

**Representative Ronda Rudd Menlove** proposes the following substitute bill:

1                                   **PILOT PROGRAM FOR AUTISM SPECTRUM**

2                                   **DISORDERS SERVICES**

3                                   2012 GENERAL SESSION

4                                   STATE OF UTAH

5                                   **Chief Sponsor: Ronda Rudd Menlove**

6                                   Senate Sponsor: \_\_\_\_\_

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8                                   **LONG TITLE**

9                                   **General Description:**

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

14                                  **Highlighted Provisions:**

15                                  This bill:

- 16                                  ▶ provides a funding mechanism for the autism Medicaid waiver;
- 17                                  ▶ directs the state Medicaid program to develop a Medicaid waiver to provide proven  
18 effective services for children between the ages of two to six with autism spectrum  
19 disorder;
- 20                                  ▶ requires the department to convene a public process to develop the Medicaid  
21 waiver;
- 22                                  ▶ requires the department to measure the cost and the effectiveness of the treatments  
23 and services for autism spectrum disorder;
- 24                                  ▶ requires the department to report to the Legislative Health and Human Services  
25 Interim Committee by November 30, 2013;



- 26 ▶ amends provisions of the Autism Treatment Account to:
- 27 • update terminology used for autism treatment options;
- 28 • amend the uses of the account to focus on diagnosis and treatment of children
- 29 between the ages of two to six years old with autism spectrum disorders; and
- 30 • create a mechanism to provide and pay for services for children and to evaluate
- 31 effectiveness of treatments; and
- 32 ▶ establishes a pilot program for autism services for certain children of state
- 33 employees administered by the Public Employees' Benefit and Insurance Program.

34 **Money Appropriated in this Bill:**

35 This bill appropriates in fiscal year 2011-12:

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

40 This bill provides intent language making certain Fiscal Year 2012 appropriations in the  
41 Department of Health nonlapsing for purposes of studying children with autism  
42 spectrum disorder.

43 **Other Special Clauses:**

44 None

45 **Utah Code Sections Affected:**

46 AMENDS:

- 47 **26-18-402**, as last amended by Laws of Utah 2010, Chapter 340
- 48 **26-52-102**, as enacted by Laws of Utah 2010, Chapter 69
- 49 **26-52-201**, as enacted by Laws of Utah 2010, Chapter 69
- 50 **26-52-202**, as last amended by Laws of Utah 2011, Chapter 340

51 ENACTS:

- 52 **26-18-407**, Utah Code Annotated 1953
- 53 **26-52-203**, Utah Code Annotated 1953
- 54 **49-20-411**, Utah Code Annotated 1953



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

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

58 **26-18-402. Medicaid Restricted Account.**

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

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

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

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

70 (iii) any penalties imposed and collected under:

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

72 (B) Section 19-1-206;

73 (C) Section 79-2-404;

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

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

76 (F) Section 72-6-107.5.

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

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

83 (3) For fiscal years 2008-09, 2009-10, [~~and~~] 2010-11, 2011-12, and 2012-13 the  
84 following funds are nonlapsing:

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

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

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

90 **26-18-407. Medicaid waiver for autism spectrum disorder.**

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

94 (a) Autistic disorder;

95 (b) Asperger's disorder; and

96 (c) pervasive developmental disorder not otherwise specified.

97 (2) The department shall, by July 1, 2012, apply for a Medicaid waiver with the  
98 Centers for Medicare and Medicaid Services within the United States Department of Health  
99 and Human Services to implement a autism spectrum disorder program within the state  
100 Medicaid program and the Children's Health Insurance Program in accordance with this  
101 section.

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

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

105 (b) accept application for the program during periods of open enrollment;

106 (c) initially provide services for 500 children, as funding permits;

107 (d) convene a public process with the Department of Human Services to develop the  
108 benefits and services to include in the autism waiver program, which services should include  
109 demonstrated effective treatments; and

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

112 (4) The department shall report to the Legislature's Health and Human Services Interim  
113 Committee by November 30, 2013, and prior to each November 30 thereafter while the waiver  
114 is in effect regarding:

115 (a) the number of children diagnosed with autism spectrum disorder and the number of  
116 children served under the waiver;

117 (b) the cost of the autism waiver program; and

118 (c) the outcomes and effectiveness of the services offered by the autism waiver

119 program.

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

121 **26-52-102. Definitions.**

122 As used in this chapter:

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

124 (2) "Applied behavior analysis" means the design, implementation, and evaluation of  
125 environmental modifications, using behavioral stimuli and consequences, to produce socially  
126 significant improvement in human behavior, including the use of direct observation,  
127 measurement, and functional analysis of the relationship between environment and behavior  
128 that are:

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

131 (b) provided or supervised by a:

132 (i) board certified behavior analyst; or

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

135 ~~[(2)]~~ (3) "Autism spectrum disorder" means a pervasive developmental disorder as  
136 defined by the most recent edition of the Diagnostic and Statistical Manual on Mental  
137 Disorders, including:

138 (a) Autistic disorder;

139 (b) Asperger's disorder; and

140 (c) pervasive developmental disorder not otherwise specified.

