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ARE YOU COVERED? THE NEED FOR IMPROVEMENT IN INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDER

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I. INTRODUCTION

Ryan was a typical toddler.¹ He would smile, wave, blow kisses, play with his older sisters, and put simple two-word sentences together.² However, at around seventeen months, a seemingly normal one-year-old took a drastic turn.³ Over a period of weeks, Ryan turned into a completely different child.⁴ The “bye-byes” and “night-nights” he once uttered suddenly vanished; he stopped speaking and giving his sisters hugs, and his eye contact severely diminished.⁵ A few months later he stopped responding when his mother called his name, he became withdrawn and began fixating on objects, and he started having tantrums on a regular basis.⁶ After months of appointments with various doctors and a fruitless search for answers, Ryan’s family finally got the diagnosis they had feared: Ryan was autistic.⁷

One and a half million Americans are affected by autism, and the rate is increasing by ten to seventeen percent every year.⁸ Each child diagnosed with autism will accumulate \$3.2 million worth of both medical and non-medical autism-related expenses

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1. Nancy Rones, *Living Autism: “Losing My Little Boy”*, WEBMD – AUTISM SPECTRUM DISORDERS HEALTH CENTER, Jan. 10, 2008, <http://www.webmd.com/brain/autism/living-autism-losing-my-little-boy?page=5>.

2. *Id.*

3. *Id.*

4. *Id.*

5. *Id.*

6. *Id.*

7. *Id.*

8. Press Release, Harvard School of Public Health, Autism Has High Costs to U.S. Society (Apr. 25, 2006) (on file with author).

during their lifetime.⁹ Societal costs of autism are estimated to be close to \$35 billion annually.¹⁰

In recent years, autism-related legislation has been a popular trend at both the federal and state level.¹¹ Congress passed the Combating Autism Act in 2006 and the Autism Treatment Acceleration Act was presented to Congress in 2009, although it did not make it past the referral stage.¹² Despite the Autism Treatment Acceleration Act not passing, many states have taken the initiative themselves to enact autism and insurance related legislation. As of January 10, 2011, twenty-three states had enacted autism insurance reform laws, and another twenty-four states were actively pursuing autism insurance reform bills.¹³ In spite of this legislation, many families are still bearing the brunt of the costs of autism diagnosis and treatment on their own. Most state legislation aimed at health insurance coverage only applies to group coverage and excludes self-insured individuals or companies.¹⁴ Usually, insurance policies that do cover autism have

9. Michael L. Ganz, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, 161 ARCHIVES OF PEDIATRIC AND ADOLESCENT MEDICINE 343, 348 (2007) [hereinafter *Societal Costs of Autism*].

10. *Id.*; see also Michael L. Ganz, *The Costs of Autism*, in UNDERSTANDING AUTISM: FROM BASIC NEUROSCIENCE TO TREATMENT 475, 493-94 (Steven O. Moldin & John L.R. Rubenstein eds., 2006) [hereinafter *Costs of Autism*] (noting that the \$35 billion estimate is a conservative estimate and does not include expenditures such as legal costs, the value of lost productivity to those other than parents, costs of psychological stress and mental services used as a result of such stress, costs of genetic testing, and the full costs of alternative therapies (i.e. special diets)); Douglas L. Leslie, *Health Care Expenditures Associated With Autism Spectrum Disorders*, 161 ARCHIVES OF PEDIATRIC AND ADOLESCENT MEDICINE 350, 354 (2007) (explaining that health care costs for autistic children and adolescents are increasing each year).

11. Nat'l Conference of State Legislatures, *Autism Policy Issues Overview – Autism*, <http://www.ncsl.org/IssuesResearch/Health/AutismPolicyIssuesOverview/tabid/14390/Default.aspx>.

12. Combating Autism Act, Pub. L. No. 109-416, 120 Stat. 2821 (codified at 42 U.S.C. §§ 280i, 280i-1 to -4, 283j) (2006); Autism Treatment Acceleration Act of 1999, S. 819, 111th Cong. § 2 (2009).

13. See Autism Speaks Government Relation Department, *2011 State Initiative Agenda: Current Status of State Autism Insurance Reform Bills*, AUTISM VOTES, Jan. 10, 2011, <http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/State%20Map%20-%201.10.11.pdf> (indicating that Arizona, Colorado, Florida, Illinois, Texas, Kansas and Wisconsin are among the twenty-three states where autism insurance reform laws have already been enacted). As of January 11, 2011, Oklahoma, Utah and Wyoming were the only three states that had not taken any steps to pursue autism insurance reform legislation. *Id.*; see also *Helping With Autism*, STATE LEGISLATURES, Jan. 2009, at 9 (citing Arizona, Connecticut, Florida, Indiana, Kentucky, Louisiana, Oregon, Pennsylvania, South Carolina, and Texas as states that require health insurers to provide coverage for autism treatment).

14. See, e.g., Justin Redman, *Mom Wins Fight for Autism Insurance*, CNN, Apr. 1, 2008, <http://www.cnn.com/2008/HEALTH/conditions/04/01/autism.insurance/index.html> (pointing out how South Carolina's recently enacted Ryan's

an annual cap on the amount of coverage provided for diagnosis and treatments, and most insurance companies still exclude coverage for autism altogether.¹⁵

The next section of this Comment provides background information on autism spectrum disorders in general, including a discussion of treatments and costs. Part III examines legislative action taken at the federal and state levels regarding ASD and health care. Part IV evaluates the Autism Treatment Acceleration Act as it was proposed in 2009, pinpointing the strengths and weaknesses. Part IV also suggests other options legislatures should consider incorporating into federal and state autism health care provisions.

II. BACKGROUND: A CLOSER LOOK AT AUTISM

A. Symptoms of Autism Spectrum Disorders

A background of ASD is necessary to better understand the health care demands faced by those with the disorder. This section will examine the range of symptoms associated with ASD, discuss the many treatment options available, and finally, will uncover the extremely high health care costs those with ASD must bear.

The American Psychiatric Association's *Diagnostical and Statistical Manual* ("DSM-IV") designates autism as a pervasive developmental disorder (PDD).¹⁶ Autism, pervasive developmental disorder-not otherwise specified (PDDNOS), and Asperger's syndrome, fall under the "umbrella term" autism spectrum disorders (ASDs).¹⁷ Autism, the most commonly diagnosed ASD,¹⁸

Law, which requires insurance companies to cover up to \$50,000 annually for behavior therapies up to age sixteen, does not apply to "people or companies who are self-insured.")

15. See, e.g., Leslie, *supra* note 10, at 354 (explaining that autism is excluded from coverage by many insurance companies); see also The Autism Treatment Acceleration Act, S. 819 § 2 (finding that those with autism spectrum disorders are frequently denied health coverage because of their ASD diagnoses).

16. See Catherine Lord & Sarah Spence, *Autism Spectrum Disorders: Phenotype and Diagnosis*, in UNDERSTANDING AUTISM: FROM BASIC NEUROSCIENCE TO TREATMENT 1, 1-2 (Steven O. Moldin & John L.R. Rubenstein eds., 2006) [hereinafter *Autism Spectrum Disorders*] (indicating that, along with autism, Asperger's disorder, pervasive developmental disorder not otherwise specified (PDDNOS), Rett Syndrome, and childhood disintegrative disorder (CDD) all fall under the "umbrella term" pervasive developmental disorders); see also Luke Tsai, *Children with Autism Spectrum Disorder: Medicine Today and in the New Millennium*, 15 FOCUS ON AUTISM AND OTHER DEVELOPMENTAL DISABILITIES 138, 138 (2000) (explaining that the term pervasive indicates that the disorders affect various areas of development, as opposed to one or two areas of development).

17. *Autism Spectrum Disorders*, *supra* note 16, at 2.

18. Supapak Phetrasuwan et al., *Defining Autism Spectrum Disorders*, 14

is characterized by three primary developmental problems: impaired social interaction, impaired language and communication, and repetitive and stereotyped patterns of behavior, interests, and activities.¹⁹ Language impairments in children with ASD range from a complete absence of speech to unusual speech patterns.²⁰ Most people with autism have both receptive and expressive language setbacks.²¹ Other common language setbacks in children with ASD include an impaired ability to begin or carry on conversations with others.²² Social deficits in those with ASD include poor peer relationships, difficulty in sharing enjoyment with others, a failure to feel genuinely concerned and offer comfort to others, the inability to form caring friendships, and challenges with maintaining joint attention.²³ Those with ASD also exhibit a variety of repetitive and stereotyped behaviors.²⁴ These include strange preoccupations and intense interests that interfere with normal behavior and functioning.²⁵ ASD is also characterized by repetitive, ritual-like, and unusual motor behaviors.²⁶

ASD symptoms are known for their early onset, usually

J. OF SPECIALISTS IN PEDIATRICS 206, 207 (2009).

19. *Id.*; see also *Autism Spectrum Disorders*, *supra* note 16, at 3-4 (characterizing the core features of ASD as social and communication deficits and repetitive and restricted behaviors and interests).

20. Tsai, *supra* note 16, at 138; see also *Autism Spectrum Disorders*, *supra* note 16, at 3 (explaining that the habit of reciting passages from favorite videos, pronoun reversal, and the use of stereotyped phrases may all be unusual speech patterns exhibited by those with ASD). A recent study using two independent samples revealed that about forty percent of a sample of nine-year-olds with ASD were able to speak fluently, and less than fifteen percent were characterized as nonverbal (meaning they used less than five words on a daily basis). *Id.*

21. *Autism Spectrum Disorders*, *supra* note 16, at 3.

22. Phetrasuwan, *supra* note 18, at 206.

23. *Id.*; *Autism Spectrum Disorders*, *supra* note 16, at 3-4.

