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HEALTH CARE FOR THE AUTISTIC CHILD IN THE U.S.: THE CASE FOR FEDERAL LEGISLATIVE REFORM FOR ABA THERAPY

LAURA C. HOFFMAN*

Autism is transforming the way we think about disability; it is affecting the balance between medical insurance coverage and educational services; it is creating new markets that beg for regulatory intervention; it is challenging traditional assumptions about retribution and punishment; it is prompting a massive investment of public and private resources; it is changing the aesthetics of suffering, and in so doing, it is rearranging legislative priorities.¹

I. INTRODUCTION

Autism is the fastest growing developmental disability today with a growth rate of 1,148%.² According to the Centers for Disease Control and Prevention (CDC), approximately 1 in 88 children in the U.S. have an autism spectrum disorder (ASD).³ The

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1. Daniela Caruso, *Autism in the U.S.: Social Movement and Legal Change*, 36 AM. J.L. & MED. 483, 486 (2010).

2. *Facts and Statistics*, AUTISM SOC'Y, <http://www.autism-society.org/about-autism/facts-and-statistics.html> (last visited Oct. 22, 2012).

3. Ctrs. for Disease Control & Prevention, *Autism Spectrum Disorders (ASDs): Data & Statistics*, CDC.GOV, <http://www.cdc.gov/ncbddd/autism/data.html> (last updated Mar. 29, 2012); see

prevalence is even greater by gender with a ratio of 5 to 1, with 1 in 54 boys having some form of an ASD compared to only 1 in 252 girls.⁴ As the number of individuals with autism continues to climb, large questions arise as to how these individuals' needs should be addressed, specifically with regard to children with autism and their well-being to ensure their presence and involvement in our society. Should society play a role in helping care for and protect children with autism? If so, what implications does this have in terms of legal protections? What responsibility does our legal system carry to ensuring that children with autism are provided the means to their future development toward adulthood? In particular, as more children with autism have been diagnosed, more challenges have been created for these children in acquiring access to health care services that meet their needs. In his presidential proclamation recognizing World Autism Awareness Day on April 2, 2012, President Barack Obama wrote: "As a Nation, we share a responsibility to ensure persons living with ASDs have the opportunity to pursue their full measure of happiness and achieve their greatest potential."⁵ In particular, as more children with autism have been diagnosed, it has become more challenging for parents of children with autism to acquire access to health care services that meet their children's needs as they are among the many children with special health needs in America.⁶ As more research has grown suggesting that the diagnosis of autism and treatment as early as possible will benefit the individual much more significantly in the long run, it is critical that health care policies are designed to ensure that autistic children are provided access to these services in the very vital period of childhood development.⁷

also Ctrs. for Disease Control & Prevention, *Morbidity and Mortality Weekly Report (MMWR): Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008: Surveillance Summaries*, CDC.GOV (Mar. 30, 2012), http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w.

4. *Id.*

5. Proclamation No. 8795, 77 Fed. Reg. 20,501 (Apr. 2, 2012), available at <http://www.whitehouse.gov/the-press-office/2012/04/02/presidential-proclamation-world-autism-awareness-day-2012>.

6. See Campaign for Child Health Care, *Children and Youth with Special Health Care Needs* 1 (Apr. 2007), <http://www.childrenshealthcampaign.org/assets/pdf/Children-with-Special-Needs.pdf> (reporting that twenty percent of families have had financial difficulty in paying for healthcare for children with special needs).

7. See Ctrs. for Disease Control & Prevention, *Autism Spectrum Disorders (ASDs): Treatment*, CDC.GOV, <http://www.cdc.gov/ncbddd/autism/treatment.html> (last updated Dec. 29, 2010) (detailing the different kinds of treatments that can benefit children with ASDs early in their development).

This Article evaluates how the law has been used to provide access to health care for children with autism and what this means for the future of shaping policies designed to afford autistic children adequate legal protections for health care services. In Part II, this Article provides an introduction and basic understanding of autism including its history, how autism is defined, its prevalence especially regarding children, issues involving diagnosis, how genetics may play a role in autism, and treatment options with particular attention to ABA therapy. Part III provides an overview of the cost of providing health care for individuals with autism and why this case is unique for autistic children even compared to children with other chronic diseases. Part IV details the history of autism and access to health care insurance coverage through litigation. The litigation section examines several cases from the U.S. involving denials of insurance coverage for children with autism for various treatments as well as an international case from the Supreme Court of Canada that provides an intriguing look at alternative legal challenges. An overview of the Vaccine Court is then provided and a summary of the most recent litigation efforts to try to secure access to health care services for autistic children. Part V explores the legislative landscape for legal protections available for securing access to health care for individuals with autism. That section is divided into three types of legislation: (1) federal law, (2) joint efforts—those that involve the cooperation of both federal and state governments, and (3) state legislative efforts. Part VI analyzes bills recently proposed at the federal level to provide greater legal protections for those with autism to ensure legal protections for access to health care and their potential as solutions to the difficulties posed in acquiring health care for individuals with autism. Finally, in Part VII, this Article argues that the federal government needs to coordinate its efforts in research and policy regarding treatments for autism that will result in greater universal care that addresses the particularized needs of autistic children and their differences across the spectrum for health care services.

II. UNDERSTANDING AUTISM

A. *History of Autism*

The history of autism and the evolution of this developmental disability is an important foundation for comprehending the nature of its complexities and how defining a disorder can be crucial to the development of policy. The initial discoveries of “autism” and “Asperger’s Syndrome” at approximately the same time may have inspired the later categorization of what is now known as the “autism spectrum” that has become a source of

tension, and often, confusion, in policy making surrounding autism generally. “From the early 1900s, autism has referred to a range of psychological conditions.”⁸ The origin of the word autism provides insight as to an understanding of the disability: “The word ‘autism,’ which has been in use for about 100 years, comes from the Greek word ‘autos,’ meaning ‘self.’ The term describes conditions in which a person is removed from social interaction—hence, an isolated self.”⁹

The first recognized use of the term “autism” occurred in 1911 by a Swiss psychiatrist, Eugen Bleuler, in reference to “symptoms of schizophrenia.”¹⁰ Eventually the term “autism” was used to refer to children in the U.S.: “In the 1940s, researchers in the United States began to use the term ‘autism’ to describe children with emotional or social problems. Leo Kanner, a doctor from Johns Hopkins University, used it to describe the withdrawn behavior of several children he studied.”¹¹

More specifically, Kanner wrote about his experience with autism:

An article written by Dr. Leo Kanner of the Johns Hopkins Hospital in 1943 marks the birth of autism in the world of psychiatry. Kanner used the label ‘infantile autism’ to describe an unusual psychiatric syndrome, characterized by an inability to relate to people, a failure to develop speech or an abnormal use of language, deviant responses to environmental objects and events, excellent rote memory, and an obsession with repetition and sameness.¹²

While Kanner had recognized “autism” for the first time, another discovery was being made: “At about the same time, Hans Asperger, a scientist in Germany, identified a similar condition that’s now called Asperger’s syndrome.”¹³ What will later be recognized as the higher functioning end of the autism spectrum, Asperger’s syndrome’s identification was due to the work of Hans Asperger:

Hans Asperger, like Kanner, was born in Austria and wrote his seminal contribution to the understanding of autism spectrum disorders in the mid 1940s. His take on autism, however, was different. He focused on the most high-functioning end of the spectrum and observed that certain individuals, while lacking common intuition, empathy, and flexibility, were capable of turning their difficulties into gifts, their obsessions into skills, and their

8. *A History of Autism*, WEDMD, <http://www.webmd.com/brain/autism/history-of-autism> (last visited Oct. 22, 2012).

9. *Id.*

10. *Id.*

11. *Id.*

12. Caruso, *supra* note 1, at 489.

13. *A History of Autism*, *supra* note 8.

perseveration into talent. Asperger's work, written in German, remained unknown to most for several decades, but was translated into English in the early 1990s and quickly gained popularity among autism researchers and activists.¹⁴

But even with the discovery of Asperger's syndrome, there was resistance to categorizing autism and Asperger's along what would later become the autism spectrum.¹⁵ Ultimately, a movement toward using the spectrum occurred and has been the predominant categorization of diagnosis until recently as is discussed more thoroughly in the section on the challenges of diagnosis.

In addition to the debate over the use of the autism spectrum for both the classic case of autism at the most severe end and the highest functioning form of autism through Asperger's, another critical question raised about autism clinically has been how to categorize autism in relation to other disorders. It was not until the 1960's that development began in distinguishing schizophrenia and autism: "Autism and schizophrenia remained linked in many researchers' minds until the 1960s. It was only then that medical professionals began to have a separate understanding of autism in children."¹⁶ According to a report by the National Institute of Child Health and Human Development (NICHD), "[e]ven though autism was first described in the 1940s, little was really known about the disorder until the 1990s. Even today, there is a great deal that researchers, scientists, and health care providers don't know about autism."¹⁷ While there has been great progress in understanding autism, the continued difficulty in determining how to classify autism as a medical diagnosis has also infiltrated the law and considerations of providing legal protections for those with autism. As legal protections depend on how a term, or in this case, a disorder, is defined, this history of the evolution of autism and the scientific developments in understanding what autism is will shed light on why the law must be careful in choosing legal definitions to properly fit the medical realities of a disorder like autism.

14. Caruso, *supra* note 1, at 489.

15. *Id.* (stating that "[n]ot everyone agrees that autism and Asperger's Syndrome are manifestations of the same pathology (differing in degree but not in substance). While severe autism is completely incapacitating, individuals with Asperger's Syndrome can be well integrated in their community, and oftentimes make fundamental contributions in their professional fields. Post-mortem diagnoses are doubtful, but Albert Einstein's life story, which begins with tales of delayed speech and abysmal performance at school, suggests that the most accomplished scientist of all time might have suffered from Asperger-like symptoms.").

16. *A History of Autism*, *supra* note 8.

17. NAT'L INST. OF CHILD HEALTH AND HUMAN DEV., *Autism Overview: What We Know* 1, NIH Pub. No. 05-5592 (May 2005), available at http://www.nichd.nih.gov/publications/pubs/upload/autism_overview_2005.pdf.

B. What Is Autism?

In order to begin any analysis of autism for law and policy considerations in access to health care, it is fundamental to establish an understanding of how autism is currently defined and what is known about the disability. According to NICHD, “[a]utism is a complex neurobiological disorder of development that lasts throughout a person’s life. It is sometimes called a *developmental disability* because it usually starts before age three, in the developmental period, and because it causes delays or problems in many different skills that arise from infancy to adulthood.”¹⁸

Among many common misconceptions about autism is that it is the same for every child or individual, where in reality, the disability is actually defined using a range that makes up a “spectrum.”¹⁹ “The term ‘spectrum disorders’ is used to indicate that ASDs encompass a range of behaviorally defined conditions, which are diagnosed through clinical observation of development.”²⁰ A basic understanding of Autism Spectrum Disorders (ASDs) is provided by the Centers for Disease Control and Prevention (CDC): “Autism spectrum disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges.”²¹ The CDC explains the meaning of the “autism spectrum” as follows:

ASDs are “spectrum disorders.” That means ASDs affect each person in different ways, and can range from very mild to severe. People with ASDs share some similar symptoms, such as problems with social interaction. But there are differences in when the symptoms start, how severe they are, and the exact nature of the symptoms.²²

As the CDC articulated, no two children or individuals with autism are exactly alike.²³ Additionally, within the autism spectrum, there are three major categories of autism spectrum disorders: autistic disorder, Asperger syndrome, and Pervasive Developmental Disorder—not otherwise specified.²⁴ Each of these specific types of autism has its own definition and unique

18. *Id.* at 2.

19. Collin Muller, *What is Autism?*, AUTISM & CULTURE (Dec. 14, 2010), <http://autism-culture.com/autism/what-is-autism/> (last visited Oct. 22, 2012).

20. Catherine Rice, *Morbidity and Mortality Weekly Report (MMWR), Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, United States, 2006 2*, CDC.GOV (Dec. 18, 2009), <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>.

21. *Autism Spectrum Disorders (ASDs): Data & Statistics*, *supra* note 3.

22. *Id.*

23. *Id.*

24. *Id.*

characteristics.²⁵ The CDC has provided explanations for each of these types of autism.²⁶ The “classic” case of autism is identified as follows: “This is what most people think of when hearing the word ‘autism.’ People with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests. Many people with autistic disorder also have intellectual disability.”²⁷ Another form of autism called Asperger’s syndrome is characterized comparatively by a child or individual displaying less severe symptoms of autism and identified as follows: “People with Asperger syndrome usually have some milder symptoms of autistic disorder. They might have social challenges and unusual behaviors and interests. However, they typically do not have problems with language or intellectual disability.”²⁸

The third category identified by the CDC is Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS) also known as “atypical autism.” PDD-NOS is identified as follows: “People who meet some of the criteria for autistic disorder or Asperger syndrome, but not all, may be diagnosed with PDD-NOS. People with PDD-NOS usually have fewer and milder symptoms than those with autistic disorder. The symptoms might cause only social and communication challenges.”²⁹

Despite these distinctions on the autism spectrum, there are still symptoms that have been recognized as common among many, but may differ substantially in onset, severity, and the nature of the symptoms, which reflects the necessity of a spectrum in describing autism.³⁰ Understanding how autism is currently defined, how different types of autism are defined, and how the autism spectrum is defined is critical to policymakers in trying to make policy decisions to best serve those with autism in protecting their legal rights. The determination of how autism is defined for the purpose of the law will have significant impact in who will gain access to the rights afforded by the law. For policymakers to ignore taking into consideration how professional/clinical definitions treat autism is an injustice to individuals with autism.

