

LEGISLATING AUTISM COVERAGE: THE CONSERVATIVE INSURANCE MANDATE

LORRI SHEALY UNUMB*

A mandate is a law that tells someone what to do.¹ An insurance mandate is a law that tells an insurance company what to do, usually dictating what or who must be covered.² Many conservative lawmakers dislike insurance mandates because they believe in free market, not dictated, solutions to health care problems.³

Since 2007, numerous state legislatures have enacted insurance mandates relating to treatment for autism.⁴ In the absence of an autism insurance mandate, health insurers typically do not cover “one of the most commonly prescribed therapies” for autism, which is an intensive therapeutic intervention based on Applied Behavior Analysis (commonly called “ABA therapy”).⁵ The autism insurance mandates that have swept the nation during the last decade require coverage for ABA therapy and other care that is ordered by a physician and deemed medically necessary to treat autism.⁶

Among the state legislatures that have mandated coverage for autism treatment, including ABA therapy, are very conservative legislatures like South Carolina, Texas, Louisiana, Kansas, Alaska, and Utah.⁷ This article (1) examines why so many legislatures that traditionally resist insurance mandates embrace this one, and (2) suggests that enactment of an

* Vice President, State Government Affairs, Autism Speaks; Adjunct Professor, Autism and the Law, George Washington University.

1. BLACK’S LAW DICTIONARY 1047 (9th ed. 2011).

2. *CAHI Identifies 2,271 State Health Insurance Mandates*, COUNSEL FOR AFFORDABLE HEALTH INS. (Apr. 9, 2013), http://www.cahi.org/cahi_contents/newsroom/article.asp?id=1115.

3. *See, e.g., Emily Le Coz, Autism Insurance Bill Passes Senate Floor*, THE CLARION LEDGER (Feb. 12, 2015, 10:01 AM), <http://www.clarionledger.com/story/politicalledger/2015/02/10/autism-insurance-bill-passes-senate-floor/23179583/>.

4. *State Initiatives*, AUTISM SPEAKS, <http://www.autismspeaks.org/state-initiatives> (last visited Feb. 18, 2015).

5. Sandra Gray, *Shriver Center Autism Experts Explain New Insurance Legislation to TV3’s Worcester News Tonight*, UNIV. MASS. MED. SCH. (July 15, 2014), <http://www.umassmed.edu/news/news-archives/2014/07/Shriver-Center-autism-experts-explain-new-insurance-legislation-to-TV3s-Worcester-News-Tonight/>.

6. *See State Initiatives, supra* note 4.

7. *See id.*

autism insurance mandate is not only consistent with traditional conservative ideology but is in fact an embodiment of conservative core values.

INSURANCE MANDATES

Virtually all laws are mandates. A legislator—or *lawmaker*—who does not believe in mandates generally might be in the wrong business. With regard to insurance mandates in particular, some legislators who oppose them are ideologically driven and others may be in part persuaded by the vehement opposition of the insurance industry and other powerful lobbying interests.⁸ There are several types of insurance mandates:

- *Benefits mandates* require that a particular health insurance benefit be included in an insurance policy.⁹ Benefits mandates can be further subdivided into:
 - *Treatment mandates*, which require that a particular treatment or service (or equipment related to the treatment or service) be included in an insurance policy.¹⁰ An example is a law that requires coverage for mastectomies.
 - *Condition mandates*, which require that a particular condition or illness be covered, usually for screening, diagnosis, and treatment.¹¹ An example is a law that requires coverage for all health care services related to breast cancer.
- *Provider mandates* require that a particular type of health insurance provider be included in an insurance policy.¹² An example is a law that requires coverage of chiropractors.
- *Population mandates* require that a particular population be covered by an insurance policy.¹³ An example is a law that requires foster children to be covered as dependents.

8. See Jill Quadagno, *Why the United States has No National Health Insurance: Stakeholder Mobilization Against the Welfare State*, 45 J. HEALTH & SOC. BEHAV. 25, 25 (2004).

9. See *Health Insurance Benefit Mandates in California State and Federal Law*, CAL. HEALTH BENEFITS REVIEW PROGRAM 1 (Nov. 30, 2012), http://www.chbrp.org/docs/ca_mandates.pdf.

10. *Id.*

11. *Id.*

12. *Provider Mandates*, U.S. HEALTH POLICY GATEWAY, <http://ushealthpolicygateway.com/vii-key-policy-issues-regulation-and-reform/1-health-care-regulation/health-insurance-regulation-2/mandated-health-providers/> (last updated July 12, 2014).

13. See VICTORIA CRAIG BUNCE, COUNCIL FOR AFFORDABLE HEALTH INS., HEALTH INSURANCE MANDATES IN THE STATES 2012 1 (2013), available at http://www.cahi.org/cahi_contents/resources/pdf/Mandatesinthestates2012Execsumm.pdf.

- *Terms mandates* require that coverage be provided per specified terms or conditions.¹⁴ An example is a mental health parity law that requires mental health coverage to be *on par* with coverage for other medical conditions.

A *mandated offering* is distinct from a mandate, in that it requires health insurers to offer purchasers (individuals or employers) the option to purchase the benefit.¹⁵ When a mandated offering is enacted, an insurer may meet its obligation by either including the benefit as part of its insurance products or offering coverage for the benefit separately at an additional cost.¹⁶ The latter option is sometimes called a *rider*.¹⁷

Insurance mandates date back to at least the 1940s.¹⁸ In 1956, Massachusetts passed a law requiring dependent coverage for handicapped children.¹⁹ The number of mandate bills skyrocketed in the 1980s and 1990s, and as many as 1,000 of them had passed by the end of the millennium.²⁰

Researchers attribute the proliferation of mandated benefit laws to several factors. First, these laws were a product of the managed care “backlash” of the 1990s. Specifically, the rise of health maintenance organizations (HMOs), and their willingness to use utilization and network controls led interest groups and elected officials to believe that legislation was necessary to curtail health plans’ ability to deny services or limit access to certain provider types Second, political factors combined to make these types of bills more likely to be enacted since the costs are relatively small and diffused over a large population while the benefits are concentrated on a small group of stakeholders

14. See *Fact Sheet on Mandated Benefits in Health Insurance Policies*, WIS. OFFICE OF THE COMM’R INS. 4 (June 2012), http://oci.wi.gov/pub_list/pi-019.pdf.

15. See *State Laws Regulating or Mandating Mental Health Benefits*, NAT’L CONFERENCE OF STATE LEGISLATURES, <http://www.ncsl.org/research/health/mental-health-benefits-state-mandates.aspx> (last updated Apr. 2015).

16. See *id.*

17. *Policy Riders: Your Policy, Your Way*, N.Y. LIFE INS. CO., <http://www.newyorklife.com/learn-and-plan/your-policy-your-way> (last visited Apr. 21, 2015).

18. See KAISER FAMILY FOUND., *TIMELINE: A HISTORY OF HEALTH REFORM IN THE U.S.* 4 (2010), available at <https://kaiserfamilyfoundation.files.wordpress.com/2011/03/5-02-13-history-of-health-reform.pdf> (discussing Harry Truman’s passage of the first national insurance mandates in the 1940s).

19. Nicole M. Bellows et al., *State-Mandated Benefit Review Laws*, 41 HEALTH SERVICES RES. 1104, 1105 (2006).

20. *Id.*

who have a strong interest in actively advocating for the legislation.²¹

Although far less active than state legislatures, the United States Congress has also passed mandate legislation:

- In 1978, Congress passed the Pregnancy Discrimination Act of 1978, amending Title VII of the federal Civil Rights Act.²² This law requires coverage for pregnancy and requires that it be on par with other coverage.²³
- In 1996, Congress passed the Newborns' and Mothers' Health Protection Act of 1996.²⁴ This law mandates that, if a policy has a maternity benefit, then that benefit must include at least a 48-hour hospital stay following childbirth or a 96-hour stay for a cesarean section.²⁵
- In 1998, Congress passed the Women's Health and Cancer Rights Act of 1998.²⁶ This law mandates that, if a policy has a mastectomy benefit, then that benefit must include coverage for certain reconstructive surgery and other post-mastectomy services.²⁷
- In 2008, Congress passed the Mental Health Parity and Addiction Equity Act of 2008.²⁸ This law, which was modified by the Patient Protection and Affordable Care Act of 2010, mandates that, if a policy has a benefit for mental health or substance use disorder services, then that benefit must be on par, in terms of financial requirements and treatment limitations, with the predominant terms or limits applied to medical and surgical benefits.²⁹
- In 2010, Congress passed the Affordable Care Act,³⁰ which contains a number of mandates such as:
 - Coverage of "essential health benefits" in certain plans;³¹

21. CAL. HEALTH BENEFITS REVIEW PROGRAM, IMPLEMENTATION OF ASSEMBLY BILL 1540: ANALYSIS OF LEGISLATION MANDATING OR REPEALING HEALTH CARE BENEFITS AND SERVICES 15 (2013) (internal citations omitted).

