

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: Curtis S. Bramble**

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 include services for children located in rural and
23 underserved areas of the state;
- 24 ▶ requires the department to measure the cost and the effectiveness of the treatments
25 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 evaluate effectiveness of treatments; and
- 36 ▶ establishes a pilot program for autism treatment 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;
- 42 ▶ to Department of Human Services - Child and Family Services
- 43 • from General Fund, One-time (\$1,500,000) to fund autism treatment; and
- 44 ▶ to the Department of Health - Medicaid Optional Services
- 45 • from General Fund, One-time \$3,000,000 to fund autism treatment.

46 This bill provides intent language making certain fiscal year 2012 appropriations in the
47 Department of Health nonlapsing for purposes of studying children with autism
48 spectrum disorders.

49 This bill appropriates for fiscal year 2012-13:

- 50 ▶ to Autism Treatment Restricted Account
- 51 • from General Fund, One-time \$1,000,000 to fund autism treatment.
- 52 ▶ to Department of Health - Family and Preparedness
- 53 • from Autism Treatment Restricted Account, One-time \$1,000,000 to fund
- 54 autism treatment.

55 Other Special Clauses:

56 None

57 Utah Code Sections Affected:

58 AMENDS:

59 **26-18-402**, as last amended by Laws of Utah 2010, Chapter 340

60 **26-52-102**, as enacted by Laws of Utah 2010, Chapter 69

61 **26-52-201**, as enacted by Laws of Utah 2010, Chapter 69

62 **26-52-202**, as last amended by Laws of Utah 2011, Chapter 340

63 ENACTS:

64 **26-18-407**, Utah Code Annotated 1953

65 **26-52-203**, Utah Code Annotated 1953

66 **49-20-411**, Utah Code Annotated 1953

67

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

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

70 **26-18-402. Medicaid Restricted Account.**

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

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

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

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

82 (iii) any penalties imposed and collected under:

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

84 (B) Section 19-1-206;

85 (C) Section 79-2-404;

- 86 (D) Section 63A-5-205;
- 87 (E) Section 63C-9-403; or
- 88 (F) Section 72-6-107.5.

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

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

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

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

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

101 Section 2. Section ~~26-18-407~~ is enacted to read:

102 **26-18-407. Medicaid waiver for autism spectrum disorder.**

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

106 (a) autistic disorder;

107 (b) asperger's disorder; and

108 (c) pervasive developmental disorder not otherwise specified.

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

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

- 114 (a) provide services to children between the ages of two years and six years with
- 115 autism spectrum disorders;
- 116 (b) accept applications for the program during periods of open enrollment;
- 117 (c) initially provide services for up to 500 children, as funding permits;
- 118 (d) convene a public process with the Department of Human Services to develop the
- 119 benefits and services to include in the autism waiver program, including:
- 120 (i) demonstrated effective treatments;
- 121 (ii) methods to engage family members in the treatment process; and
- 122 (iii) outreach to children in rural and underserved areas of the state; and
- 123 (e) include a mechanism to evaluate the cost, effectiveness, and outcomes of the
- 124 different services provided as part of the autism waiver program.

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

- 128 (a) the number of children diagnosed with autism spectrum disorder and the number of
- 129 children served under the waiver;
- 130 (b) success involving families in supporting treatment plans for autistic children;
- 131 (c) the cost of the autism waiver program; and
- 132 (d) the outcomes and effectiveness of the services offered by the autism waiver
- 133 program.

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

135 **26-52-102. Definitions.**

136 As used in this chapter:

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

138 (2) "Applied behavior analysis" means the design, implementation, and evaluation of
139 environmental modifications using behavioral stimuli and consequences to produce socially
140 significant improvement in human behavior, including the use of direct observation,
141 measurement, and functional analysis of the relationship between environment and behavior

142 that are:

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

145 (b) provided or supervised by a:

146 (i) board certified behavior analyst; or

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

149 ~~[(2)]~~ (3) "Autism spectrum disorder" means a pervasive developmental disorder as
150 defined by the most recent edition of the Diagnostic and Statistical Manual on Mental
151 Disorders, including:

152 (a) autistic disorder;

153 (b) asperger's disorder; and

154 (c) pervasive developmental disorder not otherwise specified.

155 ~~[(3)]~~ (4) "Committee" means the Autism Treatment Account Advisory Committee
156 created under Section 26-52-202.

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

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

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

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

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

163 **26-52-201. Autism Treatment Account -- Medical loss ratio calculation -- Use of**
164 **account.**

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

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

168 ~~[(a)]~~ (i) gifts, grants, devises, donations, and bequests of real property, personal
169 property, or services, from any source, or any other conveyance that may be made to the

170 account from private sources;

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

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

173 (b) (i) For purposes of this subsection, the Affordable Care Act is as defined in Section
174 31A-2-212.

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

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

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

183 (i) prioritizing and allocating uses for account money, as permitted under Subsection
184 (4);

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

188 (iii) authorization of all other distributions from the account, except that disbursements
189 for expenses authorized under ~~[Subsection]~~ Subsections (6) and (7) shall also require the
190 approval of the executive director.

191 (4) Account money may be used to:

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

194 (b) provide ~~[persons]~~ a child between the age of two and six years with an autism
195 spectrum disorder with treatments that utilize ~~[early intensive behavior therapy; and]~~ applied
196 behavior analysis and other proven effective treatments included under Subsection
197 26-52-202(4)(b)(ii).