24. *Autism Spectrum Disorders*, *supra* note 16, at 4.

25. See *id.* (explaining that children with ASD may have preoccupations with things such as flags, TV show credits, or parts of an object, such as a wheel on a toy).

26. See *id.* (describing how those with ASD are preoccupied with sameness, which leads to the creation of rituals like lining their toes up on sidewalk cracks, or taking a bath at the same time every day). Those with ASD become aggravated when departing from these routines and rituals. *Id.* Unusual motor behaviors exhibited by those with ASD include rapid moving of the hands and fingers, or movements of the whole body like flapping or spinning. *Id.*; see also Phetrasuwan, *supra* note 18, at 206 (describing how those with autism typically exhibit repetitive and stereotyped behavior patterns, interests, and activities that may include "preoccupation and intense focus in restricted areas of interest, inflexible adherence to routines or rituals, stereotyped and repetitive motor mannerisms, and persistent preoccupation with parts of objects.").

emerging before a child reaches age three.²⁷ Symptoms vary across individuals and, based on the severity of impairment, children diagnosed with ASD are classified as either “high functioning” or “low functioning.”²⁸ Aside from the symptoms associated with ASD itself, those faced with ASD also face other health care challenges.²⁹ A variety of psychiatric diagnoses are often seen in those with ASD, including anxiety, obsessive-compulsive behaviors, depression, and attention deficits (including attention deficit disorder and attention deficit hyperactive disorder).³⁰ Autism is also associated with epilepsy and seizures.³¹ Other conditions that have been linked with autism include Fragile X Syndrome and tuber sclerosis.³² Due to the high incidence of other health problems found in those with ASD, combined with the costs

27. See Chris Hayhurst, *Treating Kids With Autism*, MAGAZINE OF PHYSICAL THERAPY, Dec. 2008-Jan. 2009, at 20, 22 (explaining that in some cases ASD can be diagnosed as early as eighteen months).

28. See Marsha Boutelle, *Reaching and Teaching Autistic Kids*, EDUCATION DIGEST, Oct. 2008, at 39, 40 (describing those categorized as low functioning as displaying “clear cut social and language impairment” and those labeled as high functioning as “much less debilitated and may be highly intelligent but still suffer from severe social and communication deficits.”).

29. *Autism Spectrum Disorders*, *supra* note 16, at 8-9; Tsai, *supra* note 16, at 141; James G. Gurney et al., *Parental Report of Health Conditions and Health Care Use Among Children With and Without Autism*, 160 ARCHIVES OF PEDIATRIC AND ADOLESCENT MEDICINE 825, 828 (2006).

30. See *Autism Spectrum Disorders*, *supra* note 16, at 8-9 (explaining that attention deficits and hyperactivity are the most common psychiatric issues accompanying ASD). Depression is also thought to affect those categorized as high-functioning more often than it affects those who are low-functioning. *Id.* at 9. Some studies have also found schizophrenia present in those with autism. *Id.*; see also *Medicine Today*, *supra* note 16, at 141-42 (showing that, in one study, forty percent of those with ASD were hyperactive, thirty-seven percent had obsessive phenomena, seventeen to seventy-four percent had anxiety or fears, nine to forty-four percent showed depressive mood, irritability, agitation, and inappropriate affect, and eleven percent had sleep problems); Gurney, *supra* note 29, at 828 (describing that, in a sample of 324,000 children with autism, 45.1% exhibited ADD or ADHD and 38.9% exhibited depression or anxiety problems).

31. Fred R. Volkmar et al., *Autism and Pervasive Developmental Disorders*, 45 J. OF CHILD PSYCHOLOGY AND PSYCHIATRY 140, 140-41 (2004); see also Gurney, *supra* note 29, at 828 (describing how one study found that epilepsy may occur in up to twenty-nine percent of those with autism); *Autism Spectrum Disorders*, *supra* note 16, at 7 (estimating epilepsy prevalence in those with autism as ranging from five to forty-four percent).

32. Volkmar, *supra* note 31, at 141; see also *Autism Spectrum Disorders*, *supra* note 16, at 11 (explaining that a high percentage of patients with both Fragile X and tuberous sclerosis complex (TSC) will also show autistic features). According to one study, autism has been reported in “up to 44% of patients with Fragile X syndrome, but fewer than 5% of autism patients have Fragile X.” *Autism Spectrum Disorders*, *supra* note 16, at 11. In terms of TSC, autism has been reported in seventeen to sixty-one percent of those with TSC, but less than three percent of those with autism have TSC. *Id.*

of treating the ASD itself, ASD patients are burdened with much higher health care demands than those without ASD.³³ In turn, higher health care demands lead to a significant increase in health care costs.³⁴

Currently, there is no known cure for ASD, and the exact causes are still unknown. However, scientists suspect that both genetics and the environment play a role in its development.³⁵ A variety of treatments are available that target specific symptoms of autism. It is a commonly held belief in the research community that early diagnosis and treatments provide the best outcome for those with ASD.³⁶ Some even predict that early diagnosis and treatment may reduce the costs of lifelong care by two-thirds.³⁷

B. Treatment of Autism Spectrum Disorders

A variety of treatments exist to manage the symptoms of ASD, including behavior modification, sensory integration training, music therapy, speech therapy, occupational therapy, social skills training, and the use of psychotropic medication.³⁸ In fact, a combination of different therapies is thought to be the best approach to the treatment of ASD.³⁹

Behavioral treatment approaches aim to increase the occurrence of appropriate behaviors while decreasing the

33. See, e.g., Gurney, *supra* note 29, at 828 (finding that parents of children with autism reported their children incurring a significantly higher amount of physicians visits than children without autism. For example, the mean number of nonemergency care visits for children with autism was 2.80, compared to 1.56 for children without autism).

34. See *infra* Section II.C.

35. Hayhurst, *supra* note 27, at 22 (explaining that, in some cases, ASD can be diagnosed as early as eighteen months); see also *Autism Policy Issues Overview-Autism*, *supra* note 11 (explaining that environmental factors could have the effect of triggering the manifestation of certain genes).

36. The Autism Treatment Acceleration Act, S. 819 §2; *Autism Policy Issues Overview-Autism*, *supra* note 11; Hayhurst, *supra* note 27, at 22; see also KAREN SIFF EXKORN, THE AUTISM SOURCEBOOK: EVERYTHING YOU NEED TO KNOW ABOUT DIAGNOSIS, TREATMENT, COPING, AND HEALING 98 (Harper Collins Publishers, 2005) (describing how early intervention is key because studies show that children's brain elasticity is at its maximum during early years). Intensive early intervention, beginning as early as twelve to fourteen months of age, can improve the overall ASD prognosis, maximize the child's ability to learn, and can eliminate specific problem behaviors. SIFF EXKORN, *supra*, at 88-89.

37. The Autism Treatment Acceleration Act, S. 819 § 2.

38. Tsai, *supra* note 16, at 141; see also Frank M. Gersham et al., *A Selective Review of Treatments for Children with Autism: Description and Methodological Considerations*, 28 SCHOOL PSYCHOL. REV. 559, 559 (1999) (explaining that a combination of behavioral, educational, and biological intervention programs can be helpful in managing autism).

39. See Volkmar, *supra* note 31, at 150 (describing that the trend has been to move towards an "interplay between different treatments").

occurrence of inappropriate behaviors.⁴⁰ Applied behavior analysis (ABA) is one specific form of behavioral treatment. There are a number of different forms of ABA, but in general, it involves over thirty hours per week of intense, one-on-one, positive reinforcement exercises that target areas such as language, play, learning, and real-life functioning.⁴¹ Two successive studies examined the effects of behavioral treatment on children with autism. The initial study, conducted in 1987, found that nineteen autistic children who underwent intensive behavioral intervention had higher IQs after a two-year period than a control group of autistic children who did not receive the treatment.⁴² The 1993 follow-up study examined the same subjects from the initial study and found that the experimental group still had a significantly higher mean IQ, and had more adaptive behaviors and fewer maladaptive behaviors than those in the control group.⁴³ These studies provide support for the conclusion that intensive behavioral treatment during the early ages of life leads to a long-

40. Alexis Ann Schoen, *What Potential Does the Applied Behavior Analysis Approach Have for the Treatment of Children and Youth With Autism*, 30 J. OF INSTRUCTIONAL PSYCHOL. 125, 126 (2003).

41. Erica Noonan, *Push On For Insurers to Share Autism Costs*, THE BOSTON GLOBE, Sept. 16, 2008, http://www.boston.com/news/health/articles/2008/09/16/push_on_for_insurers_to_share_autism_costs/; see also Sally J. Rogers & Sally Ozonoff, *Behavioral, Educational and Developmental Treatments for Autism*, in UNDERSTANDING AUTISM: FROM BASIC NEUROSCIENCE TO TREATMENT 443, 445-46 (Steven O. Moldin & John L.R. Rubenstein eds., 2006) (describing how ABA can be applied through a didactic behavioral approach or a naturalistic approach). The didactic approach uses prompts or cues to trigger targeted behavior in the presence of certain stimuli in an extremely controlled environment. Rogers & Ozonoff, *supra*, at 445. The naturalistic approach is characterized by: (1) initiating teaching when the child requests and/or gestures for a specific item; (2) teaching takes place within the child's normal environment; (3) the teaching stimuli are chosen by the child, and the child's access to these stimuli act as the reinforcement; and (4) strategies for elaborated language depending on the specific child's development. *Id.* at 446.