25. *Id.*

26. *Id.*

27. *Id.*

28. *Id.*

29. *Id.*

30. Ctrs. for Disease Control & Prevention, *Autism Spectrum Disorders (ASDs): Signs and Symptoms*, CDC.GOV, <http://www.cdc.gov/ncbddd/autism/signs.html> (last updated May 13, 2010).

C. The Prevalence of Autism

1. A Public Health Concern by the Numbers

As important as it is to know what autism is, it is also critical to any policy considerations involving autism to understand that the prevalence of the incidence of autism make it an urgent public health concern regarding children and their access to health care. Autism is the fastest-growing serious developmental disability in the U.S.³¹ Each year, children are being impacted by autism “more than AIDS, diabetes & cancer combined.”³² According to the CDC: “About 1 in 88 children has been identified with an autism spectrum disorder (ASD) according to estimates from CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network.”³³ The report also recognized a 23% increase in autism since the last Autism and Development Disabilities Monitoring (ADDM) Network report in 2006.³⁴ In coming to these statistics, the ADDM Network makes the following statement in its 2008 report regarding children who are included as autistic for purposes of its analysis:

A child is included as meeting the surveillance case definition for an ASD if he or she displays behaviors (as described on a comprehensive evaluation completed by a qualified professional) consistent with the American Psychiatric Association’s Diagnostic and Statistical Manual-IV, Text Revision (DSM-IV-TR) diagnostic criteria for any of the following conditions: Autistic Disorder; Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder.³⁵

The 2008 ADDM report on the prevalence of autism made the following recommendation regarding autism and public health:

Given substantial increases in ASD prevalence estimates over a relatively short period, overall and within various subgroups of the population, continued monitoring is needed to quantify and understand these patterns. With 5 biennial surveillance years completed in the past decade, the ADDM Network continues to monitor prevalence and characteristics of ASDs and other developmental disabilities for the 2010 surveillance year. Further work is needed to evaluate multiple factors contributing to increases in estimated ASD prevalence over time. ADDM Network investigators continue to explore these factors, with a focus on understanding disparities in the identification of ASDs among certain subgroups and on how these disparities have contributed to

31. Autism Speaks, *What Is Autism?*, AUTISMSPEAKS.ORG, <http://www.autism-speaks.org/what-autism> (last visited Apr. 23, 2012).

32. *Id.*

33. *Autism Spectrum Disorders (ASDs): Data & Statistics*, *supra* note 3.

34. *Morbidity and Mortality Weekly Report (MMWR)*, *supra* note 3.

35. *Id.*

changes in the estimated prevalence of ASDs. CDC is partnering with other federal and private partners in a coordinated response to identify risk factors for ASDs and to meet the needs of persons with ASDs and their families.³⁶

A 2005 report by the National Institute of Child Health and Human Development (NICHD) also pointed out that it is difficult to identify the cause of the increase of autism:

Researchers are not certain whether autism is more prevalent now than in the past for a number of reasons. Although more cases of autism are being identified, it is not clear why. Some of the increase may result from better education about the symptoms of autism or from more accurate diagnoses of autism.³⁷

But the statistics involving autism were not always this severe.³⁸ A 2006 ADDM report acknowledged that the broadening of the identification of autism through a spectrum composed of various types of autism has contributed to this increase in prevalence of the disability:

Before the 1980s, the term ‘autism’ was used primarily to refer to autistic disorder and was thought to be rare, affecting approximately one in every 2,000 (0.5%) children. Autism now is considered to be one of three disorders classified together as ASDs. Using diagnostic criteria established in the early 1990s, which encompass a broad spectrum of disorders, the best estimate of ASD prevalence is that approximately six or seven of every 1,000 (0.6%-0.7%) children have an ASD. These estimates are approximately 10 times higher than estimates using earlier criteria. However, some recent population-based studies have documented even higher ASD prevalence estimates of >1% of children in areas of Japan, Sweden, the United Kingdom, and the United States, with ASD symptoms identified in 2.7% of children in one study from Norway.³⁹

Part of the difficulty in identifying the number of individuals with autism has been the lack of uniformity in tools for diagnosis:

Since the early 1990s, the number of persons receiving services for ASDs has increased substantially. However, identifying children for services for autism might not be equivalent to using consistent diagnostic standards to identify persons in the population because services within communities are not available uniformly to all persons with ASDs. For this reason, studies that rely exclusively on single-source administrative datasets (e.g., disability service records or annual reports of special education counts) most likely underestimate ASD prevalence and might not adequately capture

36. *Id.*

37. NAT'L INST. OF CHILD HEALTH AND HUMAN DEV., *supra* note 17, at 4.

37. *Id.*

38. *Id.*

39. Rice, *supra* note 20 (footnotes omitted).

changes in the ASD population over time.⁴⁰

The 2008 ADDM report expresses a lack of understanding of the continued increase in cases of autism but acknowledges the significance of autism as a public health concern:

These data confirm that the estimated prevalence of ASDs identified in the ADDM network surveillance populations continues to increase. The extent to which these increases reflect better case ascertainment as a result of increases in awareness and access to services or true increases in prevalence of ASD symptoms is not known. ASDs continue to be an important public health concern in the United States, underscoring the need for continued resources to identify potential risk factors and to provide essential supports for persons with ASDs and their families.⁴¹

Despite the continued uncertainty over what is causing an increase in autism, the statistics still support a prevalence necessitating increased attention in policy matters impacting the lives of individuals with autism in such essential aspects as healthcare.

2. Differences in Gender and Race and Ethnicity

Although the latest 2008 ADDM report does not reveal anything greater regarding what is causing an increase in autism, it does provide valuable insight on how autism affects two categories: gender and race. There is a difference between the rate of autism occurring between boys and girls:

Combining data from all fourteen ADDM sites, estimated ASD prevalence was 18.4 per 1,000 (one in 54) males and 4.0 per 1,000 (one in 252) females (RR: 4.6 for all sites combined). ASD prevalence estimates were significantly ($p < 0.01$) higher among boys than among girls in all 14 ADDM sites, with male-to-female prevalence ratios ranging from 2.7 in Utah to 7.2 in Alabama.⁴²

The 2008 ADDM report also acknowledged disparities in autism by race and ethnicity.⁴³ According to the report:

Estimated ASD prevalence also varied by race and ethnicity (Table 2). When data from all sites were combined, the estimated prevalence among non-Hispanic white children (12.0 per 1,000) was significantly greater than that among non-Hispanic black children (10.2 per 1,000) and Hispanic children (7.9 per 1,000). Estimated ASD prevalence was significantly lower among Hispanic children than among non-Hispanic white children in nine sites and significantly lower than among non-Hispanic black children in five sites. Only one site (Florida) identified a significantly higher ASD

40. *Id.* (footnotes omitted).

41. *Morbidity and Mortality Weekly Report (MMWR)*, *supra* note 3.

42. *Id.*

43. *Id.*

prevalence among Hispanic children compared with either non-Hispanic white or non-Hispanic black children. New Jersey was the only site that identified approximately the same estimated ASD prevalence among non-Hispanic white children, non-Hispanic black children, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 2.2 to 19.0 per 1,000 although wide confidence intervals suggest that these findings should be interpreted with caution.⁴⁴

Additionally, the 2008 ADDM report provided comparative information by race and ethnicity since the previous report in 2006. This comparison provided the following data:

Changes in estimated ASD prevalence during 2006-2008 also varied by race within individual ADDM sites and when combining data from all sites. The combined estimates indicated a 16% increase in ASD prevalence among non-Hispanic white children (10.0-11.5 per 1,000), a 42% increase among non-Hispanic black children (7.0-10.0 per 1,000), and a 29% increase among Hispanic children (6.1-7.9 per 1,000). The percentage increase was statistically significant for all three racial/ethnic groups. Alabama identified a lower prevalence among non-Hispanic black children in 2008, and Arizona identified a lower prevalence among Hispanic children in 2008 compared with 2006 results.⁴⁵

This data may be pertinent to policymakers in ensuring that particular populations that may already experience disparities in access to health care are not further denied access concerning autism. The 2008 ADDM report gives the latest statement of research on autism prevalence and provides guidance as our nation moves forward in trying to understand autism and how best to respond to its challenges, especially with regard to the law.

3. *Risk Factors Influencing Occurrence and Onset of Autism*

As recently as July 2011, research again confirmed that a number of factors may contribute to the development of autism.⁴⁶ “Looking at 40 previous studies, researchers found that a range of factors around the time of birth have been linked to the risk of autism later in life.”⁴⁷ However, this same research indicates that there is no single factor contributing to autism, and that a single risk factor is unlikely due to the complexity of autism.⁴⁸ While there is no one single factor that has been determined as a cause of autism, several factors have been considered as possible

44. *Id.* (footnote omitted).

45. *Id.*

46. Amy Norton, *Risk Factors for Autism Remain Elusive: Study*, REUTERS (July 11, 2011), <http://www.reuters.com/article/2011/07/11/us-risk-factors-autism-idUSTRE76A6 2Q20110711>.

47. *Id.*

48. *Id.*

contributors to children who will develop an ASD including, “low birth weight, certain delivery complications like problems with the umbilical cord, fetal distress during labor and signs of ‘poor condition’ in the newborn—such as problems with breathing or heart rate.”⁴⁹ Additionally, the CDC has identified a number of risk factors for autism.⁵⁰ These include: twins, when parents have one child with autism, certain genetic or chromosomal conditions, older parents, prematurity or low birth weight, and some co-occurrence with other disorders.⁵¹ Regarding twins: “Studies have shown that among identical twins, if one child has an ASD, then the other will be affected about 36-95% of the time. In non-identical twins, if one child has an ASD, then the other is affected about 0-31% of the time.”⁵² For parents who have one child with an ASD, the likelihood of having a second child born with an ASD is 2-18%.⁵³ Research has shown that children with autism often also have certain genetic or chromosomal conditions.⁵⁴ “About 10% of children with autism are also identified as having down syndrome, fragile X syndrome, tuberous sclerosis, and other genetic and chromosomal disorders.”⁵⁵ An increased risk of autism also occurs for a child born to older parents.⁵⁶ “A small percentage of children who are born prematurely or with low birth weight are at greater risk for having ASDs.”⁵⁷ The CDC also acknowledges the prevalence of autism’s co-occurrence with certain conditions.⁵⁸ “ASD commonly co-occurs with other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses. The co-occurrence of one or more non-ASD developmental diagnoses is 83%. The co-occurrence of one or more psychiatric diagnoses is 10%.”⁵⁹ Most recently, research is also demonstrating a link between autism and the mother’s obesity.⁶⁰ “Researchers said mothers who are obese are significantly more likely to have a child with autism or another developmental abnormality. The finding adds to the increasingly complex picture of possible factors that contribute to the disorders.”⁶¹ According to this research on the connection

49. *Id.*

50. *Autism Spectrum Disorders (ASDs): Data & Statistics*, *supra* note 3.

51. *Id.*

52. *Id.*

53. *Id.*

54. *Id.*

55. *Id.*

56. *Id.*

57. *Id.*

58. *Id.*

59. *Id.*

60. Shirley S. Wang, *Autism Linked to Obesity in Mothers*, WALL ST. J., (Apr. 9, 2012), <http://online.wsj.com/article/SB10001424052702304072004577328203742847094.html>.

61. *Id.*

between the development of autism in children and mothers: “It showed that compared to nonobese mothers, those who were obese before pregnancy had a 60% increase in the likelihood of having a child with autism and a doubling in risk of having a child with another type of cognitive or behavioral delay.”⁶² Additionally, this research suggested an even greater link between autism and the mother’s obesity when the mother had either high blood pressure or diabetes.⁶³ But despite this latest research linking autism to mother’s obesity, researchers continue to support the contention that no single factor is responsible for the development of autism.⁶⁴

As the prevalence of autism has played a major role in creating awareness of a national public health epidemic, how a diagnosis of autism is made becomes critical and must be examined. How autism is defined and the tools used to make the diagnosis can have a substantial impact on understanding the severity of the need and the role law will or should play in protecting those in need.