22. Pregnancy Discrimination Act of 1978, Pub. L. No. 95-555, 92 Stat. 2076 (amending 42 U.S.C. § 2000e (2014)).

23. See 42 U.S.C. § 2000e(k) (2014).

24. Newborns' and Mothers' Health Protection Act of 1996, Pub. L. No. 104-204, 110 Stat. 2935.

25. See 29 U.S.C. § 1185 (2014).

26. Women's Health and Cancer Rights Act of 1998, Pub. L. No. 105-277, 112 Stat. 2681-436.

27. 29 U.S.C. § 1185b (2014).

28. Mental Health Parity and Addiction Equity Act of 2008, Pub. L. No. 110-343, 112 Stat. 3765.

29. See 29 U.S.C. § 1185a (2014).

30. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119.

31. 42 U.S.C. § 18022(b)(1) (2014).

- A prohibition on pre-existing condition exclusions, first for children and then for adults;³²
- Coverage of certain preventive services, without cost-sharing;³³ and
- A prohibition on the lifetime and annual limits on the dollar value of benefits.³⁴

Not all of these federal mandates apply to all types of health insurance policies. For example, most of the ACA's mandates do not apply to plans that are grandfathered, i.e., in existence and essentially unchanged since March 23, 2010.³⁵ Likewise, not all state mandates apply to all state-regulated policies. An insurance mandate, whether federal or state, typically specifies the types of policies to which it applies. Sometimes individual policies (issued to an individual for the individual and his or her dependents) or small group policies (issued to businesses employing, typically, fewer than fifty employees) are carved out of mandate legislation.³⁶ Additionally, state mandates can reach only state-regulated—or *fully-funded*—plans and cannot reach *self-funded* plans, which are governed by ERISA and subject to regulation only by Congress.³⁷ Most large corporations operate self-funded health benefit plans and thus are not subject to state mandates.³⁸

Around the turn of the millennium, insurers and some business interests organized in concerted opposition to mandates, arguing primarily that mandates cause premiums to increase unreasonably, which in turn leads to fewer people being able to afford insurance at all.³⁹ Against this backdrop of a spike in mandates over the last few decades and mounting

32. 42 U.S.C. § 18011(a)(4)(B)(i) (2014).

33. § 18022(b)(1)(I).

34. § 18011(a)(4)(A)(ii); § 18011(a)(4)(B)(i).

35. § 18011.

36. § 18024 (2014) (defining a large group as more than 100 employees). Most states define a large group as a group that is not a small group, i.e., more than fifty employees. The ACA allows states to treat groups with more than fifty but fewer than 100 employees as “large” until 2016.

37. Self-funded plans are not really “insurance,” because the employer who funds its own health plans is not contracting out the risk to a third party, which is a key ingredient of “insurance.” 42 U.S.C. § 18021 (2014). Self-funded employers usually contract out the administration of the plan to a third party insurance company, but the risk remains with employer itself. *See* 29 U.S.C. § 1144 (2014).

38. Many self-funded corporations voluntarily include any benefits that are mandated by the state in which the company is headquartered, or sometimes by any state in which the corporation has offices. *See* LAWRENCE F. WOLPER, HEALTH CARE ADMINISTRATION: PLANNING, IMPLEMENTING, AND MANAGING ORGANIZED DELIVERY SYSTEMS 551 (4th ed. 2004).

39. *See* VIRGINIA GRAY ET AL., INTEREST GROUPS AND HEALTH CARE REFORM ACROSS THE UNITED STATES 129 (2013).

organized opposition to all mandate legislation, the autism community began to seek coverage via state legislative action.⁴⁰

AUTISM

Autism is a complex neurodevelopmental disorder that occurs through no apparent fault of the affected individual or his family.⁴¹ Having no physical abnormality, autism is characterized by developmental abnormality in social communication, accompanied by excessively repetitive behaviors, restricted interests, and insistence on sameness.⁴²

Although symptoms are unique in intensity and combination for every individual, common features include delayed speech or lack of speech; repetitive, obsessive actions; inflexible adherence to routine; unusual sensitivity to light, sound, or touch; and lack of social or emotional reciprocity.⁴³

Typically manifesting by age three, autism is a lifelong disability that is more common than childhood cancer, juvenile diabetes, and pediatric AIDS combined.⁴⁴ According to the Centers for Disease Control (CDC), the current prevalence of autism is around one in sixty-eight persons,⁴⁵ a staggering increase from a prevalence of approximately one in 2,500 just a few decades ago.⁴⁶ While reportedly four times more common in boys than in girls, autism occurs in all racial, ethnic, and socioeconomic categories.⁴⁷

The breadth of autism affects the family in many ways, from the heartbreak of not being able to hold one's child to the exhaustion accompanying a child's inability to sleep. Children with autism often suffer from comorbid conditions, such as gastrointestinal disorders, sleep disturbance, seizures, tics, oral motor deficits, anxiety disorders, depression,

40. See generally LORRI SHEALY UNUMB & DANIEL R. UNUMB, *AUTISM AND THE LAW: CASES, STATUTES, AND MATERIALS* 7 (2011); *CAHI Identifies 2,271 State Health Insurance Mandates*, COUNSEL FOR AFFORDABLE HEALTH INS. (Apr. 9, 2013), http://www.cahi.org/cahi_contents/newsroom/article.asp?id=1115.

41. This section providing background on autism is drawn from the author's book. LORRI UNUMB, *AUTISM AND THE LAW: CASES, STATUTES, AND COMMENTARY* (2011).

42. The diagnostic criteria for autism spectrum disorder is found in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition under Code 299.0. See Figures 1 and 2. *DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL HEALTH DISORDERS: [hereinafter DSM-5]* (Am. Psychiatric Ass'n 5th ed.) (2013).

43. *Id.*

44. Geraldine Dawson, *Congressional Briefing on Military Children with Autism*, AUTISM SPEAKS (Jan. 31, 2012), <https://www.autismspeaks.org/blog/2012/01/31/congressional-briefing-military-children-autism>.

45. Ctrs. for Disease Control and Prevention, *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010*, 63 *MMWR SURVEILLANCE SUMMARIES* 2, 11 (2014), available at <http://www.cdc.gov/mmwr/pdf/ss/ss6302.pdf>.

46. *Id.* at 2.

47. *Id.* at 9.

and attention deficit hyperactivity disorder.⁴⁸ On average, medical expenditures for individuals with autism are four to six times greater than for individuals without autism.⁴⁹ Nevertheless, due to difficulty accessing or affording care, children with autism are more likely than other special needs children to delay or forego care entirely.⁵⁰ Their families have greater out-of-pocket costs, diminished work hours, more lost income, and more negative health plan experiences.⁵¹

Autism obtained official recognition in the twentieth century, after Dr. Leo Kanner of the Johns Hopkins Hospital published a paper in 1943 describing a group of children with impaired language skills and social interactions and restricted, repetitive behaviors.⁵² Kanner used the term “early infantile autism” to refer to the condition.⁵³ About the same time that Kanner made his observations, an Austrian pediatrician named Hans Asperger published an account of children with an “autistic psychopathy.”⁵⁴ The work of Kanner and Asperger helped to establish autism as a distinct condition.⁵⁵ In 1980, the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders for the first time placed “infantile autism” in a separate diagnostic category.⁵⁶

48. TREATING AUTISM & AUTISM TREATMENT TRUST, MEDICAL COMORBIDITIES IN AUTISM SPECTRUM DISORDERS 3 (2013), available at <http://nationalautismassociation.org/pdf/MedicalComorbiditiesinASD2013.pdf>.

49. *Autism Spectrum Disorder: Data and Statistics*, CTNS. FOR DISEASE CONTROL, <http://www.cdc.gov/ncbddd/autism/data.html> (last updated Feb. 26, 2015).

50. Michael D. Kogan et al., *A National Profile of the Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005–2006*, 122 PEDIATRICS e1149, e1149 (2008).

51. Susan H. Busch & Colleen L. Barry, *Does Private Insurance Adequately Protect Families of Children with Mental Health Disorders?* 124 PEDIATRICS S399, S399 (2009); Guillermo Montes & Jill S. Halterman, *Association of Childhood Autism Spectrum Disorders and Loss of Family Income*, 121 PEDIATRICS e821, e821 (2008).

52. Leo Kanner, *Autistic Disturbances of Affective Contact*, 2 NERVOUS CHILD 217 (1943).

53. Leo Kanner, *Early Infantile Autism*, 25 PEDIATRICS 211 (1944).

54. Hans Asperger, “*Autistic Psychopathy*” in *Childhood*, AUTISM AND ASPERGER SYNDROME 37 (Utah Fifth ed. & trans., 1991).