42. See John J. McEachin et al., *Long-Term Outcome for Children With Autism Who Received Early Intensive Behavioral Treatment*, 97 AMERICAN J. ON MENTAL RETARDATION 359, 359 (1993) (describing how Lovaas's 1987 study gave the experimental group of nineteen autistic children forty hours a week of one-on-one behavioral treatment for at least two years). The findings revealed that these children gained an average of twenty IQ points and nine out of the original nineteen subjects completed first grade in regular and non special education classes. *Id.* at 359-60. The control groups (two groups totaling forty children) did not see an IQ increase as high as the experimental group, and only one of the children was able to complete first grade in a non special education environment. *Id.* at 360.

43. See *id.* at 360-61 (describing how eleven subjects in the experimental group and only three subjects in the control group obtained IQs of at least eighty). In terms of maladaptive behaviors, the mean score for the control group was found to be in the clinically significant range, however the experimental group's mean score was not. *Id.*

term and beneficial outcome for children with autism.

Occupational therapy is another treatment option for those with ASD. Occupational therapy aims at improving overall quality of life by developing a variety of children's skill sets including coping, motor, self-help, and socialization skills.⁴⁴ Another therapy frequently used by those with ASD is sensory integration therapy, which focuses on strengthening the nervous system and helping children with ASD process sensory input more normally than they otherwise would.⁴⁵ Speech therapy is another common treatment used for language development.⁴⁶ Through speech therapy, the individual's language abilities are assessed by trained professionals, and a program is developed to strengthen the child's language and communication skills.⁴⁷ Drug treatments, such as tranquilizers, anti-depressants, anti-anxiety drugs, and stimulants, are also used to treat symptoms of ASD.⁴⁸ A number of alternative treatment methods are also available, including dietary regimens that eliminate gluten and casein.⁴⁹ With the wide

44. *Treatments for Autism*, AUTISMSPEAKS.ORG, <http://www.autismspeaks.org/whattodo/index.php> (last visited Feb. 21, 2011) (describing how through occupational therapy, children with ASD learn to engage in behaviors that children without ASD are able to do with little trouble, such as writing, dressing, and feeding themselves, or riding a bike).

45. See *id.* (explaining how children with autism often have difficulty processing information through their senses). Sensory integration has the potential to improve attention, concentration, listening, balance, comprehension, coordination, and impulsivity control. *Id.*

46. *Id.*

47. *Id.*

48. Schoen, *supra* note 40, at 126; see also Christopher J. McDougle et al., *Pharmacological Treatments*, in UNDERSTANDING AUTISM: FROM BASIC NEUROSCIENCE TO TREATMENT, 417, 417-18 (Steven O. Moldin & John L.R. Rubenstein eds., 2006) (describing how both psychostimulants and antidepressants are used to treat ADHD symptoms in children with ASD). Antipsychotics, such as clozapine and risperidone, are used to treat aggression and self-injurious behavior in children with autism. McDougle et al., *supra*, at 426-28.

49. See Jennifer Harrison Elder et al., *The Gluten Free, Casein Free Diet in Autism: Results of a Preliminary Double Blind Clinical Trial*, 36 J. OF AUTISM AND DEVELOPMENTAL DISORDERS 413, 415 (2006) (providing the results of a study done on fifteen children with ASD to determine how a gluten and casein free diet affected their ASD symptoms). Each child followed a diet regimen for twelve weeks based on their own personal food preferences. *Id.* at 417. The study did not yield significant results when the children were retested following their twelve-week diet, however researchers did receive a number of parental reports indicating improvements in their child's language, hyperactivity, and tantrums. *Id.* at 418. See also CHANTAL SICILE-KIRA, *AUTISM SPECTRUM DISORDERS: THE COMPLETE GUIDE TO UNDERSTANDING AUTISM, ASPERGER'S SYNDROME, PERVASIVE DEVELOPMENTAL DISORDER AND OTHER ASDS* 121 (Perigee Books ed., The Berkley Publishing Group 2004) (providing examples of other dietary treatments such as an anti-yeast diet, the Feingold Diet, which removes artificial colorings and flavorings, salicylates, and other preservatives from the diet, and the Ketogenic Diet, which includes

variety of therapies and treatments offered for ASD, they are a large contributor to the high costs associated with the disorder.

C. Medical and Non-Medical Costs Associated with ASD

The costs of autism are significant. Between diagnosis, treatments, medical costs, and lost productivity, it is estimated that autism can cost a person a staggering \$3.2 million over their lifetime.⁵⁰ A study conducted by Dr. Michael Ganz analyzed both the direct and indirect costs a person with autism incurs over their lifetime.⁵¹ Direct costs assess the value of goods and services used by an individual with autism, and indirect costs measure the value of lost productivity caused by autism.⁵² Dr. Ganz found that direct medical costs are the highest during the first five years of life, averaging about \$35,000 per year.⁵³ Most direct medical costs during early years come from behavioral therapies.⁵⁴ Direct non-medical costs are the highest between ages twenty-three and twenty-seven, averaging \$27,500 per year.⁵⁵ The most startling

foods high in fats, and low in proteins and carbohydrates).

50. *The Costs of Autism*, *supra* note 10, at 476; *Societal Costs of Autism*, *supra* note 9, at 343.

51. *Societal Costs of Autism*, *supra* note 9, at 343.

52. *See id.* at 344 (explaining that direct costs can be medical or nonmedical). Direct medical costs include services provided by physicians or other professionals, hospital services, and drugs, while direct nonmedical costs include treatments, transportation, and childcare. Indirect costs include “the value of lost or impaired work time (income), benefits, and household services of individuals with autism and their caregivers because of missed time at work, reduced hours, switching to a lower-paying but more flexible job, or leaving the workforce.” *Id.*; *see also The Costs of Autism*, *supra* note 10, at 483-85 (estimating direct medical costs: annual physician, outpatient, and clinic services costs of \$1,896, prescription medication costs of between \$166 and \$295, behavioral therapy costs of \$41,295 for children ages three to six, and hospital and emergency services of \$1,394). Estimated annual direct nonmedical costs include child care of \$3,509 to \$6,502 depending on level of disability, respite care of between \$1,044 and \$1,308, and special education costs of \$16,128 for children six to twenty-one years of age. *The Costs of Autism*, *supra* note 10, at 486-88.

53. *See Societal Costs of Autism*, *supra* note 9, at 346 (showing that direct medical costs average about \$35,000 per year during ages one to five, decline to around \$6,000 per year at age eight, and further decrease to \$1,000 per year through the end of life).

54. *See id.* (estimating costs of behavioral therapies to be around \$32,000 per year during the first five years of life, \$4,000 during the ages of eight to twelve, and \$1,250 per year for those eighteen to twenty-two years of age). Behavioral therapies comprise a total of 6.5% of lifetime autism costs. *Id.*; *see also Susan McClelland, Fighting for a Better Life*, MACCLEAN’S, Sept. 4, 2000, at 56 (estimating that ABA can cost up to \$40,000 per year); SIFF EXKORN, *supra* note 36, at 98 (explaining that treatments can range from \$40 to \$150 per hour and how home programs and special autism schools can cost anywhere between \$25,000 to \$80,000 per year).

55. *Societal Costs of Autism*, *supra* note 9, at 343 (explaining that direct

numbers come in the indirect costs category. Indirect costs average around \$43,000 per year early in life, and peak during ages twenty-three through twenty-seven to around \$52,000 per year.⁵⁶

A number of studies examined the medical expenditures for children with ASD, finding that they are significantly higher for ASD children than non-ASD children.⁵⁷ One 2007 study examined 1,202,861 privately insured individuals, ages one to twenty-one, 3,481 of which had ASD diagnoses.⁵⁸ The findings revealed that, across all age groups, those with ASD had total medical expenditures 4.1 to 6.2 times greater than non-ASD individuals.⁵⁹ Those with ASD spent between \$4,110 and \$6,200 more per year on medical expenditures than non-ASD individuals.⁶⁰

These studies reveal that the costs of autism do not diminish as adulthood progresses. As an autistic individual gets older the costs of non-medical care and productivity losses rise.⁶¹ Moreover, it is estimated that only five percent of adults with autism are able

nonmedical costs range from \$10,000 to \$16,000 during the ages zero to twenty, peak during the years of twenty-three to twenty-seven, and then drop off to around \$8,000 per year through the end of life).

56. *See id.* at 347 (indicating that indirect costs make up 59.3% of total lifetime costs). An individual's indirect costs are highest from ages twenty-three to twenty-seven (at \$33,000 per year), and indirect costs incurred by others, for example, the individual's caretakers or parents, are the highest during the ages three to seven (at \$43,000 per year). *Id.*; *see also Study: Autism costs strain family finances*, MSNBC, Dec. 1, 2008, <http://www.msnbc.msn.com/id/27988021/> (stating that parents with autistic children are three times more likely than those without autistic children to quit their jobs or reduce their hours).

57. *See* Tom T. Shimabukaro et al., *Medical Expenditures for Children with an Autism Spectrum Disorder in a Privately Insured Population*, 38 J. OF AUTISM AND DEVELOPMENTAL DISORDERS 546, 546 (2008) (reporting that a Pennsylvania study using data collected from 1994 to 1999 found that children from ages zero to twenty-one with an ASD had mean medical expenditures nine times greater than children without an ASD). Additionally, a national survey of 1999-2000 data reported that a sample of children with ASD had mean medical expenditures seven times greater than non-ASD children. *Id.*

58. *See id.* at 548 (explaining that the study sample was made up of individuals enrolled in a fee-for-service health care plan, and that the sample was divided into four different age groups: one to four years old, five to ten years old, eleven to seventeen years old, and eighteen to twenty-one years old).

