  
129 director of the department shall be responsible for administering the account.

130 ~~[(b)]~~ (5) The committee shall ~~[be responsible for the following actions in relation to the~~  
131 ~~account]~~, consistent with the requirements of this title:

132 ~~[(i) prioritizing and allocating uses for account money,]~~

133 (a) prioritize spending of account funds, as permitted under Subsection ~~[(4)]~~ (6);

134 ~~[(ii) determining which providers of services for the treatment of autism spectrum~~  
135 ~~disorder]~~

136 (b) determine which treatment providers qualify for disbursements from the account  
137 for services rendered; and

138 ~~[(iii) authorization of]~~

139 (c) authorize all other distributions from the account, except that disbursements for  
140 expenses authorized under Subsections ~~[(6) and (7)]~~ (6)(b) and (c) shall also require the  
141 approval of the executive director.

142           ~~[(4)]~~ (6) Account money may be used to:

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

145           ~~[(b) provide a child between the age of two and six years with an autism spectrum~~  
146 ~~disorder with treatments that utilize]~~

147           (a) evaluate and treat a qualified child by utilizing applied behavior analysis [and] or  
148 other proven effective treatments [included under] as determined by the committee under  
149 Subsection 26-52-202(4)(b)[(ii)].;

150           ~~[(5) An individual who receives services that are paid for from the account shall:]~~

151           ~~[(a) be a resident of Utah;]~~

152           ~~[(b) have been diagnosed by a qualified professional as having an autism spectrum~~  
153 ~~disorder;]~~

154           ~~[(c) be between the age of two and six years; and]~~

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

156           ~~[(6) AH]~~ (b) pay all actual and necessary operating expenses for the committee and  
157 staff [shall be paid by the account.]; and

158           ~~[(7) No more than 9% of the account money may be used for]~~

159           (c) pay administrative or other expenses of the Department of Health related to the  
160 program, except where those expenses are greater than 9% of the total account funds.

161           ~~[(8)]~~ (7) All interest and other earnings derived from the account money shall be  
162 deposited into the account.

163           ~~[(9)]~~ (8) The state treasurer shall invest the money in the account under Title 51,  
164 Chapter 7, State Money Management Act.

165           Section 4. Section 26-52-202 is amended to read:

166           **26-52-202. Autism Treatment Account Advisory Committee -- Membership --**

167 **Time limit.**

168           (1) (a) There is created an Autism Treatment Account Advisory Committee consisting  
169 of six members appointed by the governor to two-year terms of office as follows:

- 170 (i) one ~~[person]~~ individual holding a doctorate degree who has experience in treating  
171 persons with an autism spectrum disorder;
- 172 (ii) one ~~[person who is a]~~ board certified behavior analyst;
- 173 (iii) one ~~[person who is a]~~ physician licensed under Title 58, Chapter 67, Utah Medical  
174 Practice Act, or Title 58, Chapter 68, Utah Osteopathic Medical Practice Act, who has  
175 completed a residency program in pediatrics;
- 176 (iv) one ~~[person who is employed in]~~ employee of the Department of Health; and
- 177 (v) two ~~[persons from the community]~~ individuals who are familiar with autism  
178 spectrum disorders and their effects, diagnosis, treatment, rehabilitation, and support needs,  
179 including:
- 180 (A) family members of a person with an autism spectrum disorder;
- 181 (B) representatives of an association which advocates for persons with an autism  
182 spectrum disorder; and
- 183 (C) specialists or professionals who work with persons with autism spectrum disorders.
- 184 (b) Notwithstanding the requirements of Subsection (1)(a), the governor shall, at the  
185 time of appointment or reappointment, adjust the length of terms to ensure that the terms of  
186 committee members are staggered so that approximately half of the committee is appointed  
187 every year.
- 188 (c) If a vacancy occurs in the committee membership for any reason, ~~[a replacement~~  
189 ~~may be appointed]~~ the governor may appoint a replacement for the unexpired term.
- 190 (2) The department shall provide staff support to the committee.
- 191 (3) (a) The committee shall elect a chair from the membership on an annual basis.
- 192 (b) A majority of the committee constitutes a quorum at any meeting, and, if a quorum  
193 exists, the action of the majority of members present shall be the action of the committee.
- 194 (c) The executive director may remove a committee member:
- 195 (i) if the member is unable or unwilling to carry out the member's assigned  
196 responsibilities; or
- 197 (ii) for good cause.