55. Autism appears to long predate the studies of Kanner and Asperger:

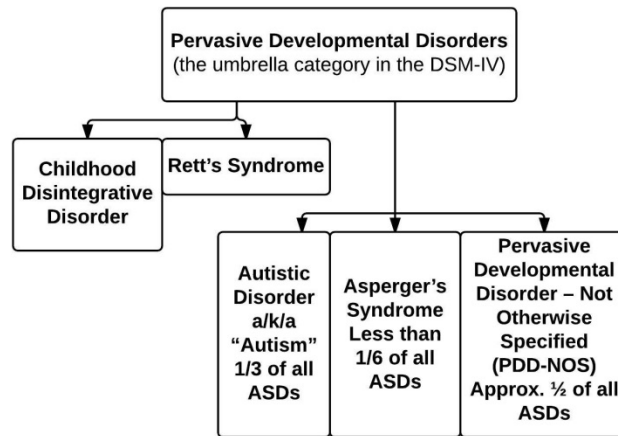
As early as 1867, attention was drawn to mental disorders in young children with severe distortion of the developmental process. Disintegrative psychosis, a condition similar to autism, was first described in 1908. In 1919, Lightner Witmer, considered the father of Clinical Psychology in the United States, described a two-and-a-half-year-old boy, who behaved like an autistic child. In the 1920’s, a Russian child psychiatrist described children having characteristics similar to those described by Asperger.

Vidya Bhushan Gupta, *The History, Definition, and Classification of Pervasive Developmental Disorders*, 33 THE EXCEPTIONAL PARENT 58 (2003).

56. Jeffrey P. Baker, *Autism at 70—Redrawing the Boundaries*, 369 NEW ENG. J. MED. 1089, 1091 (2013)

The term “autism” (from the Greek word “autos” for “self”) has been used somewhat imprecisely, even by those in the autism community. In common use, “autism” is over-generalized to represent a complex spectrum of related developmental disorders. The three primary diagnoses that historically fell within the traditional category of autism spectrum disorders were:

- Autistic Disorder (also known as *early infantile autism*, *classic autism*, *childhood autism*, or *Kanner’s autism*);
- Asperger’s Disorder; and
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).⁵⁷

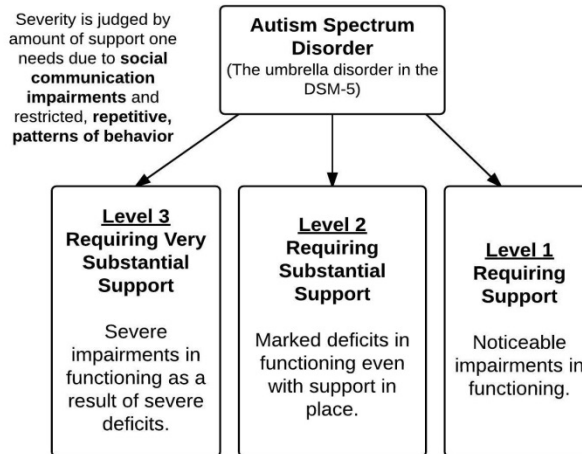


Some people loosely used the term “autism” to mean “Autistic Disorder”; others used “autism” to refer to the entire spectrum. The three autism spectrum disorders were part of a larger category known in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) as “Pervasive Developmental Disorders.”⁵⁸ The fifth edition of the DSM, released in 2013, altered the traditional categorization of the autism spectrum disorders; the distinct diagnoses of autistic disorder, Asperger’s disorder, and pervasive developmental disorder-not otherwise specified were consolidated into a single diagnosis of “Autism Spectrum Disorder” – with varying levels of severity across a single continuum.⁵⁹

57. *Autism Spectrum Disorder (ASD)*, CTRS. FOR DISEASE CONTROL AND PREVENTION, <http://www.cdc.gov/ncbddd/autism/facts.html> (last updated Feb. 24, 2015).

58. THE DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS, [hereinafter DSM-IV-TR] 40 (Am. Psychiatric Ass’n 4th ed.) (2000).

59. DSM-5, *supra* note 42, at xlii.



Across the autism continuum or spectrum, people with ASD vary greatly in type and severity of deficits.⁶⁰ People with mild autism spectrum disorder (perhaps those formerly classified with Asperger’s disorder) may be only slightly impaired and lead relatively normal lives, while persons on the other end of the spectrum may have to be institutionalized for their safety or the safety of their families.⁶¹ The autism spectrum contains verbal and non-verbal people, self-injurious people, persons with savant gifts, and others who obsess over narrow topics, such as train schedules or calendars.⁶²

The complexity of an ASD diagnosis is further heightened by the fundamental mystery that surrounds the cause of this disorder.⁶³ Despite much research, there has yet to be conclusive evidence of a cause for ASD.⁶⁴ Kanner believed that it was caused by cold, unloving mothers.⁶⁵ Bruno Bettelheim, a renowned professor of child development, perpetuated this misinterpretation of autism.⁶⁶ Their promotion of the idea that unloving mothers, termed “refrigerator mothers,” caused their children’s

60. DSM-5, *supra* note 42, at 50.

61. See *Autism Spectrum Disorder*, NAT’L INST. OF MENTAL HEALTH, <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml#part7> (last visited Mar. 10, 2015).

62. DSM-5, *supra* note 42, at 67.

63. See generally Lisa T. Eyler et al., *A Failure of Left Temporal Cortex to Specialize for Language is an Early Emerging and Fundamental Property of Autism*, BRAIN: A J. OF NEUROLOGY 2 (2012).

64. *Id.*

65. AUTISM SPEAKS, DIAGNOSIS, CAUSES & SYMPTOMS 5 (2010), available at http://www.autismspeaks.org/sites/default/files/100_day_kit_section_1.pdf.

66. F. Edward Yazbak, *Autism in the United States: A Perspective*, 8 J. OF AM. PHYSICIANS & SURGEONS 103, 103 (2003).

autism created a generation of parents who carried the tremendous burden of guilt for their children's disability.⁶⁷

ASD is now considered to likely be the result of a genetic predisposition interacting with environmental factors.⁶⁸ Since the unknown cause cannot be the target of treatment, therapies that seek to alleviate the debilitating nature of the symptoms must be tailored for the unique experience of every individual.⁶⁹ Fortunately, the spectrum nature of ASD, while complicating accurate diagnosis, also allows individuals to move along the symptom continuum.⁷⁰ With intensive treatment, the symptoms of ASD can often be made far less disabling.⁷¹ This substantial potential for improvement gives rise to both tremendous hope and tremendous pressure on parents struggling to secure adequate and timely treatment for their child. It is why the stakes are so high, and early, efficient, and intensive treatment is critical in the autism context. With proper treatment and education, a non-verbal child may gain the ability to communicate; a non-social child may gain interaction skills.⁷² While individuals who make such progress are not "cured" and typically do not lose the autism diagnosis, they might overcome the disabling aspects of the condition enough to participate as functioning members of society.⁷³

Indeed, the immense potential for improvement is one aspect of autism spectrum disorder that sets it apart from most developmental or intellectual disabilities.⁷⁴ Under the DSM-IV, the autism spectrum disorders appeared on Axis I, which was for *Clinical Disorders and Other Conditions That May Be a Focus of Clinical Attention*, rather than Axis II, which was for the more static *Personality Disorders and Mental Retardation*.⁷⁵ And because autism spectrum disorder is dynamic, families affected by autism are more likely to spend themselves into debt in pursuit of progress than are families affected by other special needs. According to the 2005/2006 National Survey of Children with Special Health Care Needs, the presence of autism in a family causes financial problems and

67. David Farrugia, *Exploring Stigma: Medical Knowledge and the Stigmatization of Parents and Children Diagnosed with Autism Spectrum Disorder*, 31 SOC. OF HEALTH & ILLNESS 1011, 1013 (2009).

68. *Autism Fact Sheet*, NAT'L INST. OF NEUROLOGICAL DISORDERS AND STROKE, http://www.ninds.nih.gov/disorders/autism/detail_autism.htm (last visited Jan. 9, 2015).

69. Laura Schreibman, Ph.D., *Individualized Treatments Are Future of Autism Therapies, According to Psychologist*, <http://www.apa.org/news/press/releases/2012/04/autism-therapies.aspx> (April 25, 2012).

70. *Signs and Symptoms*, CTRS FOR DISEASE CONTROL AND PREVENTION, <http://www.cdc.gov/ncbddd/autism/signs.html> (last visited Feb. 14, 2015).