D. Diagnosing Autism

1. The DSM and Diagnostic Criteria

“The American Psychiatric Association’s Diagnostic and Statistical Manual-IV, Text Revision (DSM-IV-TR) 1 provides standardized criteria to help diagnose ASDs.”⁶⁵ Autism Disorder currently appears in DSM-IV as follows:

DIAGNOSTIC CRITERIA FOR 299.00 AUTISTIC DISORDER

Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

qualitative impairment in social interaction, as manifested by at least two of the following:

marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

failure to develop peer relationships appropriate to developmental level

a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

62. *Id.*

63. *Id.*

64. *Id.*

65. Ctrs. for Disease Control & Prevention, *Autism Spectrum Disorders (ASDs): Diagnostic Criteria*, CDC.ORG, <http://www.cdc.gov/ncbddd/autism/hcp-dsm.html> (last updated Aug. 17, 2009).

lack of social or emotional reciprocity

qualitative impairments in communication as manifested by at least one of the following:

delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

stereotyped and repetitive use of language or idiosyncratic language

lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

apparently inflexible adherence to specific, nonfunctional routines or rituals

stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)

persistent preoccupation with parts of objects

Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.⁶⁶

Separate diagnostic criteria also exist for Asperger's syndrome and PDD-NOS in the DSM-IV under 299.80.⁶⁷

Recent news of the proposed revision of the DSM-V⁶⁸ that

66. *Id.*

67. *Id.*

68. Am. Psychiatric Ass'n, *A09 Autism Spectrum Disorders*, DSM5.ORG, <http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#> (last visited Jan. 26, 2011).

Autism Spectrum Disorder must meet criteria A, B, C, and D:

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction.

may include substantial changes to the diagnosis of autism has sparked controversy and talk of “crisis” in the autism community.⁶⁹ Many fear that the revisions may be so drastic as to cause widespread change to who is considered autistic and who is eligible to have access to services.⁷⁰ The American Psychiatric Association, however, argues that the changes of diagnostic criteria are meant to more accurately diagnose autism across the spectrum, whereas previous definitions had frequently overlapped: “Differentiation of autism spectrum disorder from typical development and other ‘nonspectrum’ disorders is done reliably and with validity; while distinctions among disorders have been found to be inconsistent over time, variable across sites and often associated with severity, language level or intelligence rather than

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2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
 3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people.
- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:
1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
 3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).
- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities).
- D. Symptoms together limit and impair everyday functioning.

Id.

69. See Benedict Carey, *New Definition of Autism Will Exclude Many, Study Suggests*, N.Y. TIMES (Jan. 19, 2012), http://www.nytimes.com/2012/01/20/health/research/new-autism-definition-would-exclude-many-study-suggests.html?_r=1&emc=eta1 (explaining the potential impact of the proposed DSM-V revisions on the autism diagnosis).

70. *Id.*

features of the disorder.”⁷¹ Additionally, the American Psychiatric Association has defended the decision to alter the definition as it is better served under the umbrella of the spectrum:

Because autism is defined by a common set of behaviors, it is best represented as a single diagnostic category that is adapted to the individual’s clinical presentation by inclusion of clinical specifiers (e.g., severity, verbal abilities and others) and associated features (e.g., known genetic disorders, epilepsy, intellectual disability and others.) A single spectrum disorder is a better reflection of the state of knowledge about pathology and clinical presentation; previously, the criteria were equivalent to trying to “cleave meatloaf at the joints.”⁷²

In a statement released by the American Psychiatric Association following the release of the drafted definitions for autism for the DSM-V, dated January 12, 2012, the Association stressed that, based on extensive research, the movement to diagnose based on the spectrum is appropriate based on extensive research and will actually serve those with autism better in acquiring treatment.⁷³

2. *Age of Diagnosis/Signs of Autism*

Another critical consideration in identifying signs and symptoms of autism is an understanding of when autism may first appear in a child.⁷⁴ This understanding becomes important for policymakers as many laws have provided for health care services for autistic children based on the child’s age.⁷⁵ According to the CDC, the following observations can be made regarding a child:

ASDs begin before the age of 3 and last throughout a person’s life, although symptoms may improve over time. Some children with an ASD show hints of future problems within the first few months of life. In others, symptoms may not show up until 24 months or later. Some children with an ASD seem to develop normally until around 18 to 24 months of age and then they stop gaining new skills, or they lose the skills they once had. Studies have shown that one third

71. Am. Psychiatric Ass’n, *supra* note 68; *A Message from the DSM-5 Task Force Chairs: How Implementation of the DSM-V Will Impact Autism Spectrum Disorders*, AUTISMTRUTHS, at 1, 2 available at <http://www.autismtruths.org/doc/1.%20How%20implementation%20of%20the%20DSM-V%20will%20impact%20autism%20spectrum%20disorders.doc>.

72. *Id.* at 2.

73. Am. Psychiatric Assoc., *DSM-5 Proposed Criteria for Autism Spectrum Disorder Designed to Provide More Accurate Diagnosis and Treatment* (Jan. 20, 2012), <http://www.dsm5.org/Documents/12-03%20Autism%20Spectrum%20Disorders%20-%20DSM5.pdf>.

74. Ctrs. for Disease Control & Prevention, *Autism Spectrum Disorders (ASDs): Facts About ASD*, CDC.GOV, <http://www.cdc.gov/ncbddd/autism/facts.html> (last updated Mar. 29, 2012).

75. *Id.*

to half of parents of children with an ASD noticed a problem before their child's first birthday, and nearly 80%-90% saw problems by 24 months of age.⁷⁶

According to the CDC, "red flags" that autism might be present in children are such that the children will

not respond to their name by 12 months of age, not point at objects to show interest (point at an airplane flying over) by 14 months, not play "pretend" games (pretend to "feed" a doll) by 18 months, avoid eye contact and want to be alone, have trouble understanding other people's feelings or talking about their own feelings, have delayed speech and language skills, repeat words or phrases over and over (echolalia), give unrelated answers to questions, get upset by minor changes, have obsessive interests, flap their hands, rock their body, or spin in circles, have unusual reactions to the way things sound, smell, taste, look, or feel.⁷⁷

The CDC has also acknowledged several categories of common symptoms indicating the potential for autism, such as impaired social skills and communication skills, unusual interests and behaviors, and other symptoms.⁷⁸ The CDC has stated that social symptoms are the most prevalent in autistic individuals: "Social issues are one of the most common symptoms in all of the types of ASD. People with an ASD do not have just social 'difficulties' like shyness. The social issues they have cause serious problems in everyday life."⁷⁹

In terms of a lack of typical social interactions, there are some noticeable things that may be observed regarding a child who may be autistic in terms of a lack of typical social interactions.⁸⁰ The CDC describes some of the differences between a child's normal social interactions and those of a child who may be autistic:

Typical infants are very interested in the world and people around them. By the first birthday, a typical toddler interacts with others by looking people in the eye, copying words and actions, and using simple gestures such as clapping and waving "bye bye." Typical toddlers also show interests in social games like peek-a-boo and pat-a-cake. But a young child with an ASD might have a very hard time learning to interact with other people.⁸¹

A child with autism may also have difficulty in developing friendships with other children, which is due to the child's desire not to engage in interaction and the challenges he or she actually has in interacting appropriately, such as having difficulty

76. *Id.*

77. *Id.*

78. *Id.*

79. *Id.*

80. *Id.*

81. *Id.*

sharing.⁸² According to the CDC, there are also other indicators in terms of struggles with social interactions.⁸³ Children may also have difficulties when it comes to emotions in comprehension and demonstration.⁸⁴ Additionally, they may not want to have physical contact in relation to social interactions such as hugging.⁸⁵

Understanding the signs of autism becomes critical for the age of diagnosis. As more states have developed autism legislation to specifically address access to health care for children with autism, the age of the child, as is discussed later in this Article, will often be tied to the extent coverage.

3. *The Dilemma of Diagnostic Tools*

The diagnosis of autism necessary to acquire any health care services that may be protected by law depends on the effectiveness of diagnostic tools. Even when a child exhibits some or many of the signs and symptoms that may suggest the child is autistic, making a diagnosis of autism has not yet reached the point of being an exact science.⁸⁶ According to the CDC: “Diagnosing autism spectrum disorders (ASDs) can be difficult, since there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child’s behavior and development to make a diagnosis.”⁸⁷

Intense debate continues over whether or not testing all children for autism is necessary. Some argue that because there is no test that passes the muster for accuracy, the number of children with autism may be inflated by this lack of an effective diagnostic tool.⁸⁸ Even with the current diagnostic tools available, an article appearing in *Pediatrics* in May 2009 suggested that there are still challenges in evaluating young children:

With increased public awareness of the early signs and recent American Academy of Pediatrics recommendations that all 18- and 24-month-olds be screened for autism spectrum disorders, there is an increasing need for diagnostic assessment of very young children. However, unique challenges exist in applying current diagnostic guidelines for autism spectrum disorders to children under the age

82. *Id.*

83. *Id.*

84. *Id.*

85. *Id.*

86. Ctrs. for Disease Control & Prevention, *Autism Spectrum Disorders (ASDs): Screening and Diagnosis*, CDC.GOV, <http://www.cdc.gov/ncbddd/autism/screening.html> (last updated May 13, 2010).

87. *Id.*

88. Michelle Diamant, *Researchers Question Screening All Children for Autism*, DISABILITY SCOOP (June 13, 2011), <http://www.disabilityscoop.com/2011/06/13/researchers-question-screening/13313/>.

of 2 years.⁸⁹

What is known is that a child's primary care physician plays a vital role in all aspects of the child's well-being throughout a diagnosis of autism and beyond: "However, the role of the primary health care professional extends beyond recognizing signs of ASDs, referring for diagnostic evaluation, conducting an etiologic investigation, providing genetic counseling, and educating caregivers about ASDs and includes ongoing care and management." There are typically two steps required in making a diagnosis of autism: (1) developmental screening and (2) comprehensive diagnostic evaluation.⁹⁰ Developmental screening is described as follows:

Developmental screening is a short test to tell if children are learning basic skills when they should, or if they might have delays. During developmental screening the doctor might ask the parent some questions or talk and play with the child during an exam to see how she learns, speaks, behaves, and moves. A delay in any of these areas could be a sign of a problem.⁹¹

While there are specific points in a child's development where a child should be tested for developmental disabilities in general, the CDC identifies certain ages that a child should be specifically tested for autism: eighteen months, twenty-four months, and in cases where a child is at risk for developing an ASD such as the fact that a sibling or other family member has an ASD.⁹² Despite these recommendations, evidence shows that pediatricians are frequently dismissing check-ups for developmental disabilities that later may have a more serious impact on these children.⁹³ There are a number of tools that may be used for developmental screening.⁹⁴ Different developmental screening tools identified by the CDC include Ages and Stages Questionnaires (ASQ), Communication and Symbolic Behavior Scales (CSBC), Modified Checklist for Autism in Toddlers (M-CHAT), and Screening Tool for Autism in Toddlers and Young Children (STAT).⁹⁵ STAT is designed to have a test that is readily available for community

89. Lonnie Zwaigenbaum et al., Abstract, *Clinical Assessment and Management of Toddlers with Suspected Autism Spectrum Disorder: Insights from Studies of High-Risk Infants*, 123 PEDIATRICS 1383, 1383 (2009), <http://pediatrics.aapublications.org/content/123/5/1383.full.pdf+html>.

90. *Id.*

91. *Id.*

92. *Id.*

93. Michelle Diamant, *Most Pediatricians Skip Developmental Screening, Study Finds*, DISABILITY SCOOP (June 27, 2011), <http://www.disabilitycoop.com/2011/06/27/most-skip-screening/13418/>.

94. *Autism Spectrum Disorders (ASDs): Screening and Diagnosis*, *supra* note 86.

95. *Id.*

services to be able to test for autism:

The STAT is an empirically based, interactive measure developed to screen for autism in children between 24 and 36 months of age. It is designed for use by community service providers who work with young children in assessment or intervention settings and who have experience with autism. The STAT consists of 12 items and takes about 20 minutes to administer. Activities assess key social and communicative behaviors including imitation, play, requesting, and directing attention.⁹⁶

In addition to developmental screening, a comprehensive diagnostic examination must be done on a child in order to reach an autism diagnosis.⁹⁷ The CDC provides the following definition for comprehensive diagnostic evaluation: “This thorough review may include looking at the child’s behavior and development and interviewing the parents. It may also include a hearing and vision screening, genetic testing, neurological testing, and other medical testing.”⁹⁸

In the case of comprehensive diagnostic testing, a child’s primary care physician may refer the child to a specialist such as a developmental physician, a child neurologist, or a child psychologist or psychiatrist.⁹⁹ Researchers continue to work to find better ways of diagnosing autism, and new research suggests that brain scans may soon become a viable tool in diagnosis.¹⁰⁰ The latest news regarding diagnostic tools comes from an April 2012 report by researchers at Harvard Medical School promoting the use of an online tool to diagnose autism in minutes.¹⁰¹ “The process relies on seven questions plus a short home video of an individual child.”¹⁰² The benefits of the online diagnostic tool could be significant in early detection and treatment of autism: “The research team said its method could reduce by nearly 95 percent the time it takes to diagnose autism and could be easily included in routine child screening practices, greatly increasing the number

96. *Screening Tool for Autism in Toddlers and Young Children (STAT)*, VAND. KENNEDY CTR., <http://kc.vanderbilt.edu/triad/training/page.aspx?id=821> (last visited Oct. 26, 2012).

97. *Id.*

98. *Id.*

99. *Id.*

100. Michelle Diamant, *Brain Scans May Help Diagnose, Treat Autism*, DISABILITY SCOOP (Sept. 6, 2011), <http://www.disabilitycoop.com/2011/09/06/brain-scans-autism/13882/>.