198 (4) The committee ~~[may]~~ shall, in accordance with Title 63G, Chapter 3, Utah  
199 Administrative Rulemaking Act, make rules governing the committee's activities~~[- which rules  
200 shall: (a)]~~ that comply with the requirements of this title[-; and], including rules that:

201 ~~[(b) include:]~~

202 ~~[(i) qualification criteria and procedures for selecting children who may qualify for  
203 assistance from the account;]~~

204 ~~[(ii) qualifications, criteria, and procedures for evaluating the services and providers to  
205 include in the program, which shall include at least:]~~

206 (a) establish criteria and procedures for selecting qualified children to participate in the  
207 program;

208 (b) establish the services, providers, and treatments to include in the program, and the  
209 qualifications, criteria, and procedures for evaluating the providers and treatments; and

210 (c) address and avoid conflicts of interest that may arise in relation to the committee  
211 and its duties.

212 (5) As part of its duties under Subsection 26-52-201(5), the committee shall, at  
213 minimum:

214 ~~[(A)]~~ (a) offer applied behavior analysis provided by or supervised by a board certified  
215 behavior analyst or a licensed psychologist with equivalent university training and supervised  
216 experience;

217 ~~[(B) collaboration]~~ (b) collaborate with existing telehealth networks to reach children  
218 in rural and under-served areas of the state; and

219 ~~[(C) methods to]~~ (c) engage family members in the treatment process~~[-; and].~~

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

222 ~~[(5)]~~ (6) The committee shall meet as necessary to carry out its duties and shall meet  
223 upon a call of the committee chair or a call of a majority of the committee members.

224 ~~[(6)]~~ (7) The committee shall comply with the procedures and requirements of:

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



226 (b) Title 63G, Chapter 2, Government Records Access and Management Act.  
227 [(7)] (8) Committee members [~~shall receive no~~] may not receive compensation or per  
228 diem allowance for their services.

229 [(8)-(a)] (9) Not later than November 30 of each year, the committee shall provide a  
230 written report summarizing the activities of the committee to:

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

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

233 [(iii)] (c) the Legislature's Social Services Appropriations Subcommittee.

234 [(b)] (10) The report under Subsection [(8)-(a)] (9) shall include:

235 [(i)] (a) the number of children diagnosed with autism spectrum disorder who are  
236 receiving services under this chapter;

237 [(ii)] (b) the types of services provided to qualified children under this chapter; and

238 [(iii)] (c) results of any evaluations on the effectiveness of treatments and services  
239 provided under this chapter.

240 Section 5. Section **26-52-203** is amended to read:

241 **26-52-203. Administration of services for eligible individuals.**

242 (1) [(a)] The department shall establish [~~a mechanism~~] procedures to:

243 [(i)] (a) identify the qualified children who are eligible to receive services from the  
244 account in accordance with the standards for eligibility established in rules adopted by the  
245 committee under Subsection 26-52-202(4); and

246 [(ii)] (b) review and pay for services provided to a qualified child under this chapter.

247 [(b)] (2) The department may contract with another state agency or a private entity to  
248 [~~assist with the mechanism to~~] identify [~~eligible~~] qualified children, provide for services, and  
249 pay for services.

250 [(2)] (3) The department, or [~~the entity selected to assist the department~~] an entity  
251 contracted under Subsection [(1)] (2), may negotiate with providers of the services [~~that are~~  
252 eligible] offered under this chapter to maximize [~~efficiencies~~] the efficiency and quality of  
253 services offered to qualified children.