71. UNUMB, *supra* note 40.

72. *Id.*

73. *Id.*

74. NAT'L INST. OF NEUROLOGICAL DISORDERS AND STROKE, *supra* note 68.

75. See <http://smhp.psych.ucla.edu/conted2/dsm.htm>. The DSM-5 abandons the multi-axial system. DSM-5, *supra* note 42, at 16.

work reductions for parents significantly more often than the presence of other special health care needs in children.⁷⁶

Sadly, few individuals with autism reach their potential, because most do not have consistent access to treatment that is appropriate in quality and quantity. Appropriate care is both difficult to find and difficult to afford. The Agency for Healthcare Research and Quality has concluded that the “delivery and organization of care for ASD is very fragmented, with pieces scattered about in the primary care, school, and specialty clinical settings. It is left to the families and caregivers of patients with ASD to find and assemble these pieces.”⁷⁷

Societal systems and institutions have simply not kept pace with the increased prevalence of autism, nor with the scientific advances in treatment. Law is one of many disciplines that lag behind, which exacerbates the difficulty that families experience in accessing proper clinical and educational interventions. Recent advances in autism awareness, however, have spurred legislatures and courts across the country to respond to the autism crisis, and a proliferation of autism-related statutes and cases has resulted.⁷⁸ Autism insurance mandates have been a focal point of this proliferation, and legislatures have been driven to mandate insurance benefits in part because of the unavailability of coverage for applied behavior analysis.⁷⁹

APPLIED BEHAVIOR ANALYSIS

The most widely-prescribed and thoroughly examined treatment for autism is Applied Behavior Analysis, or ABA therapy.⁸⁰ Behavior analysis

76. On the survey, 43% of the families with autism reported that the condition caused financial problems for the family, while only 19.6% of the surveyed families of children with other special health care needs reported that the condition caused financial problems for the family. Likewise, 29.9% of families with autism reported spending eleven or more hours per week providing or coordinating the child’s health care, while 10.9% of surveyed families with a special need other than autism spent that amount of time. Furthermore, a 57.1% of families with autism reported that the autism caused a family member to cut back or stop working, while 21.6% reported such reduction or stoppage as a result of having a child with a non-autism special health care need. DATA RESOURCE CENTER FOR CHILD AND ADOLESCENT HEALTH, NATIONAL PROFILE OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND AUTISM SPECTRUM DISORDERS: KEY FINDINGS FROM THE 2009/10 NS-CSHCN & 2011/12 NSCH 2 (2013).

77. AGENCY FOR HEALTHCARE RESEARCH AND QUALITY, DEPT. OF HEALTH AND HUMAN SERVS., THERAPIES FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS 2 (2009), available at [http://effectivehealthcare.ahrq.gov/ehc/products/106/366/Therapies%20for%20Autism%20Spectrum%20Disorder%20\(2-9-2010\).pdf](http://effectivehealthcare.ahrq.gov/ehc/products/106/366/Therapies%20for%20Autism%20Spectrum%20Disorder%20(2-9-2010).pdf).

78. UNUMB, *supra* note 40, at 62, 148, 162, 182, 189, 222, 245, 271.

79. *Id.* at 85–86, 89–91, 93, 95. See Appendix 1 for additional information.

80. See, e.g., *Report of the Recommendations - Autism/Pervasive Developmental Disorders*, N.Y. STATE DEPT. OF HEALTH EARLY INTERVENTION PROGRAM, http://www.health.state.ny.us/community/infants_children/early_intervention/disorders/autism/ (last visited Mar. 18, 2015); JULIE YOUNG ET AL., IMPAQ INT’L, AUTISM SPECTRUM

is a scientific approach to understanding behavior and how it is affected by the environment.⁸¹ Applied behavior analysis (ABA) is the application of this approach to address socially important problems and to bring about meaningful behavior change.⁸² Practitioners of Applied Behavior Analysis (“behavior analysts”) can bring about significant change in an individual’s behavior, both increasing useful behaviors and reducing or eliminating harmful or undesired behaviors.⁸³

Behavior analysts examine and seek to adjust three components when examining an individual’s behavior:

- an *antecedent*, such as a command or request;
- a *behavior*, in response to the antecedent; and
- a *consequence*.⁸⁴

The consequence depends on the behavior and can include positive reinforcement, such as social praise or a desired snack. Success in an ABA program is measured by direct observation and data collection and analysis.⁸⁵ ABA treatments involve a one-on-one child-therapist interaction and often range in intensity from twenty-five to forty hours per week.⁸⁶

Studies show that, if ABA therapy is administered intensively and by properly trained therapists, approximately half of the treated individuals can “overcome” their autistic characteristics to such an extent that they can enter school indistinguishable from their peers.⁸⁷ And the other half can make significant gains, too, such that they need less support for the rest of their lives.⁸⁸ In a landmark study published in 1987, Dr. Ivar Lovaas of UCLA reported that 47% of the children who received intensive ABA therapy by properly trained therapists achieved normal intellectual

DISORDERS (ASDs) SERVICES: FINAL REPORT ON ENVIRONMENTAL SCAN (2010) *available at* <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/Autism-Spectrum-Disorders.pdf>.

81. *Applied Behavior Analysis (ABA)*, AUTISM SPEAKS, <https://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba> (last visited Mar. 15, 2015).

82. Donald M. Baer et al., *Some Current Dimensions of Applied Behavior Analysis*, 1 J. OF APPLIED BEHAVIOR ANALYSIS 91, 91 (1968).

83. *Applied Behavior Analysis*, *supra* note 81.

84. *Treatment and Therapies*, AUTISM SPEAKS, <https://www.autismspeaks.org/family-services/tool-kits/100-day-kit/treatments-therapies> (last visited Mar. 10, 2015).

85. *Applied Behavior Analysis*, *supra* note 81.

86. *Id.*

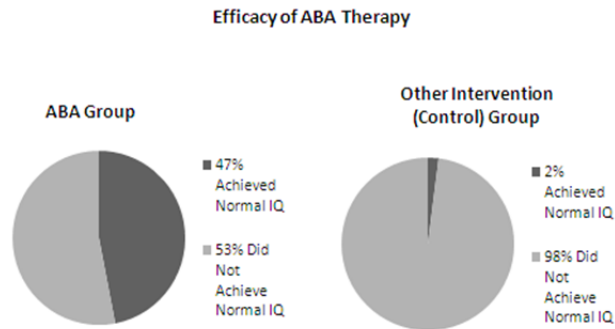
87. O. Ivar Lovaas, *Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children*, 55 J. OF CONSULTING & CLINICAL PSYCHOL. 3, 8 (1987).

88. See Howard Cohen et al., *Early Intensive Behavioral Treatment: Replication of the UCLA Model in a Community Setting*, 27 DEV. & BEHAVIORAL PEDIATRICS S145 (2006).

functioning and, as a result, were placed in mainstream general educational environments with no additional supports.⁸⁹

Lovaas conducted his study of the effectiveness of behavioral modification treatments on very young children affected by autism.⁹⁰ For his study, Lovaas split his thirty-eight subjects into two groups: nineteen subjects were put into an intensive-treatment experimental group that received more than forty hours of one-to-one treatment per week, and nineteen subjects were placed in a minimal-treatment control group that received ten hours or less of one-to-one treatment per week.⁹¹ Both groups were identical at intake in terms of intellectual functioning abilities, and both received their assigned treatment for two or more years.⁹²

Outcome of Lovaas 1987 UCLA Study



Upon follow-up at age seven, the experimental group attained significantly higher results on education placement and IQ levels than the control group.⁹³ According to the results of Lovaas's study, the nineteen-subject experimental group showed nine children (47%) who successfully passed through normal first grade in a public school and obtained an average or above average score on IQ tests.⁹⁴

89. Lovaas, *supra* note 87, at 3.

90. *Id.*

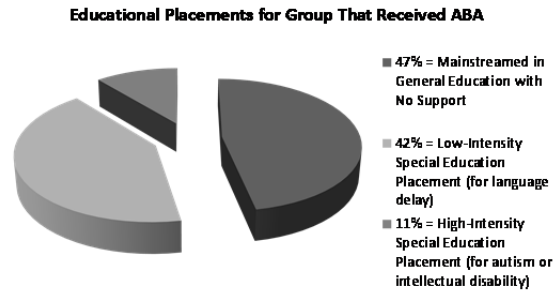
91. *Id.* at 4.

92. *Id.*

93. *Id.* at 5.

94. Lovaas, *supra* note 87, at 6.

Outcome of Lovaas 1987 UCLA Study



Lovaas's 1987 study was followed in 1993 by another study of these same thirty-eight subjects.⁹⁵ The objective of John J. McEachin's study was to discover the long-term effects of Lovaas's early intensive behavioral treatment and to find out if the results of the experimental group were preserved over time.⁹⁶ For this study, Lovaas's original subjects were evaluated at a mean age of eleven-and-a-half years.⁹⁷ The study was presented in two parts: the first examined whether the experimental group had maintained its treatment gains; the second part focused on the nine subjects who had achieved the greatest gain in the original study and examined the extent to which they "could be considered free of autistic symptomology."⁹⁸

McEachin's follow-up resulted in findings in three different categories: school placement, intellectual functioning, and presence of adaptive and maladaptive behaviors.⁹⁹ In terms of class placement, the study found that "the proportion of experimental subjects in regular classes did not change from the age 7 evaluation (9 of 19, or 47%)."¹⁰⁰ In the control group, none of the nineteen children were in a regular class, as had been true at the age seven evaluation.¹⁰¹ In terms of intellectual functioning, the study found that "the experimental group at follow-up had a significantly higher mean IQ than did the control group . . . indicat[ing] that the experimental group had maintained its gains in intellectual

95. John McEachin, Tristram Smith & O. Ivar Lovaas, *Long-Term Outcome for Children with Autism who Received Early Intensive Behavioral Treatment*, 97 AM. J. MENTAL RETARDATION 359, 361 (1993).

96. *Id.* at 360.

97. *Id.* at 359.

98. *Id.* at 360.

99. *Id.* at 362.