101. *Online Tool Could Diagnose Autism Quickly, Developers Say*, U.S. NEWS & WORLD REPORT (Apr. 10, 2012), <http://health.usnews.com/health-news/news/articles/2012/04/10/online-tool-could-diagnose-autism-quickly-developers-say>.

102. *Id.*

of at-risk children who get checked for the disorder.”¹⁰³ The report concluded as follows:

Currently, autism spectrum disorder is diagnosed through behavioral exams and questionnaires that require significant time investment for both parents and clinicians. In our study, we performed a data-driven approach to select a reduced set of questions from one of the most widely used instruments for behavioral diagnosis, the ADOS. Using machine-learning algorithms, we found the ADTree to perform with almost perfect sensitivity, specificity and accuracy in distinguishing individuals with autism from individuals without autism. The ADTree classifier consisted of eight questions, 72.4% less than the complete ADOS Module 1, and performed with >99% accuracy when applied to independent populations of individuals with autism, misclassifying only 2 out of 446 cases. Given this reduction in the number of items without appreciable loss in accuracy, our findings may help to guide future efforts, chiefly including mobile health approaches, to shorten the evaluation and diagnosis process overall such that families can receive care earlier than under current diagnostic modalities.¹⁰⁴

However, experts still acknowledge that the effectiveness of this new online tool will need to be evaluated.¹⁰⁵ The survey has been made available online.¹⁰⁶ The development of new diagnostic tools for autism will likely improve detection and hopefully result in earlier diagnosis in a child’s life. This Article will later discuss the availability of early intervention services for children with autism and even children without autism with developmental delays that may be at risk of developing autism. As improvements are made to diagnostic tools for autism, there will be greater knowledge of when treatments can and should begin for autistic children, which can, in turn, positively influence the law and policy decisions in creating access to health care services to support the earliest point of diagnosis.

4. *Training Medical Professionals for Diagnosis of Autism*

As policymakers consider how to best frame the law and policy to address access to health care for autistic children, requirements of training professionals in autism may be necessary to ensure that children with autism have legal protections not only in name. As earlier discussed, the ability to diagnosis autism early

103. *Id.*

104. D.P. Wall et al., *Use of Machine Learning to Shorten Observation-Based Screening and Diagnosis of Autism*, TRANSLATIONAL PSYCHIATRY (Apr. 10, 2012), <http://www.nature.com/tp/journal/v2/n4/full/tp201210a.html>.

105. *Online Tool Could Diagnose Autism Quickly, Developers Say*, *supra* note 101.

106. *Short Survey for Autism Diagnosis*, AUTWORKS, <http://autworks.hms.harvard.edu/community/survey> (last visited Oct. 26, 2012).

becomes critical as access to legal protections to health care are dependent on the evidence of diagnosis. Efforts to address issues of training have already begun outside of legal requirements by programs such as one recently developed by the CDC. In recognition of Autism Awareness Month in April 2012, the CDC announced the launch of a new program to assist medical professionals in diagnosing autism.¹⁰⁷ The CDC has offered a training curriculum called Autism Care Training or “ACT” as part of its “Learn the Signs. Act Early.” campaign.¹⁰⁸ According to the CDC, “ACT is designed to help educate primary care practitioners about finding, diagnosing, and managing autism spectrum disorders.”¹⁰⁹ The CDC describes this training program as follows: “The training uses real-life scenarios and consists of seven modules, each with a facilitator’s guide and supporting presentation and videos. All course materials can be downloaded and used in the classroom or for independent study.”¹¹⁰

Topics that are available in the CDC’s training materials include: Early Warning Signs, Screening, Communicating Concerns, Screening and Diagnosis Results, Making a Diagnosis, Early Intervention and Education, Treatments for Autism, and Autism-Specific Anticipatory Guidance.¹¹¹ Lawmakers must also pay attention to the extent of training professionals are receiving in medical care and treatment of individuals with autism.

E. Autism and Genetics

One of the questions that emerges in understanding autism is whether or not there is any connection between genetics and the development of autism, and how this may influence the development of the diagnosis and treatment critical for formulating law and policy.

In 1997, the NICHD and the National Institute on Deafness and Other Communications Disorders (NIDCD) started the Network on the Neurobiology and Genetics of Autism: Collaborative Programs of Excellence in Autism (CPEA). Researchers in this Network work to understand which genes might be involved in autism and how genes play a role in the condition. Working with other scientists around the world, the CPEA researchers have already learned a great deal about autism and genes.¹¹²

107. Ctrs. for Disease Control & Prevention, *Autism: New Training for Health Professionals*, CDC.GOV, <http://www.cdc.gov/features/AutismTraining/> (last updated Apr. 2, 2012).

108. *Id.*

109. *Id.*

110. *Id.*

111. *Id.*

112. NAT’L INST. OF CHILD HEALTH & DEV., *Autism and Genes 1*, NIH Pub.

Although the cause of autism is unknown, evidence suggests that genetics could play a role: “Much evidence supports the idea that genetic factors—that is, genes, their function, and their interactions—are one of the main underlying causes of ASDs.”¹¹³ In a 2005 report issued by the NICHD, evidence suggests that autism is unlikely linked to a single gene, but possibly a number of different genes: “But, researchers aren’t looking for just one gene. Current evidence suggests that as many as 12 or more genes on different chromosomes may be involved in autism to different degrees.”¹¹⁴ According to NICHD, there are various ways that genes could impact an individual’s ability to develop autism, including gene susceptibility, genes that cause symptoms of autism, and genetic mutations.¹¹⁵ The continued commitment to research on the connection between autism and genetics is based on a number of research developments already suggesting that link.¹¹⁶ Some of those research developments have included studies demonstrating a correlation in autism in both identical and fraternal twins,¹¹⁷ research showing an increased rate of autism in families (i.e., if a sibling has autism, one’s chances will be greater of developing autism),¹¹⁸ and the connection between

No. 05-5590 (May 2005), available at http://www.nichd.nih.gov/publications/pubs/upload/autism_genes_2005.pdf.

113. *Id.* at 2.

114. *Id.*

115. *Id.* at 3. “Some genes may place a person at greater risk for autism, called susceptibility. Other genes may cause specific symptoms or determine how severe those symptoms are. Or, genes with mutations might add to the symptoms of autism because the genes or gene products aren’t working properly.” *Id.*

116. *Id.*

117. *Id.*

Studies of twins with autism—Scientists have studied autism in both identical twins—who are genetically the same—and fraternal twins—who are genetically similar, but not the same. When identical twins have autism, both have autism more than 60 percent of the time, depending on the criteria used. When fraternal twins have autism, both have autism between 0 percent and 6 percent of the time. If genes were not involved in autism, the rate of autism would be the same for both types of twins.

Id.

118. *Id.*

Family studies of autism—Studies of family histories show that the chances a brother or sister of someone who has autism will also have autism is between 2 percent and 8 percent, which is much higher than in the general population. Also, some of the autism-like symptoms, such as delays in language development, occur more often in parents and adult brothers and sisters of people with autism than in families who have no members or relatives with ASDs. Because members of the same family are more likely to share genes, something about these genes’ sequences appears to be related to autism.

Id.

having a disorder distinct from autism.¹¹⁹

There continues to be hope in research as scientists have been successful in identifying particular genes as being relevant to autism: “Using genome-wide screens, scientists have identified a number of genes that might be involved in autism.”¹²⁰ However, despite, and in light of, those discoveries, it is known that autism still presents itself in a variety of ways with different symptoms, and as a result, isolating the genes that may be involved is only the initial step for scientists in understanding the relationship between autism and genetics.¹²¹

In relation to genes, researchers are also examining the chemicals of the body and how they interact with genes regarding autism.¹²² According to the 2005 NICHD report:

The body makes many chemicals that help it function correctly. When these chemicals are missing or incorrect, the body may have problems functioning properly, which may result in symptoms of autism or other disorders. Researchers are now trying to uncover how body chemicals might be involved in autism, so they can learn how the genes that make these chemicals might also play a role. Researchers are also studying whether medications might regulate or control these chemicals to create normal chemical levels. Normalizing the chemicals in a person with ASDs might reduce symptoms.¹²³

Whether it is genes or those body chemicals, researchers hope that such discoveries will create better ways to discover autism in its early stages: “Doctors could then test for the gene or genes to detect autism early in life so that intervention can begin when it is most effective. Or, researchers could develop drugs that change or regulate the gene or genes to help normalize body chemicals and body functions.”¹²⁴ Continued research on the connection between genes and chemicals regarding autism could have a profound

119. *Id.*

Diagnosable disorders and autism—In about 5 percent of autism cases, another single-gene disorder, chromosome disorder, or developmental disorder is also present. This type of co-occurrence helps researchers who are trying to pinpoint the genes involved in autism. Similar disorders or conditions with similar symptoms may have similar genetic beginnings. In cases of one disorder commonly occurring with another, it could be that one is actually a risk factor for the other. This kind of information can provide clues to what actually happens in autism. For example, many people with ASDs also have epilepsy, a condition marked by seizures. If scientists can understand what happens in epilepsy, they may also find clues to what happens in autism.

Id.

120. *Id.* at 5.

121. *Id.* at 4.

122. *Id.* at 8.

123. *Id.*

124. *Id.*

impact on diagnosing autism much earlier.

Further research has led to a better understanding of the link between autism and genetics. More recent studies, published in 2011, suggest that, contrary to the NICHD's 2005 report, autism could be the result of hundreds of genes rather than a single gene or set of genes.¹²⁵

Despite the rarity of these genetic code errors, researchers could detect some important patterns in the disparate data. One aberrant gene has already been linked to other social disorders. And by analyzing the role of these genes in neural development, one team of researchers suggests different genetic mutations might often disturb an entire common network.¹²⁶

The search for an understanding of the genetic causes of autism is also leading researchers to expand research beyond strictly autism.¹²⁷ "To decipher the code of autism, researchers are also looking outside of the ASD patient community to other developmental and social disorders."¹²⁸ Researchers are no longer simply waiting for genetic information to come to them regarding autism through mutations.¹²⁹ Instead, they are taking proactive measures to gain research through modeling.¹³⁰ "Rather than wait for additional genome scans to turn up more potential mutations, however, many research teams are already creating models of how these mutations might impact neurological development."¹³¹ As researchers gain greater knowledge of the relationship between genetics and autism, their findings will provide policymakers and those working to improve the law for individuals with autism valuable insight into the disability and how the law can be used to secure access to health care.

The latest research on genetics and autism has emerged in April 2012 during national Autism Awareness Month.¹³² That research is significant for its attention to genetic mutations and establishing a link between autism and the father's age when the father is over age thirty-five.¹³³ While the findings only account for understanding the genetics of a small amount of the population of

125. Katherine Harmon, *Autism's Tangled Genetics Full of Rare and Varied Mutations*, SCIENTIFIC AM. (June 8, 2011), <http://www.scientificamerican.com/article.cfm?id=autism-genetic-mutations>.

126. *Id.*

127. *Id.*

128. *Id.*

129. *Id.*

130. *Id.*

131. *Id.*

132. Benedict Carey, *Scientists Link Gene Mutation to Autism Risk*, N.Y. TIMES (Apr. 4, 2012), http://www.nytimes.com/2012/04/05/health/research/scientists-link-rare-gene-mutations-to-heightened-risk-of-autism.html?_r=1.

133. *Id.*

autistic children, such a development is momentous for helping researchers establish a mechanism for how to study autism and genetics: “The gene mutations are extremely rare and together account for a tiny fraction of autism cases—in these studies, only a handful of children. Experts said the new research gave scientists something they had not had: a clear strategy for building some understanding of the disease’s biological basis.”¹³⁴ This is quite a contrast compared to various previous attempts to understand the relationship between autism and genetics: “Previous studies have produced a scattering of gene findings but little consensus or confidence in how to proceed.”¹³⁵ According to some, research on gene mutations could be related to a large number of cases of autism: “An intensified search for rare mutations could turn up enough of these to account for 15 percent to 20 percent of all autism cases, some experts say, and allow researchers a chance to see patterns and some possible mechanisms to explain what goes awry.”¹³⁶ Other researchers are much more skeptical due to the limited understanding of gene mutations which still exists.¹³⁷ The latest research on gene mutations is a reminder to researchers of the complexity of autism.¹³⁸ “The emerging picture suggests that the search for therapies will probably be a very long one, and that what is known generally as autism may represent a broad category of related but biologically distinct conditions.”¹³⁹ However, research on autism and gene mutations has provided significant new understanding about autism and is a necessary vehicle for continued research and study.