59. *See id.* (indicating that the lowest expenditure costs for those with ASD (\$4,110) were found in the eleven to seventeen age group, while the highest average expenditure costs (\$6,200) were found in the one to four year old age group). When substituting a median analysis for an average analysis, those with ASD have expenditures 8.4 to 9.5 times greater than non-ASD individuals. *Id.*

60. *See id.* at 549 (describing that, in younger age groups, most of these costs go toward outpatient services, and then shift to pharmaceuticals in the older age groups).

61. Andre Picard, *Autism a lifelong burden, study shows; Because few adults with the disorder can work, the economic costs continue*, THE GLOBE AND MAIL, Apr. 3, 2007, at A13.

to support themselves.⁶² Indeed, some researchers have recommended financial counseling for parents of children with autism to help deal with the extensive costs incurred throughout life.⁶³ In comparison to other disorders, yearly expenditures for ASD are higher than annual costs to treat anxiety disorders, depression, hyperactivity, and substance abuse.⁶⁴

High costs related to autism and ASD also affect the educational system. A 2005 Government Accountability Office report indicated that during the 1999-2000 school year, “the average pupil expenditure for educating a child with autism was estimated . . . to be over \$18,000.”⁶⁵ Researchers suggest that intensive behavioral intervention at a young age can help decrease the lifetime costs of treating and providing services for those with autism.⁶⁶ Additionally, the costs associated with ASD place heavy financial burdens on parents and families, which may or may not be lessened through health insurance coverage.⁶⁷

III. ANALYSIS: EXAMINING FEDERAL AND STATE HEALTH CARE LEGISLATION

A. *State Enacted Autism Legislation*

This section will examine both previously enacted state and federal legislation, as well as currently proposed autism health care legislation. Many states have taken the initiative to improve their health care legislation to better provide for those with ASD and their families. The federal government has also taken steps to provide more benefits for those with ASD. The most impressive

62. *Id.*

63. *Autism Costs Society an Estimated \$3 Million per Patient, According to Report*, SCIENCE DAILY, Apr. 3, 2007, <http://www.sciencedaily.com/releases/2007/04/070403112757.htm>.

64. See Douglas L. Leslie & Andres Martin, *Health Care Expenditures Associated With Autism Spectrum Disorders*, 161 ARCHIVES OF PEDIATRIC AND ADOLESCENT MEDICINE 350, 353 (2007) (indicating that, in 2000, mean costs of ASD were \$4,965, compared to \$2,819 for anxiety disorder, \$3,211 for depression, \$1,704 for hyperactivity, and \$3,463 for substance abuse).

65. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-05-220, SPECIAL EDUCATION: CHILDREN WITH AUTISM 10 (2005) (estimating that this was almost three times greater than annual expenditures for children without autism). Annual expenditures for regular education students were \$6,556. *Id.* at 27.

66. 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, 213-14 (1998) (describing how expending \$32,820 as an initial annual cost for early intensive behavioral intervention can lead to saving between \$187,000 to \$203,000 (not taking into account inflation) from ages three to twenty-two, and a savings of \$656,000 to \$1,081,000 from ages three to fifty-five).

67. Picard, *supra* note 61, at A13. This will also depend on the availability of insurance coverage and locality. *Id.*

stride has been in proposing the Autism Treatment Acceleration Act. These positive steps are encouraging to the ASD community, however, much still remains to be done in order to provide the most cost effective and beneficial health care to those suffering from the disorder.

Most medical insurance policies do not cover autism treatment,⁶⁸ leaving most parents and families of autistic children unable to obtain the appropriate medical coverage necessary to treat their child's condition.⁶⁹ Autism treatments are expensive and can cost families over \$50,000 per year out-of-pocket if insurance does not provide coverage.⁷⁰ Individuals diagnosed with heart disease, cancer, or diabetes automatically expect their insurance companies to cover treatments prescribed by their physicians; however, the same expectancy does not apply to those with autism.⁷¹ Despite autism affecting more children than cancer and diabetes combined, insurance companies are leaving families to foot the bill for ASD.⁷² In light of the high costs of ASD treatments, this is an extremely excessive burden to place solely on the shoulders of those with autism and their families.

Fortunately, some states now require certain insurers to provide coverage for autism treatment.⁷³ In fact, for the last three years, the United States has seen a wave of autism legislation passed throughout the country.⁷⁴ As of January 2011, twenty-three states have enacted autism insurance reform laws.⁷⁵ For example, Indiana, Texas, and South Carolina are three states that have instituted commendable legislation, specifically requiring insurers to cover autism diagnosis and treatment.

Indiana law requires that a group-issued accident and

68. See Redman, *supra* note 14 (stating most medical insurance policies do not cover autism treatment).

69. Shelley Hendrix Reynolds, *The Autism Treatment Acceleration Act and the Autism Sandbox*, HUFFINGTON POST, May 31, 2009, http://www.huffingtonpost.com/shelley-hendrix-reynolds/the-autism-treatment-acce_b_20613.html.

70. NAT'L CONFERENCE OF STATE LEGISLATURES, *Insurance Coverage for Autism*, NCSL.ORG, Aug. 2010, <http://www.ncsl.org/Default.aspx?tabid=18246> [hereinafter *Insurance Coverage for Autism*].

71. Reynolds, *supra* note 69.

72. *Id.*

73. *Insurance Coverage for Autism*, *supra* note 70.

74. See *id.* (explaining that from 2007-2008 nine states enacted autism insurance coverage mandates, and from January 2009 to September 2009 seven states have enacted laws requiring health insurance coverage for those with autism).

75. See *2011 State Initiative Agenda: Current Status of State Autism Insurance Reform Bills*, *supra* note 13 (specifying that Arizona, Colorado, Connecticut, Florida, Iowa, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, Pennsylvania, South Carolina, Texas, Vermont and Wisconsin all have some type of legislation in place relating to autism and insurance coverage).

sickness insurance policy provide coverage for the treatment of pervasive developmental disorders (PDDs), including autism.⁷⁶ Coverage is limited to treatment “prescribed by the insured’s treating physician in accordance with a treatment plan.”⁷⁷ Significantly, coverage cannot be denied to an individual because of their PDD diagnosis.⁷⁸

An insurer issuing individual accident and sickness insurance policies is also required to provide an option offering coverage for ASD.⁷⁹ Coverage limits, including treatment and dollar limitations as well as deductible or coinsurance limits, apply to both group and individual policies, and all ages are allowed coverage under both policies.⁸⁰

Indiana also has a Medicaid buy-in program that provides for working individuals with disabilities.⁸¹ A waiver is offered for individuals diagnosed with autism who require the assistance of an intermediate care facility for the mentally retarded (ICF-MR).⁸² This waiver provides for the potential coverage of music therapy, physical therapy, occupational therapy, speech/language therapy, psychological therapy, and applied behavioral analysis therapy.⁸³ The wide variety of treatments covered by these waivers is laudable, as each individual requires different types of treatment targeting their specific symptoms. Despite Indiana providing coverage under group and individual policies, self-insured companies in Indiana are not required by law to provide for the coverage of diagnosis and treatment of autism or other ASDs.⁸⁴

76. IND. CODE § 27-8-14.2-4 (2009); *see also* IND. CODE § 27-8-14.2-3 (2009) (defining a pervasive developmental disorder as “a neurological condition, including Asperger’s syndrome and autism, as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association”).

77. IND. CODE § 27-8-14.2-4 (2009).

78. *See id.* (providing that insurers cannot refuse to cover, contract with, refuse to renew or reissue, or otherwise terminate or place restrictions on an individual’s insurance policy solely because they have a pervasive developmental disorder). Group coverage under an accident and sickness policy is also not subject to dollar limits, deductibles, or coinsurance provisions less favorable than the limits, deductibles, or coinsurance provisions that apply to a general physical illness under the same policy. *Id.*

79. IND. CODE § 27-8-14.2-5 (2009).

80. *Id.*

81. IND. CODE § 12-15-41-3 (2009).

82. *Family and Social Services Administration-Medicaid Waivers*, IN.GOV, <http://www.in.gov/fssa/ompp/2549.htm> (last visited Feb. 21, 2011).

83. Marci Wheeler, *Indiana’s Home and Community Based Waivers*, <http://www.iidc.indiana.edu/index.php?pageId=555> (last visited Feb. 21, 2011). Other services that may be provided for under the autism waiver include respite care, adult day services, personal emergency response systems, environmental modifications, assistive technology, and residential habilitation and support. *Id.*

84. *Id.*

This exception forces many people to continue bearing the financial burden of ASD on their own, despite the fact that their state has provided assistance to others with the same condition.

Similarly, Texas legislation provides for the coverage of autism related services. Under the Texas Insurance Code, health benefit plans must provide coverage to an enrollee diagnosed with ASD from the date they are diagnosed until the enrollee reaches nine years of age.⁸⁵ The Texas Code requires coverage for all “generally recognized services prescribed in relation to [ASD] by the enrollee’s primary care physician in the treatment plan recommended by that physician.”⁸⁶ Generally recognized services include evaluation and assessment, applied behavior analysis, behavior training and behavior management, speech therapy, occupational therapy, physical therapy, and medications used to treat ASD symptoms.⁸⁷ Coverage under the Code is subject to annual deductibles, copayments, and coinsurance consistent with those required for other coverage under the same plan.⁸⁸ Although it is commendable that Texas provides coverage for a variety of treatments, Texas provides coverage only until age nine. This restriction forces parents and families to pay for all treatments after age nine entirely out of their own pocket.

In 2007, South Carolina passed what has become known as “Ryan’s Law,”⁸⁹ which extends coverage to those eligible until they reach sixteen years of age.⁹⁰ Ryan’s Law requires group health insurance plans and policies, including state employee health insurance plans, to provide coverage for the treatment of ASD.⁹¹ Coverage is limited only to treatment that is prescribed by the insured’s treating medical doctor in accordance with a treatment

85. TEX. INS. CODE § 1355.015 (2009). On September 1, 2009, the age range provided in §1355.015 expanded and insurers are required to cover autism related services for individuals ages two to eighteen. H.B. 451, 2009 Leg., 81st Sess. (Tex. 2009). Under the Code, ASD is defined as a neurobiological disorder including autism, Asperger’s syndrome, or PDDNOS. TEX. INS. CODE §1355.001.