141 ~~[(3)]~~ (4) "Committee" means the Autism Treatment Account Advisory Committee  
142 created under Section 26-52-202.

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

144 ~~[(a) involves intensive behavioral intervention over an extended period of time;]~~

145 ~~[(b) is evidence-based; and]~~

146 ~~[(c) is generally accepted by the medical community or the American Academy of~~  
147 ~~Pediatrics as an effective treatment for young children with an autism spectrum disorder.]~~

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

149 **26-52-201. Autism Treatment Account.**

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

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

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

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

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

158 (b) (i) For purposes of this subsection, the Affordable Care Act is as defined in Section  
159 31A-2-212.

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

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

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

168 (i) prioritizing and allocating uses for account money, as permitted under Subsection  
169 (4);

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

172 (iii) authorization of all other distributions from the account, except that disbursements  
173 for expenses authorized under Subsection (6) shall also require the approval of the executive  
174 director.

175 (4) Account money may be used to:

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

178 (b) provide ~~[persons]~~ a child between the age of two years and six years with an autism  
179 spectrum disorder with treatments that utilize ~~[early intensive behavior therapy; and]~~ applied  
180 behavior analysis and other proven effective treatments included under Subsection

181 26-52-202(4)(b)(iii).

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

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

187 (a) be a resident of Utah;

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

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

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

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

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

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

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

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

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

204 (1) (a) There is created an Autism Treatment Account Advisory Committee consisting  
 205 of ~~[five]~~ six members appointed by the governor to two-year terms of office as follows:

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

208 (ii) one person who is a Board Certified Behavior Analyst - Doctoral Level;

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

212           ~~[(iii)]~~ (iv) one person who is employed in the Department of Health; and  
213           ~~[(iv)]~~ (v) two persons from the community who are familiar with autism spectrum  
214 disorders and their effects, diagnosis, treatment, rehabilitation, and support needs, including:  
215           (A) family members of a person with an autism spectrum disorder;  
216           (B) representatives of an association which advocates for persons with an autism  
217 spectrum disorder; and  
218           (C) specialists or professionals who work with persons with autism spectrum disorders.  
219           (b) Notwithstanding the requirements of Subsection (1)(a), the governor shall, at the  
220 time of appointment or reappointment, adjust the length of terms to ensure that the terms of  
221 committee members are staggered so that approximately half of the committee is appointed  
222 every year.  
223           (c) If a vacancy occurs in the committee membership for any reason, a replacement  
224 may be appointed for the unexpired term.  
225           (2) The department shall provide staff support to the committee.  
226           (3) (a) The committee shall elect a chair from the membership on an annual basis.  
227               (b) A majority of the committee constitutes a quorum at any meeting, and, if a quorum  
228 exists, the action of the majority of members present shall be the action of the committee.  
229           (c) The executive director may remove a committee member:  
230               (i) if the member is unable or unwilling to carry out the member's assigned  
231 responsibilities; or  
232               (ii) for good cause.  
233           (4) The committee may, in accordance with Title 63G, Chapter 3, Utah Administrative  
234 Rulemaking Act, make rules governing the committee's activities, which rules shall:  
235               (a) comply with the requirements of this title; and  
236               (b) include:  
237                   (i) ~~qualification criteria and procedures for selecting [service and treatment providers~~  
238 ~~that receive disbursements from the account, which criteria shall give additional consideration~~  
239 ~~to providers that are willing to use low interest loans when providing services to individuals;~~  
240 ~~and] individuals who may qualify for assistance from the account;~~  
241                   (ii) qualifications, criteria, and procedures for evaluating which services and providers  
242 will be included in the program, which shall include:



243 (A) applied behavior analysis provided by or supervised by a Board Certified Behavior  
244 Analyst; and

245 (B) collaboration with existing tele-health networks to reach rural and under-served  
246 areas of the state to assist with diagnosis of children; and

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

272 **26-52-203. Administration of services for eligible individuals.**

273 (1) The department shall establish a mechanism to review and pay for services

274 provided to individuals under this chapter. The department may contract with another state  
275 agency or a private entity to assist with the mechanism to provide for and pay for services.

276 (2) The department, or the entity selected to assist the department under Subsection (1)  
277 may negotiate with providers of the services that are eligible under this chapter to maximize  
278 efficiencies and quality of services to individuals.

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

280 **49-20-411. Autism Pilot Program.**

281 (1) As used in this section:

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

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

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

291 (b) "Autism spectrum disorder" means a pervasive developmental disorder, as defined  
292 by the most recent edition of the Diagnostic and Statistical Manual on Mental Disorders,  
293 including:

294 (i) autistic disorder;

295 (ii) asperger's disorder; and

296 (iii) pervasive developmental disorder not otherwise specified.