Developments in research of the relationship between autism and genetics can have a significant impact on the future of treatment methods and screening that will influence policy making.¹⁴⁰ “By better understanding the numerous routes autism can take to perturbing common pathways, new avenues of treatment might open up sooner.”¹⁴¹ New research has suggested that we are far behind on understanding autism and genetic mutations, an understanding which could lead to the earlier use of behavioral treatments and even detection of autism before birth.¹⁴² However, it has also been acknowledged that more is at play in autism than simply genetics. “Genetics are, of course, just part of the increasingly complex autism puzzle.”¹⁴³ “But one thing is well

134. *Id.*

135. *Id.*

136. *Id.*

137. *Id.*

138. Harmon, *supra* note 125.

139. *Id.*

140. *Id.*

141. *Id.*

142. *Id.*

143. *Id.*

established in autism research: as scientists look deeper into the disease the complexities multiply almost exponentially.”¹⁴⁴ Technological advancements have made the expansiveness of autism research possible, and researchers look forward to continued developments in research through high-resolution sequencing.¹⁴⁵

F. Treating Autism

Just as much remains unknown about autism as a disorder, there is likewise still uncertainty and debate in how to treat autism. However, some things about autism and treatment of autism are somewhat universal to the disability. “There is no single best treatment for all children with ASDs.”¹⁴⁶ This is the accepted position of the American Academy of Pediatrics (AAP), which otherwise states regarding treatment for autism: “The AAP strongly believes in the importance of early and continuous surveillance and screening for ASD to ensure that children are identified and receive access to services as soon as possible. The sooner an ASD is identified, the sooner an intervention program can start.”¹⁴⁷ It is also known that providing routine and structure for a child with autism has a significant impact on the child’s progress.¹⁴⁸ Furthermore, as autism can vary considerably between children, treatment will also not necessarily have the same effect from child to child: “Some children respond well to one type of treatment while others have a negative response or no response at all to the same treatment.”¹⁴⁹ What has been critical to treatment is an understanding that treatment must involve an integrated approach involving all of those connected with the autistic child to work together:

Early intensive behavioral intervention involves a child’s entire family working closely with a team of professionals. In some early intervention programs, therapists come into the home to deliver services. This can include parent training with the parent leading therapy session under the supervision of the therapist. Other programs deliver therapy in a specialized center, classroom or preschool.¹⁵⁰

144. *Id.*

145. *Id.*

146. *Treatment Resources*, HOPE INST. FOR CHILD. & FAMILIES, <http://www.thehopeinstitute.us/about-autism/treatment-resources> (last visited Oct. 26, 2012).

147. *AAP Children’s Health Topics; Autism*, AAP.ORG (Dec. 3, 2004), <http://page2rss.com/51d52e36d69df20d4acc2fc9aca2ed42>.

148. *Treatment Resources*, *supra* note 146.

149. *Id.*

150. *How Is Autism Treated?*, AUTISMSPEAKS.ORG, <http://www.autismspeaks.org/what-autism/treatment> (last visited Oct. 26, 2012).

It is also pointed out that even though a child is diagnosed as autistic and has medical issues associated with autism, the child is still subject to the same health issues as the non-autistic child.¹⁵¹ Another difficulty with the autistic child is determining when an issue is a result of the autism or something else.¹⁵² The CDC makes the following recommendation concerning the monitoring of the health of an autistic child:

Regular medical and dental exams should be part of a child's treatment plan. Often it is hard to tell if a child's behavior is related to the ASD or is caused by a separate health condition. For instance, head banging could be a symptom of the ASD, or it could be a sign that the child is having headaches. In those cases, a thorough physical exam is needed. Monitoring healthy development means not only paying attention to symptoms related to ASDs, but also to the child's physical and mental health, as well.¹⁵³

One of the approaches that has become increasingly popular in attempting to assist children who may be at risk of developing an ASD is early intervention services.¹⁵⁴ According to the CDC: "Research shows that early intervention treatment services can greatly improve a child's development. Early intervention services help children from birth to 3 years old (36 months) learn important skills. Services include therapy to help the child talk, walk, and interact with others."¹⁵⁵

Early intervention services may be available to a child through the Individuals with Disabilities Education Act (IDEA) even if the child has not been diagnosed with an ASD.¹⁵⁶ Early intervention services are discussed in another section as these services play a vital role in assisting children before they are diagnosed with ASD. While treatment for autistic children varies considerably, knowing these dynamics of what is common about treatment for autism in general provides a valuable foundation for exploring treatment options.

1. *Categories of Treatment*

Aside from early intervention services, a number of different treatments have been used to address autism.¹⁵⁷ The CDC has broken down treatments for autism into four primary categories: (1) behavior and communication approaches, (2) dietary approaches, (3) medication, and (4) complimentary and alternative

151. *Autism Spectrum Disorders (ASDs): Treatment*, *supra* note 7.

152. *Id.*

153. *Id.*

154. *Id.*

155. *Id.*

156. *Id.*

157. *Id.*

medicine.¹⁵⁸ It is important to consider each of these categories of treatment separately and the types of treatment that fall into each category.

The CDC has described behavior and communication approaches to treatment as follows: “According to reports by the American Academy of Pediatrics and the National Research Council, behavior and communication approaches that help children with ASDs are those that provide structure, direction, and organization for the child in addition to family participation.”¹⁵⁹

The CDC lists the following treatments as those involving behavior and communication: applied behavior analysis (ABA), developmental, individual differences, relationship-based approach (also known as “floortime”), Treatment and Education of Autistic and Communication handicapped Children (TEACCH), occupational therapy, sensory integration therapy, speech therapy, and the Picture Exchange Communication System (PECS).¹⁶⁰ ABA has become a commonly advocated treatment, but not without controversy. The CDC describes ABA as follows: “ABA has become widely accepted among health care professionals and used in many schools and treatment clinics. ABA encourages positive behaviors and discourages negative behaviors in order to improve a variety of skills. The child’s progress is tracked and measured.”¹⁶¹

ABA and the issues surrounding this therapy and its controversy is discussed in greater detail in the section on access to health care and how ABA treatment has played a significant role in shaping the push for insurance mandates on the state level. It is important to note that there are also a variety of different ABA therapies.¹⁶² Some different types of ABA therapy include: Discrete Trial Training (DTT),¹⁶³ Early Intensive Behavioral Intervention (EIBI),¹⁶⁴ Pivotal Response Training (PRT),¹⁶⁵ and Verbal Behavior Intervention (VBI).¹⁶⁶

158. *Id.*

159. *Id.*

160. *Id.*

161. *Id.*

162. *Id.*

163. *Id.*

DTT is a style of teaching that uses a series of trials to teach each step of a desired behavior or response. Lessons are broken down into their simplest parts and positive reinforcement is used to reward correct answers and behaviors. Incorrect answers are ignored.

Id.

164. *Id.* “This is a type of ABA for very young children with an ASD, usually younger than five, and often younger than three.” *Id.*

165. *Id.* “PRT aims to increase a child’s motivation to learn, monitor his own behavior, and initiate communication with others. Positive changes in these behaviors should have widespread effects on other behaviors.” *Id.*

166. *Id.* “VBI is a type of ABA that focuses on teaching verbal skills.” *Id.*

The CDC recommends the consideration of several other therapies under the category of behavior and communication approaches to treatment for children with ASDs.¹⁶⁷ One approach is known as Developmental, Individual Differences, Relationship-Based Approach (“DIR”; also called “floortime”).¹⁶⁸ This treatment focuses on improving the emotional and relational well-being of the autistic child with those caring for the child.¹⁶⁹ Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) is a treatment that involves helping the autistic child’s development through the use of visualization.¹⁷⁰ “TEAACH uses visual cues to teach skills. For example, picture cards can help teach a child how to get dressed by breaking information down into small steps.”¹⁷¹ Another therapy that will be considered for an autistic child is occupational therapy.¹⁷² Occupational therapy involves helping the individual with autism learn to do basic living activities to maximize opportunity for independence.¹⁷³ “Skills might include dressing, eating, bathing, and relating to people.”¹⁷⁴ Sensory integration therapy is another treatment in the category of behavioral and communication treatments that involves helping the autistic child in the processing of the senses.¹⁷⁵ “Sensory integration therapy helps the person deal with sensory information, like sights, sounds, and smells. Sensory integration therapy could help a child who is bothered by certain sounds or does not like to be touched.”¹⁷⁶ For some autistic children, communication is enhanced through speech therapy.¹⁷⁷ Through speech therapy, improvement may occur in communication for the autistic child through verbalization or visualization depending on the severity of the autism.¹⁷⁸ Another treatment to improve the development of an autistic child’s communication skills is the Picture Exchange Communication System (PECS).¹⁷⁹ “PECS uses picture symbols to teach communication skills. The person is taught to use picture symbols to ask and answer questions and have a conversation.”¹⁸⁰

167. *Id.*

168. *Id.*

169. *Id.*

170. *Id.*

171. *Id.*

172. *Id.*

173. *Id.*

174. *Id.*

175. *Id.*

176. *Id.*

177. *Id.*

178. *Id.*

179. *Id.*

180. *Id.*

The second category of treatment described by the CDC for autism is dietary approaches.¹⁸¹ While the CDC lists dietary approaches for treatment, there is skepticism for this approach based on the lack of scientific evidence currently available to substantiate its effectiveness: “Some dietary treatments have been developed by reliable therapists. But many of these treatments do not have the scientific support needed for widespread recommendation. An unproven treatment might help one child, but may not help another.”¹⁸² Changes in a child’s diet from food to the implementation of vitamin supplements is part of dietary treatment.¹⁸³ “Dietary treatments are based on the idea that food allergies or lack of vitamins and minerals cause symptoms of ASDs.”¹⁸⁴

Another category of treatment described by the CDC is medication.¹⁸⁵ However, the CDC makes clear that medication does not exist to cure or improve the major symptoms of autism: “There are no medications that can cure ASDs or even treat the main symptoms. But there are medications that can help some people with related symptoms.”¹⁸⁶ The AAP has made the following observations regarding medical interventions:

Pharmacologic interventions may be considered for maladaptive behaviors such as aggression, self-injurious behavior, repetitive behaviors (eg, perseveration, obsessions, compulsions, and stereotypic movements), sleep disturbance, mood lability, irritability, anxiety, hyperactivity, inattention, destructive behavior, or other disruptive behaviors. After treatable medical causes and modifiable environmental factors have been ruled out, a therapeutic trial of medication may be considered if the behavioral symptoms cause significant impairment in functioning and are suboptimally responsive to behavioral interventions. In some cases, the diagnosis of a comorbid disorder, such as major depression, bipolar disorder, or an anxiety disorder, can be made reasonably and the patient can be treated with medications that are useful for treating these conditions in otherwise typically developing children and adolescents.¹⁸⁷

As of the original publication of the AAP report in 2007, “Recent surveys indicate that approximately 45% of children and adolescents and up to 75% of adults with ASDs are treated with

181. *Id.*

182. *Autism Spectrum Disorders (ASDs): Treatment, supra note 7.*

183. *Id.*

184. *Id.*

185. *Id.*

186. *Id.*

187. Scott M. Myers & Chris Plauché Johnson, *Management of Children with Autism Spectrum Disorders*, 120 PEDIATRICS 1162, 1170 (2007), available at <http://pediatrics.aappublications.org/content/120/5/1162.full.pdf+html>.

psychotropic medication.”¹⁸⁸ According to the AAP, several medications are being used for children with autism.¹⁸⁹ “Risperidone has become the first medication with U.S. Food and Drug Administration-approved labeling for the symptomatic treatment of irritability (including aggressive behavior, deliberate self-injury, and temper tantrums) in children and adolescents with ASDs.”¹⁹⁰ “Surveys performed in the United States suggest that selective serotonin-reuptake inhibitors (‘SSRIs’), atypical antipsychotic agents, stimulants, and 2-adrenergic agonist antihypertensive agents are the most commonly prescribed classes of psychotropic medications for children with ASDs.”¹⁹¹ Another type of medication that has been examined for use with children with autism is stimulants.¹⁹² A few other medications have been used with respect to symptoms of hyperactivity.¹⁹³ New research finding that autism is not degenerative suggests that future medication may actually effectively reverse the disorder.¹⁹⁴ According to that research:

A study out Wednesday in the journal *Neuron* found that medication could correct the health and behavior problems of mice with a genetic condition known to lead to autism in people. The drug, which acts on the synapses, or gaps, between brain cells, reversed a vast range of symptoms often associated with autism—including lack of sociability, physical awkwardness, and hyperactivity.¹⁹⁵

The AAP made the following recommendation regarding the important considerations that should be involved in using medication as a treatment option for children with autism: “When

188. *Id.*

189. *Id.*

190. *Id.*

191. *Id.*

192. *Id.* at 1171.

Although early studies of the effects of stimulants yielded negative results, recent double-blind, placebocontrolled trials of methylphenidate have demonstrated improvement in hyperactivity, impulsivity, and inattention in children with ASDs. Methylphenidate is effective in some children with ASDs, but the response rate is lower than that in children with isolated attention-deficit/hyperactivity disorder, adverse effects are more frequent, and it is unclear whether the results can be generalized to other stimulants.

Id.

193. *Id.* “Two small double-blind, placebo-controlled trials have documented modest benefits of clonidine in reducing hyperarousal symptoms including hyperactivity, irritability and outbursts, impulsivity, and repetitive behaviors in children with ASDs.” *Id.*

194. Karen Weintraub, *Could Autism Be Reversed with a Pill?*, BOS. GLOBE (Apr. 12, 2012), <http://www.bostonglobe.com/lifestyle/health-wellness/2012/04/11/could-autism-reversed-with-pill/nb05R3OBuu4lraDNIVIMLL/story.html>.