86. *Id.*

87. *Id.*

88. *Id.*

89. See Redman, *supra* note 14 (explaining that Ryan’s Law was named after Ryan Unumb, a child with severe autism, whose mother, Lorri Unumb, wrote the original bill). Unumb lobbied state legislators, and two years later the bill was passed. *Id.*

90. S.C. CODE § 38-71-280 (2009). The Code defines ASD as autism, Asperger’s syndrome, or PDDNOS. *Id.*

91. See *id.* (explaining that treatment plans must include a diagnosis, proposed treatment type, frequency, and duration of treatment, anticipated outcomes, how often the treatment plan will be updated, the signature of the treating physician, and any other element necessary for the health insurance plan to appropriately pay claims).

plan.⁹² To be eligible under Ryan's Law, the insured must be diagnosed with ASD at eight years of age or younger.⁹³ Behavioral therapy is covered under the South Carolina Code and has a maximum annual benefit of \$50,000.⁹⁴ By providing annual benefits specifically for behavioral therapy, South Carolina's law gives those with ASD greater access to those treatments, which may result in more positive treatment-induced outcomes. Like Texas' law, Ryan's Law prohibits insurers from denying or refusing coverage because of an ASD diagnosis.⁹⁵ However, health plans for small business employers with fifty employees or less, self-insured, and individual plans are exempt from coverage under the South Carolina Code.⁹⁶

Despite the immense hope these mandates are providing for millions of American families, the health insurance industry is arguing against them, claiming that they make health care less affordable and less accessible.⁹⁷ The Council for Affordable Health Insurance has estimated that autism mandates alone only cause insurance costs to increase by less than one percent. However, when combined with other requirements, such as those requiring coverage for specific therapies, the Council argues that the mandates end up making insurance less affordable.⁹⁸ The health

92. *Id.*

93. *Id.*

94. *Id.* The maximum amount provided for behavioral therapy is to be adjusted annually on January 1 to reflect any changes in the Consumer Price Index. *Id.*

95. *Id.* The Code also prohibits insurers from subjecting coverage to dollar limits, deductibles, or coinsurance provisions less favorable to an insured than those that apply to a general physical illness under the health insurance plan. *Id.*

96. *Id.*; see Redman, *supra* note 14 (stating that people or companies that are self-insured are exempt from coverage under this law).

97. See Redman, *supra* note 14 (quoting Susan Pisano of America's Health Insurance Plans, who explains that it is not the autism mandates in particular that the health insurance industry is opposing, but mandates in general because when imposed they up the costs of health care); see also VICTORIA CRAIG BUNCE & JP WEISKE, COUNCIL FOR AFFORDABLE HEALTH INS., *Health Insurance Mandates in the States 2008*, at 2 (2008) [hereinafter *Health Insurance Mandates*] (defining a mandate as a requirement that an insurance company or health plan cover or offer to cover common health care providers, benefits and patient populations). In its 2008 report, The Council for Affordable Health Insurance explained how mandates make health insurance more expensive because they require insurers to pay for health care that the insured individuals were previously paying for on their own. *Health Insurance Mandates*, *supra*, at 2. The Council estimates that mandated benefits can increase health coverage costs from slightly less than twenty percent to over fifty percent, depending on the state and the type of mandates being offered in that state. *Id.* The council also explained that certain mandates have a higher impact on the cost of health insurance because they require insurers to cover both mental and physical care. *Id.* at 3.

98. *Parents Push States to Make Insurance Cover Autism Therapy*, USA

insurance industry is also opposed to providing coverage for behavioral therapy, especially applied behavior analysis (ABA).⁹⁹ It argues that ABA is new, unproven, and not effective in all cases.¹⁰⁰

Despite the health insurance industry's arguments against mandates requiring coverage for autism diagnosis and treatment, research on health insurance mandates proposed in Florida and Wisconsin show that health care costs have been minimally affected by the passing of such legislation.¹⁰¹ The Florida Division of Group Insurance estimated that mandates requiring the treatment of autism, Asperger's syndrome, and other PDDs would increase premium costs by only \$0.44 to \$1.67 per contract per month.¹⁰² In 2007, the Wisconsin Department of Administration estimated that a bill requiring insurance plans offered by the Group Insurance Board to provide coverage for ASD would increase monthly payments between \$3.45 and \$4.10.¹⁰³

TODAY, Oct. 20, 2008, http://www.usatoday.com/news/health/2008-10-20-autism-insurance_N.htm; see also *Health Insurance Mandates*, *supra* note 97, at 4 (showing that, in 2008, autism mandates were in existence in eleven states and increased health insurance costs less than one percent). This calculation was based on mandates enacted in Colorado, Delaware, Georgia, Iowa, Indiana, Kentucky, Maryland, Minnesota, New Mexico, and Wisconsin. *Id.* at 4-5.

99. Erica Noonan, *Push On For Insurers to Share Autism Costs*, THE BOSTON GLOBE, Sept. 16, 2008, http://www.boston.com/news/health/articles/2008/09/16/push_on_for_insurers_to_share_autism_costs/.

100. *Id.*; see also Redman, *supra* note 14 (describing how the health insurance industry views behavioral therapy as an educational measure, instead of as a medical one). Marylou Buyse, president of Massachusetts Association of Health Plans, told reporters that "health insurers should not be dragged into the educational arena[.]" Noonan, *supra* note 99. Noonan explained that to require coverage for ABA is like "asking for a blank check for therapies that we'd want more evidence to prove are really effective." *Id.*

101. IND. LEGISLATIVE SERV. AGENCY, OFFICE OF FISCAL AND MGMT. ANALYSIS, Fiscal Impact Statement for HB 1122, at 1-2 (2001), available at <http://www.in.gov/legislative/bills/2001/PDF/FISCAL/HB1122.006.pdf>; WIS. DEP'T OF ADMIN., DIV. OF EXEC. BUDGET & FIN., Fiscal Estimate for Assembly Bill 417 (2007) available at <http://legis.wisconsin.gov/2007/data/fe/AB-417fe.pdf>.

102. IND. LEGISLATIVE SERV. AGENCY, *supra* note 101, at 3. Under Florida legislation, a health insurance plan issued or renewed after April 1, 2009, is required to provide coverage for the screening and diagnosis of ASD in babies and children, treatments including speech therapy, occupational therapy, physical therapy, and ABA. Coverage is limited to a \$36,000 annual cap and a \$200,000 lifetime cap. FLA. STAT. § 627.6686 (2009).

103. WIS. DEP'T OF ADMIN., *supra* note 101, at 4. The bill that this estimate was based upon did not pass. AB 417, 2007 Leg., Reg. Sess. (Wis. 2007), available at <http://nxt.legis.state.wi.us/nxt/gateway.dll?f=templates&fn=default.htm&d=billhist07&jd=top>. However, an assembly bill is currently in place to amend legislation and require health insurance policies and self-insured governmental and school district plans to provide coverage for the costs of ASD treatment. The treatment must be prescribed by a physician and provided by someone qualified to administer the treatment. Coverage must

In addition to the estimated low costs associated with mandates requiring insurers to cover the diagnosis and treatment of ASD, such mandates are also expected to reduce the lifelong care of individuals diagnosed with ASD.¹⁰⁴ A child that does not receive adequate treatment at the early onset of ASD will incur more problems as an adult and leave their respective state with costlier challenges.¹⁰⁵ For example, Texas estimates that for each autistic child in the state that is able to receive therapies, it will save \$208,000 in long-term educational costs.¹⁰⁶ One study shows that when children have access to treatments, families save a total of \$2.4 to \$2.8 million over that child's lifetime.¹⁰⁷ These savings provide further proof that such mandates will serve to benefit not only those personally affected by ASD, but also states as a whole.

B. Federal Autism Legislation

The Combating Autism Act (CAA) went into effect in 2006.¹⁰⁸ The purpose of the legislation was to "increase awareness, reduce barriers to screening and diagnosis, and promote evidence-based interventions for individuals with [ASD] or other developmental disabilities."¹⁰⁹ The Act provides \$248 million for autism education, early detection, intervention, and for the creation of a developmental disabilities surveillance and research program.¹¹⁰ This Act aims to promote early detection and screening of individuals at high risk for ASD.¹¹¹ It targets some of the key

provide at least \$60,000 per year for intensive-level services and cover a minimum of thirty to thirty-five hours of weekly care for at least four years. Coverage must provide a minimum of \$30,000 per year for post-intensive level services. Assembly Substitute Amendment 1 to AB 15, 2009 Leg., Reg. Sess. (Wis. 2009), available at <http://nxt.legis.state.wi.us/nxt/gateway.dll?f=template&fn=default.htm&d=billhist&jd=top>.

104. Joseph J. Roberts, Jr., *Insurance Coverage for Autism an Incredible Investment*, NEW JERSEY NEWSROOM, May 28, 2009, <http://www.newjerseynewsroom.com/commentary/insurance-coverage-for-autism-an-incredible-investment>. Studies have shown that children who receive early intensive behavioral treatments show more adaptive behaviors and less maladaptive behaviors than children who did not receive such treatment. McEachin, *supra* note 42, at 360.

105. See Roberts, Jr., *supra* note 104 (explaining that "failing to help a child try to overcome the obstacles presented by autism will only lead to costlier problems later.")