100. McEachin, *supra* note 95, at 364.

101. *Id.*

functioning between age seven and the time of the current evaluation.”¹⁰² Finally, in terms of presence of adaptive and maladaptive behaviors, “the findings indicate that the experimental group showed more adaptive behaviors and fewer maladaptive behaviors than did the control group.”¹⁰³

As evidenced by the date of the landmark Lovaas study—1987—ABA therapy has been used for several decades to treat autism.¹⁰⁴ Yet the insurance industry has consistently denied coverage, frequently on the basis that ABA therapy is experimental or investigational.¹⁰⁵ While at some point in the last several decades that was true, such a conclusion is no longer supported by the science. In 1999, the United States Surgeon General said that “[t]hirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”¹⁰⁶ In 2007, the American Academy of Pediatrics said:

The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those in control groups.¹⁰⁷

Furthermore, “decades worth of scientific research provide clear and convincing support for the technique referred to as Applied Behavior

102. *Id.*

103. *Id.* at 364–365.

104. Lovaas, *supra* note 87, at 3.

105. Even insurers that offer some coverage for behavioral therapies imposed severe limitations. A 2002 study by Pamela B. Peele and others of 128 behavioral health plans administered by one of two large managed behavioral health organizations found that all the plans had some type of limit on benefits for behavioral therapies – over half of the plans had limits on the number of annual outpatient sessions and sixty-five percent of the plans imposed limits on the number of inpatient days covered per year. Pamela B. Peele et al., *Exclusions and Limitations in Children’s Behavioral Health Care Coverage*, 53 *PSYCHIATRIC SERVICES* 591 (2002), available at <http://ps.psychiatryonline.org/doi/pdf/10.1176/appi.ps.53.5.591>.

106. U.S. OFFICE OF THE SURGEON GEN., DEPT. OF HEALTH AND HUMAN SERVS., *MENTAL HEALTH: A REPORT OF THE SURGEON GENERAL* 164 (1999), available at <http://profiles.nlm.nih.gov/ps/access/NNBBHS.pdf>.

107. Scott M. Myers & Chris Plauché Johnson, *Management of Children with Autism Spectrum Disorder*, 120 *PEDIATRICS* 1162, 1664 (2007) (internal citations omitted).

Analysis (ABA).¹⁰⁸ And yet health insurance companies, as late as 2015, continue to issue coverage statements that include Applied Behavior Analysis in a list of treatments not covered “because they are considered investigational, experimental, or unproven.”¹⁰⁹

HEALTH INSURANCE COVERAGE FOR AUTISM TREATMENTS

In 2004, the *New York Times* wrote that “no disability claims more parental time and energy than autism.”¹¹⁰ Families dealing with autism face many hardships, not the least of which is financial hardship. One reason for the financial hardship is the refusal of the health insurance industry to cover treatments for, and sometimes even diagnosis of, autism.¹¹¹

In the absence of an autism insurance mandate, some insurance companies designate autism as a diagnostic exclusion, “meaning that any services rendered explicitly for the treatment of autism are not covered by the plan, even if those services would be covered if used to treat a different condition.”¹¹²

Further, in the absence of a mandate, even to the extent that insurance policies cover autism, they do not cover the treatment that is most effective and most commonly prescribed for autism. “As recently as the turn of the millennium, it was widely accepted that health insurance did not cover” applied behavior analysis (ABA).¹¹³ Claims filed on behalf of individuals with autism were denied for a variety of reasons notwithstanding a physician’s recommendation of the treatment.¹¹⁴ Sometimes treatments were denied as experimental or investigational.¹¹⁵

108. William J. Barbaresi et al., *Autism: A Review of the State of the Science for Pediatric Primary Health Care Clinicians*, 160 ARCHIVES OF PEDIATRIC & ADOLESCENT MED 1167, 1171 (2006).

109. See, e.g., CIGNA HEALTHCARE, AUTISM SPECTRUM DISORDERS/PERVASIVE DEV. DISORDERS: ASSESSMENT AND TREATMENT 3, 6 (2015), available at https://cignaforhcp.cigna.com/public/content/pdf/coveragePolicies/medical/mm_0447_coveragerepositioncriteria_autism_pervasive_developmental_disorders.pdf.

110. Jane Gross, *For Siblings of the Autistic, A Burdened Youth*, N.Y. TIMES, (Dec. 10, 2004), <http://www.nytimes.com/2004/12/10/health/10siblings.html?pagewanted=print&position=>.

111. See generally, *id.*

112. Douglas L. Leslie & Andreas Martin, *Health Care Expenditures Associated with Autism Spectrum Disorders*, 161 ARCHIVES OF PEDIATRIC AND ADOLESCENT MED. 350, 354 (2007). In a study of diagnostic exclusions in private behavioral health care plans, researchers examined a total of forty-six commercial, employment-based behavioral health plans covering a total of 496,911 lives. Peele, *supra* note 105. The researchers found that autism was a diagnostic exclusion in *all* of the plans. *Id.*

113. Laura C. Hoffman, *Ensuring Access for the Autistic Child: More is Needed than Federal Health Care Reform*, 41 SW. U. L. REV. 435, 442 (2012).

114. *Id.*

115. *Id.*

Sometimes they were deemed educational and the province of the schools.¹¹⁶ Sometimes non-existent provider credentials were demanded.¹¹⁷

Sometimes health insurance policies include an explicit blanket exclusion for ABA, in which case claims can be denied by simply referencing the contractual language.¹¹⁸ Other policies lack an explicit exclusion for ABA, but contain other general exclusions that render ABA unavailable.¹¹⁹ For example, policies may contain exclusions for behavioral therapy, for habilitative treatment, or any number of other things that have the effect of denying coverage for ABA.¹²⁰

To a family paying for health insurance who is stricken with autism, being told that one's policy covers autism but does not cover ABA is like being told the policy covers cancer but does not cover chemotherapy. For many autism families, the policy fails to cover the most-needed and most out-of-reach treatment. Children are thus unable to access potentially life-changing treatment, and society pays the price.

AUTISM INSURANCE REFORM MOVEMENT

Faced with this reality, autism families in more than forty states have successfully lobbied their legislatures to mandate meaningful health insurance coverage for autism.¹²¹ In this context, "meaningful" means that (1) the benefits include the standard treatments for autism, including applied behavior analysis, and (2) the coverage levels must be more than de minimus.¹²²

116. Autism is a health condition that is diagnosed by a physician, not by a school principal. *See Diagnosis*, AUTISM SOCIETY, <http://www.autism-society.org/what-is/diagnosis/> (last visited Mar. 18, 2015). It is not a learning disability. *See* Amanda Morin, *The Difference Between Autism and Learning and Attention Issues*, UNDERSTOOD, <https://www.understood.org/en/learning-attention-issues/getting-started/what-you-need-to-know/the-difference-between-autism-and-learning-and-attention-issues> (last updated Mar. 14, 2014).

Even to the extent that a school district has plentiful resources, allowing the district to employ a one-on-one trained therapist for each child with autism and a Board Certified Behavior Analyst to supervise in each district, the school therapists only work on educational goals for the child. Children with autism still need additional therapy in the home to acquire skills such as potty-training, dressing, use of utensils, tooth brushing, bathing, and other daily living skills that other children acquire naturally through imitation.

117. Hoffman, *supra* note 113.

118. *See Wheeler v. Aetna Life Ins. Co.*, No. 01-C6064, 2003 WL 21789029, at *3 (N.D. Ill. July 23, 2003); *CIGNA HEALTHCARE*, *supra* note 109.

119. *See, e.g., McHenry v. PacificSource Health Plans*, 679 F. Supp. 2d 1226, 1229 (D. Or. 2010).

120. *See, e.g., Developmental Disability Exclusion Violated MHPAEA, Court Rules*, 17 No. 4 Employers Guide to HIPAA News 1.

121. *State Initiatives*, *supra* note 4; *Insurance Coverage for Autism*, NAT'L CONFERENCE OF STATE LEGISLATURES, <http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx> (last visited May 25, 2015).

122. A 1998 Kentucky statute that requires autism coverage up to \$500 per month, for example, is not counted among the meaningful autism insurance mandates. Kentucky has

Autism Speaks created model autism insurance mandate legislation in 2008.¹²³ Although the model bill has changed over the years to respond to a changing landscape and new laws such as the Affordable Care Act, the models generally have included these essential elements:

- Requires insurers to cover the screening, diagnosis, and treatment of autism.
- Defines “treatment,” usually to include:
 - Psychological care;
 - Psychiatric care;
 - Pharmacological care;
 - Therapeutic care (including speech, occupational and physical therapies); and
 - Behavioral health treatment or habilitative treatment (including applied behavior analysis).¹²⁴

Most of the autism mandates in the United States and the U.S. Virgin Islands are to some extent patterned after the Autism Speaks model bill.¹²⁵ The states that have passed meaningful autism insurance mandates, in order of enactment, are:¹²⁶

2001-Indiana	2009-New Mexico	2011-New York
2007-South Carolina	2010-Maine	2012-Michigan
2007-Texas	2010-Kentucky	2012-Alaska
2008-Arizona	2010-Kansas	2012-Delaware
2008-Florida	2010-Iowa	2013-Minnesota
2008-Louisiana	2010-Vermont	2013-Oregon
2008-Pennsylvania	2010-Missouri	2014-Utah
2008-Illinois	2010-New Hampshire	2014-Nebraska
2009-Colorado	2010-Massachusetts	2014-Maryland
2009-Nevada	2011-Arkansas	2014-Washington
2009-Connecticut	2011-West Virginia	2015-S. Dakota

since passed an autism insurance mandate requiring coverage up to \$50,000 per year. Ky. Rev. Stat. Ann. § 304.17A-142(2)(a) (West 2011).