195. *Id.*

medications are used, potential benefits and adverse effects should be explained, informed consent should be obtained, baseline data regarding behaviors and somatic complaints should be collected, and potential strategies for dealing with treatment failure or partial response should be reviewed.”¹⁹⁶ It also continues to be of importance to have some ability to measure the effectiveness of medication as treatment.¹⁹⁷ The National Institute of Mental Health (NIMH) also provides information for parents regarding the use of medication for children with autism.¹⁹⁸

Finally, the CDC includes the category of complementary and alternative medicine for treatment of autism.¹⁹⁹ Despite the inclusion of this category, the CDC notes that this category involves treatment options that may be considered contrary to physician recommendation:

To relieve the symptoms of ASDs, some parents and health care professionals use treatments that are outside of what is typically recommended by the pediatrician. These types of treatments are known as complementary and alternative treatments (CAM). They might include special diets, chelation (a treatment to remove heavy metals like lead from the body), biologicals (e.g., secretin), or body-based systems (like deep pressure).²⁰⁰

The CDC also emphasizes that this category of treatment has been utilized by many parents, even though it has been known to be controversial: “These types of treatments are very controversial. Current research shows that as many as one third of parents of children with an ASD may have tried complementary or alternative medicine treatments, and up to 10% may be using a potentially dangerous treatment.”²⁰¹

196. Myers & Johnson, *supra* note 187, at 1171.

197. *Id.* at 1171-72.

It is important to have some quantifiable means of assessing the efficacy of the medication and to obtain input from a variety of sources, such as parents, teachers, therapists, and aides. Consistent use of validated, treatment-sensitive rating scales and medication adverse-effect scales is desirable. A wide variety of outcome measures have been used in research trials and in clinical practice to measure maladaptive behavior treatment effects. Among the most common are the Clinical Global Impression Scale, Aberrant Behavior Checklist, and Nisonger Child Behavior Rating Form.

Id.

198. *A Parent's Guide to Autism Spectrum Disorder*, NIMH.NIH.GOV, <http://www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/how-is-asd-treated.shtml> (last visited Oct. 27, 2012).

199. *Autism Spectrum Disorders (ASDs): Treatment*, *supra* note 7.

200. *Id.*

201. *Id.*

2. *The ABA Debate: Why Is ABA the “Gold Standard” for Autism Treatment?*

Despite the various options described above that have been developed and researched for treating autism, the most talked about and controversial of these has been ABA therapy.²⁰² However, a lack of understanding of how ABA is defined and what is known about ABA therapy exists in the public, specifically, that it is not just a treatment that is limited by a particular standard but a group of therapies that share common characteristics.²⁰³ First, it is important to understand what behavioral analysis is in general. “Behavior analysis is the systematic study of variables that influence behavior.”²⁰⁴ Applied behavioral analysis is then the application of interventions to promote behavioral changes in these environments as described by the Kennedy Krieger Institute:

Applied behavior analysis (ABA) is a discipline concerned with the application of behavioral science in real-world settings such as

202. Maura Lerner, *Questions Over \$100,000 Treatment for Autism*, STAR TRIB. (Apr. 4, 2011), <http://www.startribune.com/lifestyle/health/119121174.html?source=error>; see also Lea Winerman, *Autism Diagnoses Bring Slew of Costs for Families*, PBS NEWSHOUR (Apr. 13, 2011), http://www.pbs.org/newshour/updates/health/jan-june11/autismcosts_04-13.html (explaining how ABA therapy is controversial and expensive).

203. Louis P. Hagopian & Eric W. Boelter, *Applied Behavior Analysis and Neurodevelopmental Disorders: Overview and Summary of Scientific Support*, KENNEDY KRIEGER INST. & JOHNS HOPKINS UNIV. SCH. OF MED., <http://www.kennedykrieger.org/patient-care/patient-care-programs/inpatient-programs/neurobehavioral-unit-nbu/applied-behavioral-analysis> (last visited Oct. 27, 2012)

([D]espite more than 40 years of applied behavior analytic research there continues to be misconceptions about ABA. One misconception is that ABA is a standardized treatment program that is used for a specific type of problem and with specific types of individuals. For example, some incorrectly believe that ABA is a type of therapy or a specific procedure for teaching children with autism, and that it is synonymous with “Lovaas Therapy” or “discrete trial training.” Although discrete trial training represents one type of ABA-based approach, the field of ABA is much broader and includes a range of tactics, methods and procedures that have been shown to be effective for many different types of problems. Features common to all ABA-based approaches are the objective measurement of behavior, precise control of the environment and use of procedures based on scientifically established principles of behavior. Any clinical procedure or research investigation adhering to these basic criteria can be considered to be an ABA-based procedure. This includes “functional behavioral assessment,” and approaches such as “Positive Behavioral Support,” and forms of “Behavior Therapy” that rely on direct observation of behavior and analysis of behavior-environment relations.).

204. *Id.* (citation omitted).

clinics or schools with the aim of addressing socially important issues such as behavior problems and learning (Baer, Wolf, & Risley, 1968). Procedures derived from the discipline of ABA have been implemented to assess and treat a broad range of behaviors with individuals diagnosed with intellectual and developmental disabilities.²⁰⁵

The American Academy of Pediatrics described the impact of using ABA therapy as follows:

ABA methods are used to increase and maintain desirable adaptive behaviors, reduce interfering maladaptive behaviors or narrow the conditions under which they occur, teach new skills, and generalize behaviors to new environments or situations. ABA focuses on the reliable measurement and objective evaluation of observable behavior within relevant settings including the home, school, and community.²⁰⁶

3. *For or Against ABA Therapy?*

Over the years, advocates and researchers have come out for or against ABA therapy as a treatment option for autism. As more legislators, especially at the state level, have moved toward laws to require insurance providers to cover ABA therapy as a treatment, the effectiveness of ABA therapy and whether or not it should have insurance coverage as a treatment has become more important. Among the criticism that has mounted over the years against the use of ABA therapy has been the lack of evidence-based support to demonstrate its effectiveness, which has resulted in ABA therapy's classification as "experimental" by insurers using that classification as a way to deny insurance coverage for the treatment. Despite that criticism, the Kennedy Krieger Institute has documented a body of research dating back to 1946 that supports the scientific backing of the effectiveness of ABA therapy as a treatment for individuals with autism.²⁰⁷ The

205. *Id.*

206. Myers & Johnson, *supra* note 187, at 1164.

207. Hagopian & Boelter, *supra* note 203

("Several review articles and meta-analyses have been published summarizing this large body of literature. Six of these articles (DeMyer, Hingtgen, & Jackson, 1981; Herbert, Sharp, & Gaudiano, 2002; Hingtgen & Bryson, 1972; Kahng, Iwata, & Lewin, 2002; Matson, Benavidiz, Compton, Paclawskyj, & Baglio, 1996; Sturmey, 2002) collectively reviewed thousands of published studies spanning the years 1946 to 2001. Each of these reviews supported efficacy of ABA-based procedures in the assessment and treatment of problem behavior associated with autism, mental retardation and related disorders. Similarly, three meta-analyses (Didden, Duker, & Korzilius, 1997; Lundervold & Bourland, 1988; Weisz, Weiss, Han, Granger, & Morton, 1995) that collectively analyzed hundreds of studies published between 1968 and 1994 concluded that treatments based on operant principles of learning were more effective for reducing problem behavior displayed by

Kennedy Krieger Institute has stated: “Over the past 40 years a large body of literature has shown the successful use of ABA-based procedures to reduce problem behavior and increase appropriate skills for individuals with intellectual disabilities (ID), autism and related disorders.”²⁰⁸ The Kennedy Krieger Institute concludes its support of scientific backing of ABA therapy as follows:

The large body of literature reviewed in these studies provides empirical evidence indicating that procedures developed using ABA-based principles are effective at assessing and treating a variety of socially important behaviors engaged in by individuals with a variety of diagnoses. Furthermore, ABA-based approaches for educating children with autism and related disorders have been extensively researched and empirically supported (e.g., Howard, Sparkman, Choen, Green, & Stanislaw, 2005; Koegel, Koegel, & Harrower, 1999; Krantz & McClannahan, 1998; Lovaas, 1987; McGee, Morrier, & Daly, 1999; Strain & Kohler, 1998).²⁰⁹

Additionally, there is support for the use of ABA in a variety of environments, and ABA has been used for improving various behavioral problems.²¹⁰ ABA has also been used to treat a number of different disorders.²¹¹ A consensus has been demonstrated

individuals with ID as well as typically-developing individuals than were alternative treatments.”).

208. *Id.*

209. *Id.*

210. *Id.*

(“ABA-based procedures have been implemented across a variety of settings including hospitals (e.g., Iwata, et al., 1994), schools (e.g., Boyajian, DuPaul, Handler, Eckert, & McGoey, 2001; Northup et al., 1997) and homes (e.g., Derby, et al. 1997; Harding et al., 1999); across a variety of forms of problem behavior including self-injurious behavior (e.g., Iwata, Dorsey, Slifer, Bauman, & Richman, 1982/1994; Kahng, Iwata, & Lewin, 2002), aggression (e.g., DeLeon, Fisher, Herman, & Crosland, 2000; Oliver, Oxener, Hearn, & Hall, 2001.), stereotypic behavior (e.g., Ahearn, Clark, DeBar, & Florentino, 2005; Durand & Carr, 1997; Rapp, Vollmer, St. Peter, Dozier, & Cotnoir, 2004) and pica (e.g., Hagopian, & Adelinis, 2001; McCord, Grosser, Iwata, & Powers, 2005; Piazza, Roane, Keeney, Boney, & Abt, 2002). Additionally, ABA-based procedures have been employed to establish and increase adaptive behaviors as alternatives to problem behavior including communication (e.g., Carr & Durand, 1985; Durand, & Carr, 1992; Hagopian, Fisher, Sullivan, Acquisto, & LeBlanc, 1998; Wacker et al., 1990), daily living skills (e.g., Cuvo, Jacobi, & Sipko, 1981; Horner & Keilitz, 1975) and academic skills (e.g., Daly & Martens, 1994; McComas, Wacker, & Cooper, 1996).”).

211. *Id.*

(“ABA-based procedures have also been used with individuals with a variety of diagnoses including schizophrenia (e.g., Wilder, Masuda, O’Connor, & Baham, 2001), mental retardation (e.g., Lindauer, Zarcone, Richman, & Schroeder, 2002; Saunders, McEntee, & Saunders, 2005), autism (e.g., Hoch, McComas, Thompson, & Paone, 2002; Lerman, Vorndran, Addison, & Kuhn, 2004; Lovaas et al. 1987), attention deficit

through the government and numerous organizations that ABA therapy is effective.²¹² “Based on the empirical evidence, many scientific, government, and professional agencies and organizations have concluded that ABA-based procedures represent best practices for individuals with autism and mental retardation.”²¹³ The use of ABA therapy has been given the recommendation of “highly recommended” by the American Association on Intellectual and Developmental Disabilities,²¹⁴ which represents the largest interdisciplinary organization advocating for individuals with developmental disabilities.²¹⁵ The Kennedy Krieger Institute lists a number of scientific organizations that support the use of ABA therapy including the NIMH,²¹⁶ the National Academies Press,²¹⁷ the Association for Science in Autism Research,²¹⁸ Autism Speaks,²¹⁹ and the Organization for Autism Research.²²⁰ The AAP²²¹ has also supported the effectiveness of ABA therapy. In a 2007 report by the AAP, which was reaffirmed in 2010, the following was said of ABA therapy:

The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research 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

hyperactivity disorder (e.g., Northup et al. 1997), stereotypic movement disorder with self-injury (e.g., Kahng, Iwata, & Lewin, 2002; Smith, Iwata, Goh, & Shore, 1995), Down Syndrome (e.g., Dalton, Rubino, & Hislop, 1973), and pediatric feeding disorders (e.g., Cooper et al., 1995; Kerwin, Ahearn, Eicher, & Burd, 1995; Piazza, et al., 2003).”

212. *Id.*

213. *Id.*

214. AM. ASS'N ON INTELL. AND DEVELOPMENTAL DISABILITIES, <http://www.aamr.org/> (last visited Oct. 27, 2012).

215. Hagopian & Boelter, *supra* note 203.

216. *Autism Spectrum Disorders (Pervasive Developmental Disorders)*, NIMH.NIH.GOV, <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml> (last visited Oct. 27, 2012).

217. COMM. ON EDUC. INTERVENTIONS FOR CHILD. WITH AUTISM, EDUCATING CHILDREN WITH AUTISM 120 (Catherine Lord & James P. McGee eds. 2001), *available at* http://www.nap.edu/openbook.php?record_id=10017&page=120.

218. ASS'N FOR SCI. IN AUTISM TREATMENT, <http://www.asatonline.org/> (last visited Oct. 27, 2012).

219. *Applied Behavioral Analysis (ABA)*, AUTISMSPEAKS.ORG, <http://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba> (last visited Oct. 27, 2012).

220. ORG. FOR AUTISM RESEARCH, *The Best of the OARacle: A Compilation of Articles from 2002-2007* (Oct. 26, 2007), *available at* <http://www.researchautism.org/resources/reading/documents/BestOfOARacle.pdf>.