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

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

203 (a) be a resident of Utah;

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

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

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

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

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

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

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

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

218 **26-52-202. Autism Treatment Account Advisory Committee -- Membership --**
219 **Time limit.**

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

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

224 (ii) one person who is a board certified behavior analyst;

225 ~~[(ii)]~~ (iii) one person who is a physician licensed under Title 58, Chapter 67, Utah

226 Medical Practice Act, or Title 58, Chapter 68, Utah Osteopathic Medical Practice Act, who has
227 completed a residency program in pediatrics;

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

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

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

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

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

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

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

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

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

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

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

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

248 (ii) for good cause.

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

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

252 (b) include:

253 (i) qualification criteria and procedures for selecting ~~service and treatment providers~~

254 ~~that receive disbursements from the account, which criteria shall give additional consideration~~
255 ~~to providers that are willing to use low interest loans when providing services to individuals;~~
256 ~~and] children who may qualify for assistance from the account;~~

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

259 (A) applied behavior analysis provided by or supervised by a board certified behavior
260 analyst or a licensed psychologist with equivalent university training and supervised
261 experience;

262 (B) collaboration with existing telehealth networks to reach children in rural and
263 under-served areas of the state; and

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

290 **26-52-203. Administration of services for eligible individuals.**

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

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

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

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

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

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

302 **49-20-411. Autism Pilot Program.**

303 (1) As used in this section:

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

309 (i) necessary to develop, maintain, or restore, to the maximum extent practicable, the

310 functioning of an individual; and

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

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

316 (i) autistic disorder;

317 (ii) asperger's disorder; and

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

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

322 (2) (a) Beginning July 1, 2012 and ending July 1, 2014, the Public Employees' Benefit
323 and Insurance Program shall provide a pilot program for the treatment of autism spectrum
324 disorders in accordance with Subsection (2)(b) for up to 50 children who:

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

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

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

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

330 (i) diagnosis of autism spectrum disorder by a physician or qualified mental health
331 professional, and the development of a treatment plan;

332 (ii) applied behavior analysis provided by a certified behavior analyst or someone with
333 equivalent training for a child with an autism spectrum disorder; and

334 (iii) an annual maximum benefit of \$30,000 for autism spectrum disorder treatments
335 with the following cost sharing from the parents of the child with autism spectrum disorder:

336 (A) the parents will pay the first \$250 of expenses for autism treatments provided by
337 the pilot program;

338 (B) the pilot program will pay 80% of the cost of the treatment after the first \$250, and
339 the parents will pay 20% of the cost of treatment; and

340 (C) the pilot program will pay a maximum of a \$150 per day for treatment of autism
341 spectrum disorder under Subsection (1)(c).

342 (3) The autism pilot program is a limited pilot to study the efficacy of providing autism
343 treatment and is not a mandate for coverage of autism treatment within the health plans offered
344 by the Public Employees' Benefit and Insurance Program.

345 **Section 8. Appropriation.**

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

351 To Department of Human Services - Child and Family Services

352 From General Fund, One-time (\$1,500,000)

353 Schedule of Programs:

354 Service Delivery (\$1,500,000)

355 To Department of Health - Medicaid Optional Services

356 From General Fund, One-time \$1,500,000

357 Schedule of Programs:

358 Other Optional Services \$1,500,000

359 To Department of Health - Medicaid Optional Services

360 From General Fund, One-time \$3,000,000

361 Schedule of Programs:

362 Other Optional Services \$3,000,000

363 The Legislature intends that the Department of Health use the appropriations of
364 \$3,000,000 to provide services and treatment for children with autism spectrum disorder
365 between the age of two to six years within Medicaid.

366 Under the terms and conditions of Title 63J, Chapter 1, Budgetary Procedures Act, the
367 following sums of money are appropriated from resources not otherwise appropriated, or
368 reduced from amounts previously appropriated, out of the funds or accounts indicated for the
369 fiscal year beginning July 1, 2012 and ending June 30, 2013. These are additions to any
370 amounts previously appropriated for fiscal year 2013.

371 To General Fund Restricted - Autism Treatment Account

372 From General Fund, One-time \$1,000,000

373 Schedule of Programs:

374 General Fund Autism Treatment Restricted Account \$1,000,000

375 To Department of Health - Family Health and Preparedness

376 From General Fund Restricted - Autism Treatment

377 Account, One-time \$1,000,000

378 Schedule of Programs:

379 Children with Special Health Care Needs \$1,000,000

380 Under Section 63J-1-603 of the Utah Code, the Legislature intends that up to
381 \$4,500,000 of appropriations provided for the Department of Health - Medicaid Optional
382 Services line item not lapse at the close of Fiscal Year 2012. The use of any nonlapsing funds
383 is limited to the autism waiver program to provide services and treatment for children with
384 autism spectrum disorder between the age of two to six years.

385 Under Section 63J-1-603 of the Utah Code, the Legislature intends that up to
386 \$4,500,000 of appropriations provided for the Department of Health - Medicaid Optional
387 Services line item not lapse at the close of Fiscal Year 2013. The use of any nonlapsing funds
388 is limited to the autism waiver program to provide services and treatment for children with
389 autism spectrum disorder between the age of two to six years.

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