106. *Id.* It is also estimated that Texas will save a total of \$774.1 million in education costs by 2017 due to legislation requiring insurance companies to cover autism treatments. *Id.*

107. *Id.*

108. Combating Autism Act, Pub. L. No. 109-416, 120 Stat. 2821 (codified at 42 U.S.C. §§ 280i, 280i-1 to -4, 283j (2006)).

109. 42 U.S.C. § 280i-1 (a)(1).

110. 42 U.S.C. § 280i-4.

111. 42 U.S.C. § 280i-1 (a)(1). The Combating Autism Act also creates the Interagency Autism Coordinating Committee, which is responsible for

areas needing attention in terms of ASD. Appropriations promoting early detection are essential, as such detection is critical to positive treatment outcomes and the age of diagnosis can also have an effect on insurance coverage provided to a particular individual. Additionally, the research efforts supported by the CAA are critical to further understanding a disorder whose origins and cures have evaded researchers thus far.

The Individuals with Disabilities Education Act (IDEA), passed in 2004, provides states with federal funds for the implementation of special education programs.¹¹² IDEA guarantees a free and appropriate public education to children with disabilities, including those diagnosed with ASD.¹¹³ IDEA provides early intervention services for children under three years of age aimed at “minimizing the impact of disabilities” on the development of children with ASD.¹¹⁴ IDEA also provides special education services for those ages three to twenty-one.¹¹⁵ One element of these services includes the creation of an Individualized Education Program aimed at targeting an individual child’s educational and functional needs.¹¹⁶ Both IDEA and the CAA provide excellent resources and opportunities to those with ASD, however, neither of them deals with health insurance coverage.

The Autism Treatment Acceleration Act of 2009 (ATTA) made provisions for insurance coverage. The ATAA was introduced to Congress in 2009, however it did not make it past the referral stage.¹¹⁷ The goal of the ATAA was “to provide for enhanced

developing and annually updating a summary of advances in ASD research, monitoring federal activities involving ASD, making recommendations regarding changes to ASD related federal activities, making recommendations regarding public participation in decision making related to ASD, developing and annually updating a plan for the conduction of ASD research, and submitting the plan to Congress. 42 U.S.C. § 280i-2.

112. 20 U.S.C. § 1411(a) (2006).

113. 20 U.S.C. § 1411(e)(3)(F). Treatment services provided under the free and appropriate education clause of IDEA must be provided free to the parents of the disabled child. SIFF EXHORN, *supra* note 36, at 121. Such services may include speech and language therapy, occupational therapy, physical therapy, psychological treatment, social work interventions, and transportation costs. *Id.* at 122.

114. *Id.* at 124. Early intervention services may include ABA, speech and language instruction, occupational therapy, and physical therapy. *Id.*

115. *Id.* at 131.

116. 20 U.S.C. § 1414(d). An IEP is a written statement for disabled children that includes: (1) a statement of that child’s current levels of academic achievement and functional levels; (2) a statement with attainable yearly goals; (3) a statement of how progress toward those annual goals will be measured; and (4) a statement of the special education and related services the child will be receiving. 20 U.S.C. § 1414(d)(1)(A)(i).

117. S. 819: *The Autism Treatment Acceleration Act of 2009*, GOVTRACK.US, <http://www.govtrack.us/congress/bill.xpd?bill=s111-819> (last visited Feb. 21, 2011); S. 819, 111th Cong. (2009).

treatment, services, and research for individuals with [ASDs] and their families.”¹¹⁸ The legislation, as written, would have alleviated many of the costs associated with the care of those with ASD by requiring certain health insurance carriers to provide coverage for ASD.¹¹⁹ The ATAA would have required group health plans to provide coverage for both the diagnosis and treatment of ASD.¹²⁰ Coverage for the diagnosis of ASD provides for assessments, evaluations, or tests deemed medically necessary in order to diagnose the insured with an ASD.¹²¹ In providing for the treatment of ASDs, the ATAA would have supplied coverage for care prescribed or provided by physicians, psychologists, or other professionals qualified to administer such care.¹²² Treatment covered by the legislation as it was proposed included: (1) medications; (2) occupational therapy; (3) physical therapy; (4) speech therapy; (5) direct or consultative services provided by psychiatrists or psychologists; (6) professional, counseling, and guidance services and treatment programs, including ABA; and (7) augmentative communication and assistive technology devices.¹²³ Coverage for a variety of treatments provided those with ASD numerous options in creating their individual treatment plans. The ATAA also prohibited group health plans from denying coverage on the basis that the coverage would not develop skills or functioning, maintain skills or functioning, restore skills or functioning, or prevent the loss of skills or functioning.¹²⁴

In addition to proposing provisions for insurance coverage, the ATAA would have also created the Autism Care Center Program.¹²⁵ This program was intended to improve: (1) comprehensive ASD care delivery; (2) access to appropriate health care services; (3) patient satisfaction; (4) communication among

118. S. 819.

119. *Id.* § 12(a).

120. *Id.* § 12(a)(1). Coverage under the ATAA was subject to limitations, but such limitations were not to be “less favorable to the individual than such financial requirements or limits for substantially all other medical and surgical benefits covered by the plan.” *Id.* § 12(b).

121. *Id.* § 12(f)(2).

122. *Id.* § 12(d)(3).

123. *Id.* § 12(b)(1)(A)-(E). The ATAA defined ABA as “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.” *Id.* § 12(f)(3)(D).

124. *Id.* § 12(d)(2)(A)-(D). Under the ATAA, a group health plan was not allowed to deny an individual eligibility, continued eligibility, or an opportunity to enroll in or renew coverage to avoid the mandates provided for in the proposed legislation. *Id.* § 12(d)(1).

125. *Id.* § 5. These care centers would have created networks of health care professionals to provide a full array of services to those with ASD.

ASD health care providers; (5) transitioning into postsecondary education and vocational or job training or placement; and (6) the quality of life of those with ASD.¹²⁶ Another key aspect of the ATAA was its focus on adult care in an effort to facilitate the independence of adults with ASD.¹²⁷ The ATAA provided for grants to be awarded to fund programs aimed at providing services such as postsecondary education, vocational training, self-advocacy skills, and employment.¹²⁸ These services would alleviate the high costs associated with the lost productivity of adults with ASD.¹²⁹ Unfortunately, the ATAA did not make it past the referral stage of the legislative process; however, this does not close the door to future legislation for which the ATAA should be used as a model.¹³⁰

IV. PROPOSAL

Health insurance coverage is thought to be the principal means through which children's health care can become accessible and affordable.¹³¹ In spite of this fact and the rising incidence of this condition, insurance coverage for ASD has remained inadequate in most states. The ATAA is a great model for future legislation aimed at providing adequate coverage for those with ASD. However, in addition to the coverage which was extended by the ATAA, a number of other elements should be incorporated into federal and state legislation in order to provide the best and most complete coverage for those with ASD. The ideal legislation would include: (1) coverage for diagnosis and treatment of ASD by group, individual, and self-insured plans; (2) coverage for a variety of treatment options, most importantly coverage for applied behavior analysis; (3) annual limits of no less than \$55,000; (4) coverage for an unlimited number of doctors visits; and (5) a support system providing services to adults with autism.¹³²

A. Group, Individual, and Self-Insured Coverage

Legislation should mandate that group, individual, and self-insurers cover the diagnosis and treatment of ASD. Many states,

126. *Id.*

127. *Id.* § 6(a).

128. *Id.* § 5(b).

129. *Societal Costs of Autism*, *supra* note 9, at 347.

130. *S.819: Autism Treatment Acceleration Act of 2009*, GOVTRACK.US, <http://www.govtrack.us/congress/bill.xpd?bill=s111-819>.

131. Pamela B. Peele et al., *Exclusions and Limitations on Children's Behavioral Health Care Coverage*, 53 *PSYCHIATRIC SERVICES* 591, 591 (2002).

132. See generally Autism Speaks, *Arguments In Support of Private Insurance Coverage of Autism-Related Services* (Oct. 24, 2007), available at <http://www.azautisminsurance.org/files/Arguments%20for%20private%20insurance%20coverage%20-%20Autism%20Speaks.pdf>.

including Connecticut, Illinois, Indiana, Nevada, Maine, and Massachusetts, currently have legislation that requires group health insurers to cover diagnosis and treatment.¹³³ In addition, a number of states mandate that individual policies also provide ASD coverage.¹³⁴ However, such legislation does not extend to those who are self-insured, including those insured through union plans.¹³⁵ Those insured under such plans are either forced to go

133. See CONN. GEN. STAT. ANN. § 38a-514b (West 2009) (mandating that every group health insurance policy provide coverage for ASD, including physical therapy, speech therapy and occupational therapy). Such policies are subject to the following limitations: a \$50,000 per year cap for children less than nine years of age, \$35,000 for children at least nine years of age and less than thirteen, and \$25,000 for children at least thirteen and less than fifteen years of age. *Id.*; 215 ILL. COMP. STAT. 5/536z.14 (2010) (requiring group or individual accident and health insurance policies or managed health care plans to provide those under twenty-one years of age with coverage for the diagnosis and treatment of ASD); ME. REV. STAT. ANN. tit. 24-A § 4234-A (2009) (mandating that health maintenance organizations providing individual and group insurance contracts provide benefits for those diagnosed with PDD or autism). Maine also requires nonprofit hospital or medical service organizations providing individual or group policies to provide benefits to those with PDD or autism. ME. REV. STAT. ANN. tit. 24 § 2325-A (2009); MASS. GEN. LAWS ANN. ch. IV §32A-22 (West 2009) (providing that current or retired employees of the Commonwealth insured under the group insurance commission shall receive coverage on a nondiscriminatory basis for the diagnosis and treatment of a number of biologically-based mental disorders, including autism); A.B. 162, 75th Leg. §3 (Nev. 2009) (requiring health benefit plans to provide coverage for the diagnosis and treatment of ASDs to those covered under group health insurance plans). Coverage is required until age eighteen or until the age of twenty-two if the individual is enrolled in high school. A.B. 162, 75th Legis. §3. This legislation provides a maximum benefit of \$36,000 a year for ABA. *Id.*

134. COLO. REV. STAT. § 10-16-104.5 (1993) (requiring that autism be covered just as any other ailment); 215 ILL. COMP. STAT. 5/536z.14 (2009) (providing for insurance benefits to diagnose and treat ASDs); IND. CODE § 27-8-14.2-5 (2009) (requiring that insurers provide for developmental disorders just as any other illness); ME. REV. STAT. ANN. tit. 24-A § 4234-A (2009) (mandating health care coverage for pervasive developmental disorders); ME. REV. STAT. ANN. tit. 24 § 2325-A (2009) (providing for health care coverage for pervasive developmental disorders); A.B. 162, 75th Leg. §8 (Nev. 2009) (including diagnosis and treatment of ASDs in required insurance coverage).