254 Section 6. Section **49-20-411** is amended to read:

255 **49-20-411. Autism Spectrum Disorder Treatment Program.**

256 (1) As used in this section:

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

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

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

266 (b) "Autism spectrum disorder" [~~means a pervasive developmental disorder;~~] is as  
267 defined by the most recent edition of the Diagnostic and Statistical Manual on Mental  
268 Disorders[~~;~~ ~~including;~~] or a recent edition of a professionally accepted diagnostic manual.

269 [~~(i) autistic disorder;~~]

270 [~~(ii) asperger's disorder; and~~]

271 [~~(iii) a pervasive developmental disorder not otherwise specified.~~]

272 (c) "Health plan" does not include the health plan offered by the Public Employees'  
273 Benefit and Insurance Program that is the state's designated essential health benefit package for  
274 purposes of the PPACA, as defined in Section [31A-1-401](#).

275 (d) "Parent" means a parent of a qualified child.

276 (e) "Program" means the autism spectrum disorder treatment program created in  
277 Subsection (2).

278 (f) "Qualified child" means a child who is:

279 (i) at least two years of age but less than seven years of age;

280 (ii) diagnosed with an autism spectrum disorder by a qualified professional; and

281 (iii) the eligible dependent of a state employee who is enrolled in a health plan that is

282 offered under this chapter.

283 ~~[(e)]~~ (g) "Treatment ~~[of autism spectrum disorders]~~" means any treatment generally  
284 accepted by the medical community or the American Academy of Pediatrics as an effective  
285 treatment for an individual with an autism spectrum disorder, including applied behavior  
286 analysis.

287 (2) ~~[(a) Beginning July 1, 2012 and ending July 1, 2014, the]~~ The Public Employees'  
288 Benefit and Insurance Program shall ~~[provide]~~ offer a ~~[pilot]~~ program for the treatment of  
289 autism spectrum disorders in accordance with Subsection ~~[(2)(b) for up to 50 children who:]~~  
290 (3).

291 ~~[(i) are between the age of two and six years old by July 1, 2012;]~~

292 ~~[(ii) enroll in the pilot program on or before July 1, 2012; and]~~

293 ~~[(iii) have a parent who is a state employee and is enrolled in a health plan that was  
294 offered under this chapter on or before January 1, 2012.]~~

295 ~~[(b) The autism services provided in this pilot program shall include:]~~

296 (3) The program shall offer qualified children:

297 ~~[(i)]~~ (a) diagnosis of autism spectrum disorder by a physician or qualified mental health  
298 professional, and the development of a treatment plan;

299 ~~[(ii)]~~ (b) applied behavior analysis provided by a certified behavior analyst or someone  
300 with equivalent training ~~[for a child with an autism spectrum disorder]; and~~

301 ~~[(iii)]~~ (c) an annual cost-shared maximum benefit of \$30,000 ~~[for autism spectrum  
302 disorder treatments with the following cost sharing from the parents of the child with autism  
303 spectrum disorder] toward the cost of treatment that the program covers, where, for each  
304 qualified child, for the cost of the treatment:~~

305 ~~[(A) the parents will pay the first \$250 of expenses for autism treatments provided by  
306 the pilot program;]~~

307 ~~[(B) the pilot program will pay 80% of the cost of the treatment after the first \$250, and  
308 the parents will pay 20% of the cost of treatment; and]~~

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

310 ~~spectrum disorder under Subsection (1)(c):]~~

311 (i) the parent pays the first \$250;

312 (ii) after the first \$250, the program pays 80% and the parent pays 20%;

313 (iii) the program pays no more than \$150 per day; and

314 (iv) the program pays no more than \$24,000 total.

315 ~~[(3)]~~ (4) The [autism pilot] purpose of the program is [a limited pilot] to study the  
316 efficacy of providing autism treatment and is not a mandate for coverage of autism treatment  
317 within the health plans offered by the Public Employees' Benefit and Insurance Program.

318 (5) The program shall be funded on an ongoing basis through the risk pool established  
319 in Subsection [49-20-202\(1\)\(a\)](#).