221. AM. ACAD. OF PEDIATRICS, www.aap.org (last visited Oct. 27, 2012).

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 of children in control groups.²²²

Additionally, governmental bodies have recognized and promoted the effectiveness of ABA therapy.²²³ “Various government agencies have also advocated for the use of ABA-based procedures—particularly for individuals with mental retardation and autism who display problem behavior.”²²⁴ Specifically, the U.S. Surgeon General’s 1999 report stated: “Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”²²⁵ Other governmental entities supporting the use of ABA therapy include the New York State Department of Health²²⁶ and the Maine Administrators of Services for Children with Disabilities.²²⁷ Most recently, the U.S. government’s Office of Personnel Management has changed its policy position to one of now supporting ABA therapy as a medical treatment for federal workers health care benefits.²²⁸ That change is discussed in greater detail in the section on current federal legislation for health care. Finally, a number of journals have supported the use of ABA therapy for individuals with autism.²²⁹ “Several academic and trade journals that represent specific medical disciplines have published articles indicating that treatments for autism and mental retardation derived from ABA-based procedures are empirically supported treatments.”²³⁰ While controversy continues about ABA therapy, there are a number of government and private institutions backing its use and effectiveness as well as medical journals. As policymakers continue to struggle over how best to formulate laws to provide access to health care for autistic children, research on ABA therapy will continue to be necessary

222. Myers & Johnson, *supra* note 187, at 1164.

223. *Id.*

224. *Id.*

225. ASS’N FOR SCI. IN AUTISM TREATMENT, *Applied Behavior Analysis (ABA)*, <http://www.asatonline.org/treatment/treatments/applied> (last visited Oct. 27, 2012).

226. N.Y. ST. DEP’T OF HEALTH, <http://www.health.ny.gov/> (last visited Oct. 27, 2012).

227. ME. ADM’RS OF SERVS. FOR CHILD. WITH DISABILITIES, <http://www.madsec.org/> (last visited Oct. 27, 2012).

228. Michelle Diamant, *Feds Approve ABA Therapy as Medical Benefit*, DISABILITY SCOOP (June 4, 2012), <http://www.disabilityscoop.com/2012/06/04/feds-aba-medical-benefit/15771/>.

229. Hagopian & Boelter, *supra* note 203.

230. *Id.*

and imperative as a treatment option.

III. THE COST OF HEALTHCARE FOR INDIVIDUALS WITH AUTISM

Autism and treatment for its various complications is becoming one of the most discussed and demanded state benefit mandates. But there is a growing debate over whether, and to what extent, autism is a health-related condition as opposed to a behavioral condition or educational challenge. While health insurance does and should cover health-related aspects of autism, policymakers who want to ensure that families facing the real financial and other challenges posed by autism should develop safety net programs that meet their needs, rather than trying to impose autism-related costs on health insurance.²³¹

A. *What Makes the Health Care of Children with Autism an Issue?*

A primary consideration for those who have not been exposed to the challenges parents of children with autism have confronted in acquiring access to health care services is: What makes the health care needs of autistic children unique compared to others? Some may argue that autistic children should be treated no different than those of children with chronic illnesses when it comes to the legal protections available for their health care needs. However, closely examining the health care needs of autistic children demonstrates the urgency and necessity of ensuring greater legal protections regarding health care for children with autism and their families. Parents of autistic children's needs are broad and may require a combination of different services:

From the perspective of a family whose child presents with autistic symptoms in pre-school years, the goal is to obtain immediate access to all recommended services, most typically behavioral, occupational, and speech therapy, at rates proportional to the severity of the child's specific needs. In theory health insurance should pay for the therapeutic interventions medically necessary to improve the condition of patients, because autism is ordinarily diagnosed by pediatricians. In practice, early treatment is still out of the reach of many and, unsurprisingly, the autism community faces the same sorts of problems that make health reform so urgent across the board.²³²

First, it is important to point out that autism is a medical diagnosis, and children with autism may require numerous types of treatment as described above. As previously discussed, the costs

231. Victoria C. Bunce & J.P. Wieske, *The Growing Trend Towards Mandating Autism Coverage*, 152 ISSUES & ANSWERS 1, 1 (2009), available at http://www.cahi.org/cahi_contents/resources/pdf/n152AutismTrend.pdf.

232. Caruso, *supra* note 1, at 527.

associated with the different treatments are enormous, making it difficult, if not impossible, for parents and families to be able to shoulder such costs on their own. A study in 2005-2006 in the journal *Pediatrics* was the first of its kind to consider the financial burden to families of children with autism compared to children with other chronic conditions.²³³ The results of that study provide valuable insight of the unique challenge to families of children with autism in financing the care necessary for those children:

Children with special health care needs with autism spectrum disorder were more likely to live in families that report financial problems, need additional income for the child's medical care, reduce or stop work because of the child's condition, spend ≥ 10 hours per week providing or coordinating care, and paid more than \$1000 in the previous year for the child's care. The financial impacts of autism spectrum disorder were significantly more burdensome when children with special health care needs did not have a medical home.²³⁴

The costs of caring for children with autism can have a crippling impact on families. Such an impact is inevitably felt by society to a larger extent by the loss of valuable workers. It is felt in terms of the family members that must significantly limit working due to the need to care for their autistic children, and the loss of production to society that is borne by individuals with autism who are unable to contribute to society due to the limitations created by their disability. The study also revealed that children with autism compared to children with other chronic conditions were generally more likely to lack general access to health care services.²³⁵ For example:

Compared with other children with special health care needs without emotional, developmental, or behavioral problems, children with special health care needs with autism spectrum disorder were more likely to have unmet needs for specific health care services, family support services, delayed or foregone care, difficulty receiving referrals, and care that is not family centered.²³⁶

Clearly, children with autism face a more significant dilemma when it comes not only to the cost of health care services, but also in having access to these services to begin with. The most recent study performed to evaluate the relationship between autistic children and health care in June 2012 revealed the continued disparity that exists for children with autism in both cost and

233. 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 (2008), available at <http://pediatrics.aappublications.org/content/122/6/e1149.full.pdf+html>.

234. *Id.* at e1149.

235. *Id.*

236. *Id.*

access to health care.²³⁷

While the costs in and of themselves are an enormous barrier, children with autism of minority status have endured even greater difficulty historically in access to treatments critical during a child's development.²³⁸ One of the reasons provided for such lack of treatment is that those children have often not been properly diagnosed as autistic: "Among racial and ethnic minorities, children with autism are more likely to be misdiagnosed as having mental retardation, a label that makes a much feebler case for behavioral therapy."²³⁹ In addition to being misdiagnosed, minority children may also be diagnosed for autism at a much later age than Caucasians, as has been the case for African American children as demonstrated by a 2002 study by David S. Mendell: "On average, white children first received their autism diagnosis at 6.3 years of age compared with 7.9 years for African-American children and 8.8 years for Latino children. On average, white children entered the mental health system at an earlier age than African-American or Latino children."²⁴⁰ The initial diagnosis of autism in minority children will determine treatment needs and how soon treatment actually begins. With evidence of these problems of diagnosis among minority children, more research is needed to ensure minority children are getting access to treatment as soon as possible: "These delays in diagnosis and misdiagnoses create challenges to the provision of the vital early intervention necessary to improve a child's developmental trajectory. While these disparities are documented, little is known about the dynamics that influence these differential outcomes."²⁴¹ Thus, minority autistic children face critical barriers in both delays in access to treatment and the enormous cost for those treatments and services.

There are a number of reasons why the plight of children with autism and their families in securing access to health care services is more difficult compared to others. While health care law is generally already complex, the complexity is only magnified when

237. *Kids with Autism Face Health Care Disparities, Study Finds*, PHILA. INQUIRER (June 16, 2012), http://www.philly.com/philly/health/HealthDay665706_20120615_Kids_With_Autism_Face_Health_Care_Disparities_Study_Finds.html?cmpid=138896554

238. Caruso, *supra* note 1, at 527.

239. *Id.* at 525.

240. Donald Oswald, *Children with Autism Spectrum Disorders in the Latino Community* 4 (2012), http://www.vcu-projectempowerment.org/conference/documents/Oswald_030212_Presentation_82D509263CBF354B.pdf.

241. Nat'l Inst. of Child Health & Human Dev. et al., *Meeting Summary: Disparities in the Identification of Children with Autism Spectrum Disorders (ASDs)*, NICHD.NIH.GOV (Aug. 19, 2010), http://www.nichd.nih.gov/about/meetings/2010/upload/DSP_autism_workshop_2010_summary_final.pdf.

it comes to considerations of the autistic child. The cost of necessary services for children with autism can be enormous. This cost of health care for families of children with autism even surpasses costs for families of children with chronic conditions. Finally, there are difficulties faced by minority children with autism in securing access to health care services that may be significantly delayed due to missed diagnosis or misdiagnosis. It is critical to continue to search for innovative ways to provide access to health care for autistic children for the benefit of children with autism, their families, and society as a whole.

B. The Current Cost of Healthcare for People with Autism

Understanding how the cost of healthcare for autistic children relates to the lifetime costs of an individual with autism is critical to policy considerations involving health care access as many treatments for autistic children are incredibly expensive. “Recent studies have estimated that the lifetime cost to care for an individual with an ASD is \$3.2 million.”²⁴² Additionally, research has demonstrated that the cost of medical care for those with autism compared to those without autism is substantial:

Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. Adult care, which has the largest lifetime cost of all direct costs, is typically more than 5 times larger than the next 3 largest costs, which include care incurred during childhood (behavioral therapies, child/respite care, and special education). Alemayehu and Warner reported that the typical American spends about \$317 000 over his or her lifetime in direct medical costs, incurring 60% of those costs after age 65 years. In contrast, people with autism incur about \$306 000 in incremental direct medical costs, implying that people with autism spend twice as much as the typical American over their lifetimes and spend 60% of those incremental direct medical costs after age 21 years.²⁴³

According to a 2007 study, the cost of autism that occurs during childhood is only the beginning of the cost which will be felt by a family and/or society in financing treatment.²⁴⁴ That study concluded:

Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. The substantial costs resulting from adult care and lost productivity of both individuals with autism and their parents have important implications for those aging members of the baby boom generation approaching

242. *Autism Spectrum Disorders (ASDs): Data & Statistics*, *supra* note 3.

243. Michael L. Ganz, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, 161 PEDIATRICS & ADOLESCENT MED. 343, 348 (2007), available at <http://arch.pedi.ama-assn.org/cgi/reprint/161/4/343.pdf>.

244. *See id.* (describing the many costs associated with autism that continue into adulthood).

retirement, including large financial burdens affecting not only those families but also potentially society in general. These results may imply that physicians and other care professionals should consider recommending that parents of children with autism seek financial counseling to help plan for the transition into adulthood.²⁴⁵

Because of this financial reality, the amount that is spent in childhood alone for individuals with autism can have a significant impact in what a government and society at large inevitably provides for the health care of autistic children. This may affect the ability of the government to continue to finance health care for individuals with autism as they move into adulthood. In assessing such costs, Ganz's research provides the following breakdown of costs from early childhood to young adulthood:

Direct medical costs²⁴⁶ are quite high for the first 5 years of life (average of around \$35 000), start to decline substantially by age 8 years (around \$6000), and continue to decline through the end of life to around \$1000. Direct nonmedical costs vary around \$10 000 to approximately \$16 000 during the first 20 years of life, peak in the 23- to 27-year age range (around \$27 500), and then steadily decline to the end of life to around \$8000 in the last age group. Indirect costs also display a similar pattern, decreasing from around \$43 000 in early life, peaking at ages 23 to 27 years (around \$52 000), and declining through end of life to \$0.²⁴⁷

The greatest contributor to direct medical costs is the cost for behavioral therapies:

Behavioral therapies, which are the largest component of direct medical costs, make up 6.5% of total discounted lifetime costs. However, behavioral therapies, as presented herein, are only relevant for children 19 years or younger. The large direct medical costs early in life are driven primarily by behavioral therapies that cost around \$32 000 during the first 5-year age group and decline

245. *Id.*

246. *See id.* at 344 (describing that

[d]ata on physician, outpatient, clinic services, dental care, prescription medications, complementary and alternative therapies, behavioral therapies, hospital and emergency services, allied health, equipment and supplies, home health, and medically related travel were classified as direct medical. Data on child care, adult care, respite and family care, home and care modifications, special education, supported employment, and other costs, were classified as direct nonmedical. Although some dimensions of care may be misclassified between direct medical and direct nonmedical (for example, many special education programs provide behavioral therapies), because the degree of misclassification is not known, no corrections were made. Costs, as reported in the source materials, were inflated to 2003 US dollars using the all-item consumer price index. State-specific costs were transformed to national averages and foreign costs were converted to US costs using the latest available Federal Reserve exchange rates).