297 (c) "Treatment of autism spectrum disorders" means any treatment generally accepted  
298 by the medical community or the American Academy of Pediatrics as an effective treatment for  
299 an individual with an autism spectrum disorder, including applied behavior analysis.

300 (5) (a) Beginning July 1, 2012 and ending July 1, 2014, the state employee risk pool  
301 described in Section 49-20-202(1)(a) shall provide to state employees, treatment for the  
302 coverage of autism spectrum disorders in accordance with Subsection (5)(b) for up to 50  
303 children:

304 (i) who, by July 1, 2012, are between the age of two to six years old: and

- 305 (ii) who are enrolled in the pilot program on or before July 1, 2012.
- 306 (b) The autism services provided in this pilot program shall include:
- 307 (i) diagnosis of autism spectrum disorder by a physician or qualified mental health
- 308 professional, and the development of a treatment plan;
- 309 (ii) applied behavior analysis provided by a certified behavior analyst or someone with
- 310 equivalent training for a child with an autism spectrum disorder;
- 311 (c) an annual maximum benefit of \$30,000 for autism spectrum disorder treatments;
- 312 (d) a \$250 annual deductible that is separate frm the annual medical deductible;
- 313 (e) co-insurance of 80/20, which does not apply towards the out of pocket maximum
- 314 for medical insurance; and
- 315 (f) a \$150 per day maximum for treatment of autism spectrum disorder under
- 316 Subsection (1)(c).
- 317 (6) The Public Employees' Benefit and Insurance plan is instructed to pay for the cost
- 318 of services required by this section from the surplus in the state risk pool contingency reserve.

319 **Section 8. Appropriation.**

320 Under the terms and conditions of Title 63J, Chapter 1, Budgetary Procedures Act, the

321 following sums of money are appropriated from resources not otherwise appropriated, or

322 reduced from amounts previously appropriated, out of the funds or accounts indicated for the

323 fiscal year beginning July 1, 2011 and ending June 30, 2012. These are additions to any

324 amounts previously appropriated for fiscal year 2012.

325	<u>To Department of Human Services - Child and Family Services</u>	
326	<u>From General Fund, One-time</u>	<u>(\$1,500,000)</u>
327	<u>Schedule of Programs:</u>	
328	<u>Service Delivery</u>	<u>(\$1,500,000)</u>
329	<u>To Department of Health - Medicaid Optional Services</u>	
330	<u>From General Fund, One-time</u>	<u>\$1,225,000</u>
331	<u>Schedule of Programs:</u>	
332	<u>Other Optional Services</u>	<u>\$1,225,000</u>
333	<u>To Department of Health - Children's Health Insurance Program</u>	
334	<u>From General Fund, One-time</u>	<u>\$275,000</u>
335	<u>Schedule of Programs:</u>	

336 Children's Health Insurance Program \$275,000

337 The Legislature intends that the Department of Health use the appropriation of  
338 \$1,500,000 to provide services and treatment for children with autism spectrum disorder  
339 between the age of two to six years within Medicaid and the Children's Health Insurance  
340 Program.

341 Under Section 63J-1-603 of the Utah Code, the Legislature intends that up to  
342 \$3,000,000 of appropriations provided for the Department of Health - Medicaid Mandatory  
343 Services line item not lapse at the close of Fiscal Year 2012. The use of any nonlapsing funds  
344 is limited to a pilot project to provide services and treatment for children with autism spectrum  
345 disorder between the age of two to six years.

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347 \$6,000,000 of appropriations provided for the Department of Health - Medicaid Optional  
348 Services line item not lapse at the close of Fiscal Year 2012. The use of any nonlapsing funds  
349 is limited to a pilot project to provide services and treatment for children with autism spectrum  
350 disorder between the age of two to six years.

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354 is limited to a pilot project to provide services and treatment for children with autism spectrum  
355 disorder between the age of two to six years.

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357 \$3,000,000 of appropriations provided for the Department of Health - Medicaid Optional  
358 Services line item not lapse at the close of Fiscal Year 2013. The use of any nonlapsing funds  
359 is limited to a pilot project to provide services and treatment for children with autism spectrum  
360 disorder between the age of two to six years.

361 The Legislature intends that the Department of Health provide services and treatment  
362 for children with autism spectrum disorder between the age of two to six years within Medicaid  
363 and the Children's Health Insurance Program from nonlapsing funds provided for this purpose  
364 up to a maximum of \$3,000,000 in state funds. The department shall inform the Legislature if  
365 expenditures by line item for these services require a subsequent transfer of nonlapsing funds.

366 The Legislature intends that the Department of Health provide services and treatment

367 for children with autism spectrum disorder between the age of two to six years within the  
368 Children's Health Insurance Program from nonlapsing funds provided for this purpose up to a  
369 maximum of \$275,000 state funds. The Department shall inform the Legislature if  
370 expenditures by line item for these services require a subsequent transfer of nonlapsing funds.