135. Information for Families With Self-Funded Health Insurance Plans, AUTISMVOTES.ORG, http://www.autismvotes.org/site/c.frKNI3PCImE/b.5216011/k.1245/Selfinsured_Companies_and_Autism_Coverage.htm; see also Wheeler, *supra* note 83 (explaining that Indiana's Autism Insurance Mandate does not extend to "self-insured" companies, meaning that these companies are not required to provide the same coverage that group insurers are required to cover); ILL. DEPT OF INS., Illinois Insurance Facts: Insurance Coverage for Autism, <http://www.insurance.illinois.gov/pressRelease/pr08/AutismFactSheet.pdf> (last visited Feb. 21, 2011) (describing that Illinois' insurance coverage for autism does not apply to self-insured, non-public employees or self-insured health and welfare plans, such as union plans); Peele, *supra* note 131, at 593 (indicating that self-insured plans are often exempt from insurance mandates under the Employee Retirement Income Security Act (ERISA)).

without adequate treatment or forced to pay the high costs of ASD diagnosis and treatment out of pocket. The median income for a four person family in the U.S. is \$70,354;¹³⁶ during the first five years of life the average cost of ASD is \$88,000.¹³⁷ This leaves families without ASD coverage struggling to pay for treatments in addition to their cost of living. Additionally, parents of autistic children are more likely to quit their jobs or reduce their work hours in order to provide care for their child,¹³⁸ which further reduces their financial ability to pay for adequate ASD treatments. By requiring group, individual, and self-insurers to provide coverage for ASD, the financial burden placed on families will be lessened, and individuals will have more access to adequate treatments.

Increased access to treatments will promote early intervention, which is critical for proper ASD treatment.¹³⁹ Studies have shown that when a child is very young their brain has the ability to rewire itself¹⁴⁰ and thus correct many of the neural deficits that their condition has created. Intensive early intervention can increase a child's rate of learning, decrease the occurrence of behavioral problems, and increase cognitive, communication, and overall developmental skills.¹⁴¹ Early intervention has been shown to improve the overall prognosis for children with ASD,¹⁴² and it has been predicted that early

136. DEPT OF HEALTH & HUMAN SERV., Estimated State Median Income, By Family Size and by State For FY 2009, <http://www.acf.hhs.gov/programs/ocs/liheap/guidance/SMI75FY09.pdf>. This estimate is for Oct. 1, 2008 thru Sept. 30, 2009. *Id.*

137. See *Societal Costs of Autism*, *supra* note 9, at 346 (estimating direct medical costs to be, on average, \$35,000 a year, direct nonmedical costs to be around \$10,000 a year, and indirect costs to be an average of \$43,000 during the first five years of life, totaling \$88,000 spent annually on ASD costs).

138. *Study: Autism Costs Strain Family Finances*, ASSOC. PRESS (Dec. 1, 2008), <http://www.msnbc.msn.com/id/27988021/>.

139. See SIFF EXKORN, *supra* note 35, at 88 (stating that intensive intervention beginning as early as twelve to fourteen months of age can improve the child's overall ASD prognosis, can maximize the child's ability to learn, and can eliminate specific problem behaviors).

140. See *id.* (describing that when a child is young their brain's ability to be shaped is at its greatest). During this critical time, children's brains are "more receptive to taking in new information and can form new connections." *Id.* Treatment is recommended to begin as early as twelve to fourteen months of age. *Id.* And studies have shown that intervention beginning at three years of age is better than intervention beginning at age five. *Id.*

141. *Id.* at 89. Research also shows that, with early intensive intervention, potentially half of children with ASD will be able to develop friendships, hold jobs, and lead more productive lives. *Id.* at 88-89.

142. *Id.* at 88. The American Academy of Pediatrics adheres to the belief that "early diagnosis resulting in early, appropriate, and consistent intervention, has . . . been shown to be associated with improved long-term outcomes." *Id.*

diagnosis and treatment can reduce lifetime care costs by two-thirds.¹⁴³

B. Coverage for Variety of Treatments

Legislation for ASD coverage should provide for a variety of treatments. The symptoms of ASD are not the same across all individuals, so treatment plans need to be personalized to meet an individual's particular needs.¹⁴⁴ For this reason, insurance needs to provide coverage for a range of treatments. The ATAA, for example, called for mandated coverage of occupational, physical, and speech therapy, as well as other professional, counseling, and guidance services and treatment programs, including ABA.¹⁴⁵ In addition to those treatments, legislatures should consider specifying coverage for other treatments including relationship developmental intervention¹⁴⁶ and floor time.¹⁴⁷

The high cost of treatments also creates a demand for more comprehensive insurance coverage. For example, ABA can cost up to \$7,000¹⁴⁸ a month, which leads to an annual cost of up to \$84,000 for ABA alone; most children receive a battery of

143. S. 819 § 2.

144. See SIFF EXKORN, *supra* note 36, at 92 (describing how treatments for ASD vary widely and are more successful if highly personalized).

145. S. 819 § 12(f)(3).

146. RICHARD L. SIMPSON, *AUTISM SPECTRUM DISORDERS: INTERVENTIONS AND TREATMENTS FOR CHILDREN AND YOUTH* 42-44 (Corwin Press 2005). Relationship Development Intervention (RDI) focuses on improving interpersonal relationship skills of those with ASD. *Id.* at 42. RDI helps teach those with ASD how to form positive friendship-related emotions, how to engage in activities that are friendship based, how to maintain give-and-take relationships with others, how to manage conflict, how to share perceptions and experiences with others, how to create memories of favorable experiences, how to voluntarily participate in relationships without having to be rewarded, how to maintain relationships with others, and how to accept others. *Id.* at 42-43. However, the effects of RDI have not been scientifically proven, which can lead to battles similar to the one insurance carriers are putting up against ABA coverage. *Id.* at 43.

147. *Id.* at 26-29. Floor time (part of the developmental, individual-difference, relationship-based model) focuses on improving social and relationship skills. *Id.* at 26. It is a "play based interactive intervention approach that emphasizes individual differences, child-centered interests, and affective interactions between a child and a caregiver." *Id.* There are four goals associated with this method of treatment: (1) to encourage attention and intimacy; (2) to promote two-way communication; (3) to advance the expression and use of ideas and feelings; and (4) to further logical thought. *Id.* at 27. The method works by increasing alertness, self-initiative, tolerance of frustrations, and sequencing, improving flexibility and problem solving, and promoting communication through gestures and speech. *Id.*

148. Thalia Assuras, *Insurance Companies Refuse Autism Coverage*, CBS EVENING NEWS, Jun. 21, 2009, <http://www.cbsnews.com/stories/2009/06/21/ev eningnews/main5101691.shtml>. The \$7,000 estimate is based on the recommended 40 hours a week of ABA therapy. *Id.*

treatments to target their individual ASD symptoms.¹⁴⁹ Furthermore, children with ASD are more likely to require physical, occupational, or speech therapy¹⁵⁰ and will be able to access such treatments more readily if insurance coverage is provided for them.

Many insurers argue against coverage of certain therapies, including ABA, claiming that they are experimental and not scientifically proven.¹⁵¹ However, ABA is government endorsed¹⁵² and the National Institute of Child Health and Human Development lists ABA as a treatment recommended for autism.¹⁵³ According to a coordinator at the Marcus Autism Center in Atlanta, Georgia, “[r]esearch has shown that [ABA] is the treatment of choice, and results in the best gains in terms of skill acquisition and behavior problem reduction for kids with autism and other developmental disabilities.”¹⁵⁴

C. At least \$55,000 in Annual Coverage

Legislation should mandate that insurance companies provide general coverage up to at least \$55,000 per year. Some states that have enacted ASD health insurance legislation have placed annual caps on the amount of coverage, some of which are too low to cover all of the costs associated with ASD. For example, Illinois has a \$36,000 cap on coverage,¹⁵⁵ while South Carolina’s Ryan’s Law provides for a \$50,000 maximum annual coverage for behavioral therapies alone.¹⁵⁶ As previously noted, the costs of a single therapy can cost up to \$84,000 per year in the most severe cases,¹⁵⁷ with some estimates calling for \$50,000 annual costs of behavior

149. See Volkmar, *supra* note 31, at 150 (describing a movement toward the “interplay between different treatments” as the current trend in autism treatment).

150. Gurney, *supra* note 29, at 827.

151. Val Willingham, *Parents Press for Autism Insurance Coverage*, CNN MED. PRODUCER, Oct. 21, 2008, <http://edition.cnn.com/2008/HEALTH/conditions/10/17/autism.insurance/index.html>.