123. AUTISM SPEAKS, MODEL AUTISM INSURANCE LEGISLATION, *available at* https://www.autismspeaks.org/sites/default/files/docs/gr/as_modelbill_february_2014.pdf (last visited Mar. 18, 2015).

124. In some states, the category into which applied behavior analysis fits is called “habilitative and rehabilitative care” rather than “behavioral health treatment.” *See, e.g.*, ME. REV. STAT. tit. 24-A, § 2768(1)(C)(1) (2015).

125. *See generally* UNUMB, *supra* note 40, at 67–148.

126. *State Initiatives, supra* note 4. Note: The state of Washington did not pass an autism-specific insurance mandate but instead achieved similar results through several years of class action litigation. *See infra* note 129.

2009-Wisconsin	2011-Virginia	2015-Mississippi
2009-Montana	2011-Rhode Island	2015-Georgia
2009-New Jersey	2011-California	

While legislatures were considering and passing autism insurance mandates, the courts and legal system, to a lesser extent, were also grappling with the lack of adequate autism insurance benefits. In 2001, the Attorney General in Minnesota entered into a settlement agreement with one of that state's major insurers (Blue Cross Blue Shield of Minnesota) to require coverage for autism, including coverage of Applied Behavior Analysis therapy.¹²⁷ In 2009, attorney Dave Honigman of Michigan secured a \$1 million settlement in the class action of *Johns v. Blue Cross Blue Shield* after compelling the production of internal BCBS documents reportedly acknowledging the efficacy of ABA and its status as the standard of care, contrary to BCBS' public position that the treatment was "experimental." Mr. Honigman has also brought and settled a number of other class action suits against other insurers who similarly had denied ABA coverage on the grounds that the treatment was experimental.¹²⁸ On the West Coast, attorney Ele Hamburger litigated a series of cases establishing autistic individuals' right to coverage under state mental health parity laws.¹²⁹ And in Oregon, a United States District Court held that exclusion of ASD treatment under a developmental disabilities exemption was an impermissible nonquantitative treatment limitation under the federal Mental Health Parity and Addiction Equity Act.¹³⁰

In every state legislature that has debated an autism insurance mandate, a formidable cadre of organizations has opposed the legislation. Typical opponents include the health insurance companies, the chambers of commerce, and the National Federation of Independent Businesses. Opponents argue that mandating autism coverage, particularly ABA coverage, will cause premiums to skyrocket, will cause small companies to go out of business or at least stop offering health insurance, and will force health insurers into the practice of paying for "educational" services.¹³¹

127. See generally Elizabeth Stawicki, *Blue Cross Blue Shield Agrees to Cover Mental Health Costs*, MINN. PUB. RADIO (June 19, 2001), http://news.minnesota.publicradio.org/features/200106/19_stawickie_bluecross/.

128. See, e.g., *Potter v. Blue Cross Blue Shield of Mich*, 10 F.Supp.3d 737, 756 (E.D. Mich., 2013) (holding that Blue Cross' designation of ABA therapy as "experimental" was, and is, arbitrary and capricious and therefore illegal under ERISA); *Churchill v. CIGNA Corp.*, No. 10-6911, 2011 WL 3563489 (E.D. Pa. Aug. 12, 2011).

129. See, e.g., *R.H. v. Premera Blue Cross*, No. C13-97RAJ, 2014 WL 3056797 (W.D. Wash. July 7, 2014); *Z.D. v. Group Health Coop.*, No. C11-1119RSL, 2012 WL 5033422 (W.D. Wash. Oct. 17, 2012).

130. *A.F. v. Providence Health Plan*, 300 F.R.D. 474, 486 (D. Or. 2013).

131. James N. Boudier et al., *Brief Report: Quantifying the Impact of Autism Coverage on Private Insurance Premiums*, 39 J. AUTISM AND DEV. DISORDERS 953, 953 (2009).

The political strength of these opponent organizations has made passage of autism insurance legislation difficult. Particularly in conservative states, some legislators are unwilling to vote against the chamber, the NFIB, or a big insurance company. For example, in Tennessee, an autism insurance bill that was sponsored by a Republican state senator failed to even be considered by the Tennessee Senate after the senator, who was running for Congress, refused to calendar it.¹³² The senator ultimately lost the election for Congress.

On the other hand, some conservative legislators have not only supported autism insurance reform but have made their support an issue in campaigns for higher office. In North Carolina, the Republican Speaker of the House of Representatives vigorously supported an autism insurance mandate in 2013 and 2014, becoming its outspoken champion.¹³³ When he subsequently decided to run for the United States Senate, the Speaker campaigned on his support for autism insurance reform, even during the Republican primary.¹³⁴ He won his primary and defeated an incumbent Democratic Senator in November 2014.¹³⁵

CONSERVATIVE SUPPORT FOR AUTISM INSURANCE MANDATES

Some conservative legislators do not believe in telling insurance companies what they must cover. They argue that insurance contracts are private business matters between private parties, and the government should not interfere.¹³⁶ However, the complete inability of the overwhelming majority of the insured population in America to access coverage for autism treatments recommended by their treating physicians is evidence of a market failure. Such failure is not surprising given the grossly unequal

132. Tom Humphrey, *Bill Calling For Insurance to Cover Autism Dies Quietly in Legislature*, KNOXBLOGS (Apr. 7, 2014), <http://knoxblogs.com/humphreyhill/2014/04/07/bill-calling-insurance-cover-autism-dies-quietly-legislature>.

133. See Mark Binker, *New Ad Emphasizes Tillis' Work on Autism Despite Bill's Failure*, WRAL, <http://www.wral.com/new-ad-emphasizes-tillis-work-on-autism/14008389/> (last updated Sept. 24, 2014).

134. *Autism Insurance in NC Subject of Pro-Tillis Ad*, WASH. TIMES (Sept. 23, 2014), <http://www.washingtontimes.com/news/2014/sep/23/autism-insurance-in-nc-subject-of-pro-tillis-ad/>.

135. Justin Peligri, *Republican Thom Tillis Wins North Carolina Senate Race*, CNN (Nov. 5, 2014, 1:09 AM), <http://www.cnn.com/2014/11/05/politics/sidebar-north-carolina-senate-race-digital/>.

136. Even if one believes in free-market solutions generally, in the health care context, there is reason to embrace limited government intervention. Although in countries like the United States—where we have chosen a system other than government-run health care—health insurance policies are negotiated contracts between private parties, society has already determined that it is in our collective best interest to allow some degree of government intervention in these particular contracts. If we had not, we would not need a Department of Insurance. The state regulates insurance affairs, and it is appropriate for the state to ensure that health insurance coverage is aligned with current science.

bargaining power between most health insurance customers and insurance companies.¹³⁷ Given the market failure, and the fact that the industry has proven that it is not going to voluntarily act, legislators have been compelled to mandate coverage if they want insured families to get it.

The task of mandating coverage was made more palatable, though, once legislators examined the issue through the lens of true conservative ideology. After considering conservative principles in three broad areas—individual responsibility, fiscal responsibility, and social responsibility—conservatives have embraced autism insurance reform as consistent with classic conservative ideology.¹³⁸

I. Individual Responsibility

One hallmark of conservative ideology is a belief that individuals should take care of themselves and their families. In the absence of insurance coverage for mainstream autism treatments such as ABA, many autism families who desire to take care of themselves are unable to do so. To be effective, ABA must be administered intensively, often forty hours per week.¹³⁹ This, of course, makes it expensive. A forty-hour-per-week ABA therapy program can range from \$50,000–\$100,000 per year, depending on many variables.¹⁴⁰ The median household income in 2013 in the United States is \$51,939.¹⁴¹ Clearly, most families cannot afford to privately pay for an intensive ABA program, particularly after they have paid insurance premiums every month.

These are families who are “doing the right thing” from a conservative standpoint, by buying insurance for their families to ensure access to care and protect against financial ruin in the event of an unforeseen and unprovoked medical problem. Yet, in the absence of meaningful autism insurance coverage, they are being forced to put their

137. In most health insurance contracts, the concept of a negotiating table is illusory. Further, in a non-single payor system, the health care consumer is not even a party at the supposed negotiating table. See, e.g., James F. Blumstein & Frank A. Sloan, *Health Care Reform Through Medicaid Managed Care: Tennessee (TennCare) as a Case Study and a Paradigm*, 53 VAND. L. REV. 125, 175 (2000). A third party payor insurance system simply does not allow market forces to operate in a manner sufficient to protect society’s interest in a healthy citizenry. See D. Ward Kallstrom, *Health Care Cost Control By Third Party Payors: Fee Schedules and the Sherman Act*, 27 DUKE L.J., 645, 648–49 (1978).