152. See U.S. DEP’T OF HEALTH & HUMAN SERV., MENTAL HEALTH: A REPORT OF THE SURGEON GENERAL 163-64 (1999) (explaining how research, including the Lovaas study previously described, has demonstrated that applied behavioral methods are effective in “reducing inappropriate behavior and in increasing communication, leaning, and appropriate social behavior.”).

153. NAT’L INST. OF CHILD HEALTH & HUMAN DEV., *Autism Overview: What are the treatments for autism*, Oct. 8, 2007, <http://www.nichd.nih.gov/publications/pubs/overview/treatmentsforautism.cfm>.

154. Elizabeth Landau, *Choice Autism Treatment Offers Benefits, Has Limits*, CNN, Mar. 21, 2009, <http://www.cnn.com/2009/HEALTH/03/31/autism.applied.behavior.analysis/index.html>.

155. 215 ILL. COMP. STAT. § 5/356z.14(b).

156. S.C. CODE § 38-71-280(E) (2009).

157. See Assuras, *supra* note 148 (estimating that the costs of ABA can be as high as \$7,000 a month).

therapies.¹⁵⁸ Therefore, Illinois' \$36,000 cap on general coverage places severe limitations on the amount of services available to those with ASD through their insurance. A family in Illinois that has to pay the upper estimate of \$84,000 per year for ABA would not even have half of their ABA treatment paid for by insurance, not to mention other medical costs including doctor visits, hospital and emergency room services, prescription drugs, and other nonbehavioral based therapies.¹⁵⁹

South Carolina, however, provides a \$50,000 maximum specifically for behavioral treatments.¹⁶⁰ This limit would allow for more flexibility when it comes to treatment options and also places less of a financial burden on families in terms of other costs associated with ASD. A \$55,000 general limit on ASD insurance policies would provide some coverage for treatments, in addition to all of the other medical costs associated with ASD. Higher limits or no limit at all may be placing too much of the burden on insurance carriers, which will in turn lead to more significant premium increases. Minimum \$55,000 limits will take much of the burden off of those with ASD and their families without reallocating too much of that burden onto insurance carriers.

D. No Limit on Doctor Visits or Number of Therapy Sessions

Legislation should not put limits on the number of doctor visits or therapy sessions covered by insurance.¹⁶¹ Such limitations can seriously encumber the treatment process, and effectively cause those who exceed the limits to become uninsured.¹⁶² A 2006 study revealed that parents of children with ASD reported higher

158. *Missouri Lawmakers Seek to Mandate Autism Coverage*, USA TODAY, Mar. 5, 2009, http://www.usatoday.com/news/health/2009-03-05-autism-mandate_N.htm.

159. *See Societal Costs of Autism*, *supra* note 9, at 246 (showing that during ages three to seven average annual costs of factors besides behavioral therapies include: physician and dental costs of \$1,147 per year, drug costs of \$147 per year, complementary and alternative medicine costs of \$198 per year, emergency and hospital costs of \$828 per year, home health costs of \$467 per year, child cares costs of \$4,636 per year, respite care costs of \$1,100 per year, and special education costs of \$4,585 per year).

160. *Id.*

161. *Peele*, *supra* note 131, at 592. A 1996 study of eighty-two health plans revealed that each plan had some kind of limitation on benefits received. *Id.* at 591-94. Specifically, over half had limits on the number of yearly outpatient sessions, and sixty-five percent of the plans put annual limits on the number of inpatient days. *Id.* Such benefit limitations have disproportionate affects on children. *Id.* at 593.

162. *See id.* (explaining that benefit limits lead to insurance coverage being lost before treatment is even complete). Additionally, limits can also "mean that some children effectively become uninsured if they require more intensive services than those covered under the plan or if they need treatment for disorders that are excluded under the plan." *Id.*

prevalence of childhood conditions, as well as higher health care use, than children without ASD.¹⁶³ The study revealed that, during a twelve month period, children with ASD were more likely to require: (1) physical, occupational, or speech therapy; (2) counseling for an emotional, developmental, or behavioral problem; or (3) medication.¹⁶⁴ Additionally, parents of children with ASD experienced higher incidences of conditions such as depression, anxiety, behavioral or conduct problems, ADHD or ADD diagnoses, and allergies (especially food allergies).¹⁶⁵ Higher incidence of such conditions leads to higher demands on the health care system by those with ASD. By providing unlimited doctor's visits and therapy sessions, insurance will enable those with ASD to get the proper care required earlier, which may have the effect of ameliorating conditions and requiring less future doctor visits and therapy sessions.

E. Adult Support Services

Lastly, legislation should also provide adult support services to those with ASD. The ATAA provided an impressive example of such services.¹⁶⁶ As proposed, the ATAA provided grants to entities that carried out programs for adults, including those focused on providing: (1) postsecondary education, vocational training, self-advocacy skills; (2) residential services and supports, housing and transportation; and (3) nutrition health and wellness, recreational and social activities.¹⁶⁷ As those with ASD get older, the costs of their non-medical care and the costs of productivity both escalate significantly.¹⁶⁸ These indirect costs have the biggest impact on

163. Gurney, *supra* note 29, at 826.

164. *Id.* at 827 tbl.2. The study shows that seventy-six percent of parents of children with ASD reported that their child received special therapies such as speech, occupational or physical therapy, while only 6.3% of parents of children without ASD reported similar therapy uses. *Id.* In terms of emotional, developmental, or behavioral treatment, 75.4% of parents of those with ASD reported needing such therapy, while only seven percent of parents with non-ASD children reported such therapy. *Id.* Additionally, 54.7% of parents of ASD children reported that their children used prescription medicine, while 21.1% of parents of non-ASD children reported use of prescription medicine. *Id.*

165. *Id.*

166. S. 819 § 6.

167. *Id.* § 6(b). Those seeking to request such grants need to submit applications that contain information including the services they are expecting to provide and the outcomes that such services will have on adults with ASD, the number of adults they are expecting to serve through the grant funds, and the way the services will be coordinated among public and nonprofit providers of services for adults with disabilities. *Id.*

168. Picard, *supra* note 61; see also *Societal Costs of Autism*, *supra* note 9, at 346 (estimating that indirect costs peak during ages twenty-three to twenty-seven, to around \$52,000 per year). Indirect costs include the value of lost income, benefits, and household services of those with ASD and their

society.¹⁶⁹ Research shows that many people with ASD do not hold jobs and are still dependent on their caretakers to provide for them; this turns into economic losses averaging \$52,000 a year.¹⁷⁰ By providing adult services that promote secondary education and vocational training, adults with ASD will have more opportunities to become self-sufficient and contribute more to society than they otherwise would.

V. CONCLUSION

In recent years, ASD health coverage has undergone a major reform in the U.S.¹⁷¹ However, the incidence of ASD is increasing,¹⁷² calling for further expansion of ASD coverage. The ATAA provided an example of many of the elements crucial to an ASD coverage plan, but some additions could be made to make coverage even more effective. By providing extended coverage for ASD, treatments will be more accessible to those who need it, the lifetime costs of treating ASD will decrease,¹⁷³ and the costs ASD has on society will be minimized.¹⁷⁴ Additionally, such mandates will not result in an unduly burdensome increase in insurance premiums. Studies examining the costs of proposed legislation in Wisconsin and Florida found that monthly premiums would increase less than five dollars,¹⁷⁵ which is a small price to pay to

caregivers because of “missed time at work, reduced work hours, switching to a lower-paying but more flexible job, or leaving the workplace.” *Societal Costs of Autism*, *supra* note 9, at 344.

169. *Id.* at 347. Lost productivity at earlier ages mostly stems from caregivers or parents, but beginning around age twenty-three those with ASD start incurring their own indirect costs. *Id.*

170. Picard, *supra* note 61. Research shows that only five percent of adults with autism are self supporting. *Id.*

171. See 2011 State Initiative Agenda: Current Status of State Autism Insurance Reform Bills, *supra* note 13 (indicating that as of January 2011 almost twenty-three states had already enacted autism insurance reform legislation and twenty-four states were pursuing autism insurance reform bills).

172. See Madeline Ellis, *Prevalence of Autism Estimated at More Than 1% of All Children*, CHILD HEALTH, Oct. 6, 2009, <http://www.healthnews.com/family-health/child-health/prevalence-autism-estimated-more-than-1-all-children-3744.html> (revealing that an October 2009 study estimated the prevalence of ASD to be one in every ninety-one children, compared to a 2003 estimate of one in every 150 children).

173. See Roberts, Jr., *supra* note 104 (providing the results of a 1998 study estimating that when treatment is made available to autistic individuals, families will incur between \$2.4 and \$2.8 million in net savings).

174. See *id.* (describing that for every child that has access to therapies, the state will gain \$208,000 in long-term educational savings). Texas also estimates a \$771.5 million savings in educational costs by 2017 when children have access to treatments. *Id.*

175. See IND. LEGISLATIVE SERV. AGENCY, *supra* note 101, at 2 (estimating that Florida insurance mandates that require treatment of ASDs would

make potentially life changing treatments and services available to someone with ASD. Increasing ASD insurance coverage will provide hope to thousands of families and remove much of the heavy financial burdens associated with ASD. "The greatest cost would be the cost of doing nothing."¹⁷⁶

increase premiums between \$.44 and \$1.67 per contract per month); *see also* WIS. DEPT OF ADMIN., *supra* note 101 (indicating that a bill requiring coverage of ASD would increase monthly premiums between \$3.45 and \$4.10); *Missouri Lawmakers Seek to Mandate Autism Coverage*, *supra* note 157 (explaining that a Missouri consulting firm estimated that an autism insurance mandate would increase premiums by less than one percent).

176. Roberts, Jr., *supra* note 104.