138. Jennifer Sheridan, *Tennessee Needs Autism Insurance Reform*, THE TENNESSEAN (Apr. 7, 2014, 11:05 PM), <http://www.tennessean.com/story/opinion/2014/04/08/tennessee-needs-autism-insurance-reform/7301391/>.

139. *Getting to Know ABA*, APPLIED BEHAVIORAL STRATEGIES, <http://www.appliedbehavioralstrategies.com/what-is-aba.html> (last visited Mar. 18, 2015).

140. Maura Lerner, *Autism’s \$100,000 Question*, STAR TRIBUNE (Apr. 4, 2011, 8:46 AM), <http://www.startribune.com/lifestyle/health/119121174.html>.

141. U.S. Census Bureau, *Income, Poverty, and Health Insurance Coverage in the United States: 2013* (<http://www.census.gov/newsroom/press-releases/2014/cb14-169.html>).

hands out to the government for help. Families who are paying premiums to privately insure their families nevertheless apply for Medicaid and other government assistance for help with treatment. Further, in states where a child cannot qualify for Medicaid if the parents make too much money, parents quit jobs so that children can become Medicaid eligible.¹⁴²

This is exactly what conservatives do not want families to do. Conservatives want parents to take care of their families by working and buying private health insurance, and conservative policy should incentivize such a course of action. Meaningful autism insurance benefits, which are available only where states have mandated them, incentivize autism families to purchase and maintain coverage.

Some insurers claim that the autism community is seeking special treatment by asking to have a particular treatment covered.¹⁴³ They say the autism community is seeking special treatment because ABA is not covered for any other diagnoses. Actually, the community is seeking equal treatment, asking only that insurance cover the standard treatment for this condition. Society would not tell breast cancer patients they were seeking special treatment if they asked to have mastectomies covered, and the insurance industry would not refuse to cover that particular treatment because they don't cover it for any other disease. Equal treatment means covering for each disease the standard treatment for that disease.¹⁴⁴

II. Fiscal Responsibility

Another hallmark of conservative ideology is a belief that government should spend taxpayer dollars frugally and responsibly.

142. "In general, children in families with incomes up to \$44,700/year (for a family of four in 2011) are likely to be eligible for Medicaid or CHIP coverage. . . . All children from birth to age 6 with family incomes up to 133% (\$29,700 for a family of four in 2011) and children age 6-18 with family incomes up to 100% (\$22,350 for a family of four in 2011) are eligible for Medicaid." <http://www.medicaid.gov/medicaid-chip-program-information/by-population/children/children.html> (last visited June 24, 2015).

143. Personal account of Lorri S. Unumb.

144. Opponents of autism insurance mandates have also incorrectly asserted that the autism community has sought special treatment by asking to escape insurers' normal cost-control mechanisms, such as utilization review. In reality, the autism insurance bills do not preclude insurers from using their normal cost-control measures, nor is it the intent of the autism community to remove their ability to do so. Autism advocates have not asked to get out of deductibles, copayments, or other typical cost-control mechanisms like coordination of benefits, restrictions on family members providing services, or reviews for medical necessity. In some states, the ability of insurers to use such mechanisms is explicitly included in the legislation, although such inclusion is unnecessary. *See, e.g.*, ARK. CODE ANN. § 23-99-418(d)(2) (2014) ("The coverage may be subject to other general exclusions and limitations of the health insurance plan, including without limitation coordination of benefits, participating provider requirements, restrictions on services provided by family or household members, and utilization review of health care services, including review of medical necessity, case management, and other managed care provisions.").

As noted above, in the absence of an autism insurance mandate, some families with private health insurance reluctantly seek funding through government programs and thus are able to access autism treatments. In most states, though, government assistance has been unavailable or inadequate to pay for an intensive ABA therapy program. Without insurance coverage or government assistance available, children in those states are simply going untreated, unless their families happen to be wealthy.

A child with autism who cannot access treatment and who does not overcome his autistic deficits through intensive intervention costs society an average of \$3.3 million over his lifetime.¹⁴⁵ Societal costs include special education, vocational training, group housing or institutionalization, community supports, escalated medical costs and more. With a prevalence rate of 1 in 68 children being diagnosed, and a per-individual cost exceeding \$3 million, it is easy to see the enormous fiscal impact of autism for a state.¹⁴⁶

Conservative legislators faced with this fiscal data have easily concluded that it is unwise to allow children with autism to pass through to adulthood without access to interventions that may change the entire trajectory of their lives. Even where the state itself is the primary insurance payor—through insurance premiums paid on behalf of its own employees—states have readily determined the short-term expenditure to be a worthwhile investment.¹⁴⁷ Indeed, the potential long-term savings are immense.¹⁴⁸

145. Michael L. Ganz, *The Costs of Autism*, in UNDERSTANDING AUTISM: FROM BASIC NEUROSCIENCE TO TREATMENT 491 (Steven O. Moldin & L.R. Rubenstein eds., 2006). See generally John W. Jacobson et al., *Cost-Benefit Estimates For Early Intensive Behavioral Intervention For Young Children With Autism – General Model And Single State Case*, 13 BEHAVIORAL INTERVENTIONS 201, 201 (1998)(projecting for the state of Pennsylvania an actual direct cost savings to the state of over a million dollars per child).

146. See *CDC Estimates 1 in 68 Children Has Been Identified with Autism Spectrum Disorder*, CTRS. FOR DISEASE CONTROL, <http://www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html> (last visited Mar. 18, 2015).

147. See *State Health Plan to Offer Autism Treatment Coverage*, <https://www.nctreasurer.com/inside-the-department/News-Room/press-releases/Pages/State-Health-Plan-to-Offer-Autism-Treatment-Coverage.aspx> (last visited June 24, 2015).

148. *High-Quality Early Intervention for Autism More Than Pays For Itself*, AUTISM SPEAKS (May 1, 2013), <http://www.autismspeaks.org/science/science-news/high-quality-early-intervention-autism-more-pays-itself>. Given that the investment inures to the benefit of the state, some have suggested that the state itself, not the insurance companies, make the investment in autism intervention. In other words, rather than mandating coverage by insurance companies, the state should pay for autism treatment directly. Indeed, many states have done so and have been pleased enough in their investments to continue funding. But state-funded services should not take the place of private services funded through insurance. In states where the government funds services, parents should be able to choose between (1) accessing state-funded care and (2) securing privately-funded care. Otherwise, autism families would be relegated to a system of socialized medicine, where care is available only through government sources. In America, we have eschewed socialized health care; we should not embrace it for an autism diagnosis while eschewing it generally. Additionally, in

From a cost-benefit perspective, autism insurance mandates are supported by a solid business case. To know this is true, look no further than the self-funded market, in which large companies who fund their own health plans (rather than purchasing “insurance”) can choose whether to include autism and ABA benefits. Because the coverage they offer employees is technically not insurance, self-funded companies are not regulated by state departments of insurance and are not subject to state mandates; instead, they are governed by federal ERISA law.¹⁴⁹ As such, self-funded companies design their own benefits packages, limited only by the few restrictions in federal benefits law.¹⁵⁰ Hundreds of self-funded companies have analyzed autism/ABA coverage from a cost-benefit perspective and have voluntarily decided to add the coverage to their plans.¹⁵¹ Were there no solid business case in support of the coverage, self-funded companies operating without intrusion from a state legislature would not have added such benefits. Further, as an added benefit from a fiscal responsibility standpoint, in states where this law has passed, the overall impact on the economy has been positive, particularly in terms of job creation.¹⁵² Thousands of people have been trained and are now working full-time as therapists with children with autism.¹⁵³

Finally, lawmakers concerned with fiscal responsibility should consider not only the long-term returns noted above but also short-term gains. As noted, families who do not have adequate benefits in their health insurance plans may apply for coverage through Medicaid. In July of 2014, the federal Centers for Medicare and Medicaid Studies issued guidance reminding states of their obligation under Medicaid’s mandatory Early and Periodic Screening Diagnostic and Treatment (EPSDT) program to provide

some states that have attempted to fund services directly, service delivery is poor. State Medicaid waiver programs, even supported by federal matching dollars, routinely have waiting lists with thousands of children on them. Children with autism have been required to wait years to begin therapy, during which time the opportunity for optimal outcomes diminishes.

149. *See* Employment Retirement Income Security Act of 1974, 29 U.S.C. § 1144 (2012).

150. *See id.* § 1002, 1003.

151. JP Morgan, *Other Employers Move to Cover Costly Autism Therapies*, <http://www.reuters.com/article/2013/12/16/us-usa-health-autism-idUSBRE9BF0H820131216> (last visited June 24, 2015); *Major Employers Voluntarily Introduce Autism Benefits for 2015*, AUTISM SPEAKS (Jan. 9, 2015), https://www.autismspeaks.org/advocacy/advocacy-news/major-employers-voluntarily-introduce-autism-benefits-2015?utm_source=/advocacy/advocacy-news/major-employers-voluntarily-introduce-autism-benefits-2015&utm_medium=text-link&utm_content=Major+Employers+Voluntarily+Introduce+Autism+Benefits+For+2015+&utm_campaign=relateditems2%20Employers%20Voluntarily%20Introduce%20Autism%20Benefits%20For%202015&utm_campaign=relateditems2.

152. *See generally* *Ava’s Law to Create More Jobs*, GA. NEWSDAY (Apr. 3, 2015), <http://www.georgianewsdaily.com/news/savannah/327386-ava-s-law-to-create-more-jobs.html>.

153. *See id.*

all medically necessary care to children with autism.¹⁵⁴ As a result of this guidance, many states have transferred ABA services from optional waiver programs to the mandatory state Medicaid plan.¹⁵⁵ The significance of this shift is that, while states could limit their financial investment in waiver programs, which could be limited in terms of dollar caps, age caps, waiting lists, etc., states cannot so restrict mandatory Medicaid state plan services.¹⁵⁶ As such, it is in the best financial interest of the state to have children with autism who are privately insured accessing care through their private insurance rather than tapping into government-funded care through Medicaid. Most states have not yet experienced the fiscal impact of mandatory Medicaid coverage of ABA, and they would be wise to direct children who have access to other care away from Medicaid. From a fiscal as well as a philosophical standpoint, conservatives should want families to tap into the private insurance that they are paying for rather than accessing government-funded treatment.

III. Social Responsibility

A final relevant hallmark of conservative ideology is a belief that government *should* play a role in helping those who are *unable* to help themselves.

Autism presents a classic example of individuals who, in some instances, are unable to take care of themselves. While some individuals on the spectrum have symptoms that are barely perceptible, other have deficits that render them completely dysfunctional. Some cannot speak or otherwise communicate; some are aggressive toward family members and strangers; some are injurious to themselves. To the best of our current scientific knowledge, autism occurs through no fault of the affected individual or his family. If ever there were a proper role for even the most limited government, taking care of such individuals is surely it.

Further, as noted, autism is not a static disorder, unlike some developmental disabilities for which services are rendered to comfort individuals or make life more palatable or enjoyable. Instead, autism is dynamic, and some individuals can overcome their deficits through intensive treatment. From a moral as well as a fiscal standpoint, it simply makes sense to allow such individuals the opportunity to become productive citizens.

154. Memorandum from Cindy Mann, Director of Ctr. for Medicaid and CHIP Services, Clarification of Medicaid Coverage of Services to Children with Autism (July 7, 2014), available at <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>.

155. *Id.* See generally L&M POLICY RESEARCH, AUTISM SPECTRUM DISORDERS (ASD): STATE OF THE STATES OF SERVICES AND SUPPORTS FOR PEOPLE WITH ASD (2014), available at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf>.

156. Mann, *supra* note 156.

CONCLUSION

Mandated insurance coverage for individuals with autism is an important tool in properly caring for the families affected by this disability. States that have passed autism legislation are realizing the social and monetary benefits of taking care of children with autism by being able to integrate them into society. Autism legislation is also consistent with conservative principles of personal, fiscal, and social responsibility. More than forty states plus the District of Columbia and the U.S. Virgin Islands have enacted state legislation requiring autism coverage. Legislatures, courts, and executive branches should act swiftly to ensure that all insured individuals have meaningful coverage for autism.

MODEL BILL:

A. A health insurance policy will provide coverage for the screening, diagnosis, and treatment of autism spectrum disorder. To the extent that the screening, diagnosis, and treatment of autism spectrum disorder are not already covered by a health insurance policy, coverage under this section will be included in health insurance policies that are delivered, executed, issued, amended, adjusted, or renewed in this state, or outside this state if insuring residents of this state, on or after July 1, 2014. No insurer can terminate coverage, or refuse to deliver, execute, issue, amend, adjust, or renew coverage to an individual solely because the individual is diagnosed with or has received treatment for an autism spectrum disorder.

B. Coverage under this section will not be subject to any limits on the number of visits an individual may make for treatment of autism spectrum disorder.

C. Coverage under this section must not be subject to treatment limitation and financial requirements that are less favorable to an insured than the treatment limitations and financial requirements that apply to substantially all medical and surgical benefits under the health insurance policy. [When benefits are capped, add “except as otherwise provided in subsection (E)”.]

D. This section will not be construed as limiting benefits that are otherwise available to an individual under a health insurance policy.

E. [OPTIONAL/NOT RECOMMENDED: add as an additional paragraph, “Coverage for applied behavior analysis will be subject to a maximum benefit of \$50,000 per year. After December 31, 2015, the insurance commissioner will, on an annual basis, adjust the maximum benefit for inflation by using the Medical Care Component of the United States Department of Labor Consumer Price Index for all urban consumers (CPI-U). The commissioner will submit the adjusted maximum benefit for publication annually no later than Month X of each calendar year, and the published adjusted maximum benefit will be applicable in the following calendar year to health insurance policies subject to this act. Payments made by an insurer on behalf of a covered individual for treatment other than applied behavior analysis will not be applied towards any maximum benefit established under this section.”]

F. As used in this section:

(1) “Applied behavior analysis” means the design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior.

(2) “Autism spectrum disorder” means any of the pervasive developmental disorders or autism spectrum disorders as defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) or the edition that was in effect at the time of diagnosis.

(3) “Diagnosis of autism spectrum disorder” means medically necessary assessment, evaluations, or tests to diagnose whether an individual has an autism spectrum disorder.

(4) “Behavioral health treatment” means counseling and treatment programs, including applied behavior analysis, that are:

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

(b) provided or supervised by a Board Certified Behavior Analyst or by a licensed psychologist so long as the services performed are commensurate with the psychologist’s university training and supervised experience.

(5) “Health insurance policy” means any individual or group health policy or contract issued by an insurance entity as defined in [state statute].

(6) “Pharmacy care” means medications prescribed by a licensed physician and any health-related services deemed medically necessary to determine the need or effectiveness of the medications.

(7) “Psychiatric care” means direct or consultative services provided by a psychiatrist licensed in the state in which the psychiatrist practices.

(8) “Psychological care” means direct or consultative services provided by a psychologist licensed in the state in which the psychologist practices.

(9) “Therapeutic care” means services provided by speech therapists, occupational therapists, or physical therapists who are licensed or certified by the state in which the therapist practices.

(10) “Treatment for autism spectrum disorder” means evidence-based care and related equipment prescribed or ordered for an individual diagnosed with an autism spectrum disorder by a licensed physician or a licensed psychologist who determines the care to be medically necessary, including but not limited to:

- (a) behavioral health treatment [or habilitative treatment];
- (b) pharmacy care;
- (c) psychiatric care;
- (d) psychological care; and
- (e) therapeutic care.

G. Coverage for applied behavior analysis shall include the services of the personnel who work under the supervision of the Board Certified Behavior Analyst or the licensed psychologist overseeing the program.

H. Except for inpatient services, if an insured is receiving treatment for an autism spectrum disorder, an insurer shall have the right to review the treatment plan annually, unless the insurer and the insured’s treating physician or psychologist agree that a more frequent review is necessary. Any such agreement regarding the right to review a treatment plan more frequently shall apply only to a particular insured being treated for an autism spectrum disorder and shall not apply to all individuals being treated for autism spectrum disorder by a physician or psychologist. The cost of obtaining any review or treatment plan shall be borne by the insurer.

I. This section will not be construed as affecting any obligation to provide services to an individual under an individualized family service plan, an individualized education program, or an individualized service plan.

J. [OPTIONAL] Nothing in this section shall apply to non-grandfathered plans in the individual and small group markets that are required to include essential health benefits under the Patient Protection and Affordable Care Act or to Medicare supplement, accident-only, specified disease, hospital indemnity, disability income, long-term care, or other limited benefit hospital insurance policies.

K. (1) By February 1, 2016, and every February first thereafter, the Department of Insurance shall submit a report to the General Assembly regarding the implementation of the coverage required under this section. The report shall include, but shall not be limited to, the following:

- (a) The total number of insureds diagnosed with autism spectrum disorder;
- (b) The total cost of all claims paid out in the immediately preceding calendar year for coverage required by this section;
- (c) The cost of such coverage per insured per month; and
- (d) The average cost per insured for coverage of applied behavior analysis;

(2) All health carriers and health benefit plans subject to the provisions of this section shall provide the Department with the data requested by the Department for inclusion in the annual report.

L. In the event that any part of this legislation is rendered or declared invalid or unenforceable by a court of competent jurisdiction, such invalidation shall not invalidate the remaining portions thereof, and they shall remain in full force and effect.

M. This act will take effect in XX days.

AUTISM SPECTRUM DISORDER 299.00 (F84.0)

Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table 1).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with

transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 1).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition)

(Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Table 1. Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 “Requiring very substantial support”	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 “Requiring substantial support”	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 “Requiring support”	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.