247. *Id.* at 346.

from about \$4000 in the 8- to 12-year age group to around \$1250 for the 18- to 22-year age group.²⁴⁸

Indirect costs are also included in an analysis by Ganz regarding the loss of productivity of those with autism as well as their parents.²⁴⁹ According to age-specific estimates for lifetime incremental costs to society, a child with autism at age three will incur a total cost of \$93,642 while this can rise to as much as \$100,733 for a six year old.²⁵⁰ At those rates, an adult with autism that lives up to age sixty-six will incur the cost of an estimated \$3,160,387 on society.²⁵¹ As our country enters into a time of significant change in the federal legal framework for health care coverage through the Patient Protection and Affordable Care Act²⁵² (PPACA), the funding of health care for individuals with autism continues to raise serious concern, in particular, regarding children.²⁵³ If the United States is going to fund the health care of people with autism, there is fear over the impact that taking on such an extensive financial burden could have for all:

According to the Council for Affordable Health Insurance, an autism mandate increases the cost of health insurance by about 1 percent. However, if the incidence of autism continues to increase and as more services are covered, the cost of insurance may increase 1 to 3 percent. This debate has intensified in recent years and states are taking a variety of approaches to meet the needs of children and adults with autism.²⁵⁴

Even at the state level where a movement for mandating insurance coverage for individuals with autism has slowly emerged, skepticism that this is a costly approach still remains.²⁵⁵ The expansion of services provided by states now often includes coverage for ABA and other behavioral therapies.²⁵⁶ In his article, Ganz cited the importance of understanding the options available

248. *Id.*

249. *See id.* (explaining that for the purpose of the study productivity losses were estimated by combining standard average work-life expectancies for all men and women with average income and benefits and estimates of sex-specific labor force participation rates).

250. Ganz, *supra* note 243 (click: "eTable 1").

251. *Id.*

252. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (codified as amended in scattered sections of 42 U.S.C.A.).

253. *Autism and Medical Insurance Coverage: What Some Parents Are Doing to Help Their Autistic Children*, L.A. TIMES (Oct. 12, 2010), <http://articles.latimes.com/2010/oct/12/news/la-heb-autism-medical-insurance-20101012>.

254. Nat'l Conference of St. Legislatures, *Insurance Coverage for Autism*, NCSL.ORG (Aug. 2012), <http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx>.

255. Bunce & Wieske, *supra* note 231, at 1.

256. Nat'l Conference of St. Legislatures, *supra* note 254.

for treatment for individuals with autism in order for our society to best determine how to finance those needs: “Given the financial and nonfinancial costs we face and given increasingly more options for treatment and possibly for prevention, information on the distribution of costs is needed to help us decide on how to best allocate scarce resources to support individuals with autism and their families.”²⁵⁷ Furthermore, determinations in treatment for individuals with autism could have a significant impact on issues of funding: “Because the complementary (or competing) treatment and prevention strategies currently available, or yet to be developed, vary in effectiveness or implementation costs, understanding how total costs due to autism are distributed across the life cycle is important to make better decisions.”²⁵⁸ As advancements may be made in both treatment and prevention, it will be critical to evaluate how these findings relate to cost and benefit: “As treatment and, perhaps prevention, strategies are developed, knowledge of when costs are incurred relative to when benefits are expected is important for clinical decision-making and cost-effectiveness analysis efforts.”²⁵⁹ Such awareness is essential as the advanced knowledge will assist in yielding more cost efficient results.

The recommendations of Ganz were echoed in a 2011 report by CMS: “To make the most effective use of limited resources, federal and state policymakers need empirical data to make informed decisions about which services and support systems are safe and cost-effective in meeting the complex needs of children, adolescents, and adults with ASD.”²⁶⁰ The cost analysis done by Ganz is described as the first of its kind and, with regard to children with autism, has the backing of previous data collected: “The results presented herein for direct medical costs are consistent with recently published data on health care use and costs for children with autism.”²⁶¹ As greater study is done on the cost of healthcare for individuals with autism, such research will better inform policymakers on creating fiscally responsible policy that accommodates the health care necessities of autistic children as they will eventually become autistic adults with continued health care needs.

257. Ganz, *supra* note 243, at 343.

258. *Id.*

259. *Id.* at 348.

260. Danna Mauch et al., *Report on State Services to Individuals with Autism Spectrum Disorders (ASD) 1*, CTRS. FOR MEDICARE & MEDICAID SERVS. (Apr. 1, 2011), <http://www.cms.gov/apps/files/9-State-Report.pdf>.

261. Ganz, *supra* note 243, at 348.

C. *The Debate over ABA Therapy as Treatment and Insurance Coverage*

The availability of insurance coverage for specific treatments becomes critical for children with autism. Only a number of states currently have legislation in place that provides insurance coverage for ABA therapy—a treatment that has become known as the “gold star treatment” for autistic children.²⁶² CMS has described the acceptance of ABA therapy as follows:

Despite the growth in services to persons with ASD, including behavioral interventions, there are few randomized controlled trials providing evidence for those practices. Applied behavior analysis (ABA) is an exception, in that controlled trials have shown both the efficacy of programs based in the principles of ABA and that certain individual characteristics (age, IQ, and functional impairments) are associated with positive outcomes.²⁶³

Those favoring the availability of insurance coverage for ABA offer several reasons for this:

In addition, autism support groups and their families are looking for more financial relief from and coverage for Applied Behavior Analysis and other therapies which, according to proponents, contain some of the most effective forms of treatment, best outcomes and long term economic benefits. Proponents believe that health insurance companies should assume the financial burden—typically in the range of \$50,000 per year per child—for autistic children that families and school districts have borne.²⁶⁴

Despite these arguments, there has been resistance by health insurers to provide coverage for ABA: “Most private health insurance plans do not provide coverage for Applied Behavioral Analysis (ABA) and other autism-related services.”²⁶⁵ In general, insurance companies offer several arguments as to why it is not an easy answer as to which treatment to provide coverage for in cases of individuals with autism:

Insurance carriers argue that most medically related treatments are already covered for autism. In addition, they note that autism is an

262. See Talk About Curing Autism, *Autism Insurance Legislation*, TACA.ORG (Mar. 12, 2011), <http://www.tacanow.org/family-resources/autism-insurance-legislation/> (providing a list of states that have legislation covering ABA treatment); see also Paul Frysh, *Moving out of State to Get Autism Treatment*, CNN (Sept. 17, 2010), http://www.cnn.com/2010/HEALTH/09/17/autism.aba.legislation/index.html?section=cnn_latest (showing that some individuals are forced to move out of state to get ABA coverage despite having good insurance plans).

263. Mauch et al., *supra* note 260, at 2.

264. Bunce & Wieske, *supra* note 231, at 2.

265. Autism Speaks, *Arguments in Support of Private Insurance Coverage of Autism-Related Services* 4, DHHS.NV.GOV (Oct. 24, 2007), http://dhhs.nv.gov/autism/TaskForce/2008/ATF_Report_08/Appendix%20E.pdf.

individually based disorder, and so there is often no clear standard of care to determine the appropriate therapy. Further, some see behavioral therapy not as a medical benefit but an educational one. For example, “play therapies” can require up to 10 separate interactions per day, ensuring the child remains focused on the world around him. The therapy may be provided by unlicensed care providers (and/or parents) who can be trained to use the methods very effectively. Some of the other therapies address developmental delays, which are not typically covered under health insurance.²⁶⁶

A report by Autism Speaks in 2007 on why private insurance should cover treatment of autism offered the following reflection about including the treatment of ABA in insurance coverage: “An autism insurance mandate should specifically target coverage of Applied Behavior Analysis (ABA) and other structured behavioral therapies, which are the most effective forms of treatment and have the best outcomes, both in human costs and in long-term economic benefits.”²⁶⁷ Even the media is bringing more attention to the difficulty of this issue and the legislative climate that parents are desperately trying to alter.²⁶⁸ Since the development of ABA therapy, there is no doubt it has become an industry based on the price tag of the therapy and the desperation of parents to find some way of helping an autistic child: “Today, almost 25 years later, therapists . . . are charging up to \$100,000 per year for the treatment Lovaas pioneered, and some parents believe it is the answer to their prayers.”²⁶⁹ These variations in health care coverage available to children with autism and the struggles parents are enduring to find ways to give their children the access to treatment demonstrates that something must be done legislatively, whether it comes at the state or national level, to prevent children with autism from being denied the care they need, particularly during the most critical years of development.

An overview of both the federal and state legislative frameworks for responding to the enormous task of providing health care for people with autism shows the unique challenges this issue poses in creating legislation, and the resulting special policy considerations. As future attempts to improve health care access for people with autism are sought at either level of government, an understanding of those complexities is necessary. Before examining how law has evolved to provide health care benefits for individuals with autism, the earliest attempts to

266. Bunce & Wieske, *supra* note 231, at 2.

267. Autism Speaks, *supra* note 265, at 4.

268. Holly Robinson Peete, *It's Time... To End Insurance Discrimination Against People with Autism*, HUFFINGTON POST (Oct. 22, 2010), http://www.huffingtonpost.com/holly-robinson-peete/its-timeto-end-insurance-_b_772436.html.

269. Lerner, *supra* note 202.

secure protections of health services came through insurance litigation.

IV. THE HISTORY OF AUTISM AND HEALTHCARE ACCESS THROUGH LITIGATION

The earliest efforts to obtain insurance coverage for treatment for individuals with autism occurred through litigation.²⁷⁰ While those efforts were few, it is important in understanding the historical basis of the relationship between insurance and autism to recognize the role litigation played in the early and initial battles to gain insurance coverage for this group of individuals.²⁷¹ Cases involving treatment for autism have come as cases involving principles of contract law through challenges to insurance coverage plans and in others as a matter of statutory interpretation. Another set of cases will be examined for their specific litigation focus for ABA therapy both in the U.S. and internationally.

A. *Treatment for Autism as a Matter of Contract*

1. *Kunin v. Benefit Trust Life Insurance Co.*

In 1990, the Ninth Circuit Court of Appeals issued one of the first opinions involving a dispute over insurance coverage for autism treatment in *Kunin v. Benefit Trust Life Insurance Co.*²⁷² In *Kunin*, the Ninth Circuit examined whether Benefit Trust Life Insurance Co. (“Benefit Trust”) was required to reimburse Kunin for a claim of over \$50,000—the cost of treatment for Kunin’s autistic child under an “employee benefit welfare plan” falling under ERISA through employment with Maxim’s Beauty Salons, Inc.²⁷³ Benefit Trust served as both the insurer and the plan’s administrator.²⁷⁴ Benefit Trust initially offered only \$10,000 to Kunin after review of the plan based on a determination that any benefits for an individual with autism fell under those provided for an individual with mental illness and were subject to those limitations.²⁷⁵ The ruling of the Ninth Circuit affirmed the District Court’s ruling: “The district court concluded that autism is not a mental illness and that the denial of benefits was arbitrary and capricious, and ordered that the claim be paid in full. We agree that Benefit Trust was obligated to pay the full amount of the

270. LORRI SHEALY UNUMB & DANIEL R. UNUMB, *AUTISM AND THE LAW: CASES, STATUTES, AND MATERIALS* 12 (Carolina Academic Press 2011).

271. *Id.*

272. *Kunin v. Benefit Trust Life Ins. Co.*, 910 F.2d 534, 535 (9th Cir. 1990).

273. *Id.*

274. *Id.*

275. *Id.*

claim.”²⁷⁶ This ruling is significant for the distinction it established between autism and mental illness that is critical to examining the legislative approaches that have been used in providing insurance coverage for individuals with autism. In making that distinction, the Ninth Circuit ruled in favor of the insured based on the ambiguity of the definition of “mental illness”:

Moreover, it is unclear whether the term “mental illness” encompasses autism. Under the law of all fifty states and the District of Columbia, where an unclear or ambiguous term is used in an insurance policy, the ambiguity must be construed in favor of the insured. We therefore hold, in the alternative, that this rule of construction applies in the case before us, whether as a uniform rule of federal common law, or because federal common law incorporates state law on this point.²⁷⁷

As the Ninth Circuit examined the decision of the District Court, it explained the basis of the District Court’s determination of autism being outside of mental illness: “Although insurance contract terms are interpreted as a lay person would interpret them, the district court primarily considered the testimony of experts. However, it, correctly, relied on that testimony solely in order to determine the ‘plain and ordinary’ meaning of the term ‘mental illness.’”²⁷⁸ It was clear from this opinion that there has been diversity in the classification of autism for insurance purposes: “State-law cases have differed in their classification of organically based diseases like autism as mental illnesses.”²⁷⁹ Although the insurance policy definitional language in *Kunin* was ultimately at the center of debate of what was included in “mental illness,” it may seem to many that the advent of federal health care reform removes this worry by providing the elimination of individuals being denied insurance coverage based on “pre-existing conditions.” However, this Article later elaborates on how the classification of autism at the state level may impact the coverage that is made available to these individuals, and that challenges still exist for coverage based on how the definition of autism is categorized.

Another interesting aspect of the *Kunin* case is the importance of the analysis that determines the relationship between ERISA and state law.²⁸⁰ While ERISA is federal law that may govern many self-funded insurance policies, it does not necessarily prevent state law from being applied to non-ERISA covered plans, or for state law principles to be influential:

276. *Id.*

277. *Id.*

278. *Id.* at 536.

279. *Id.* at 538.

280. *Id.* at 539.

Of course, neither the law of California nor that of any other state is applicable here of its own force. The group health and medical policy that covers Kunin is an “employee welfare benefit plan” as defined by ERISA, 29 U.S.C. § 1002(1); section 502 of ERISA, rather than state contract law, provides the legal basis for Kunin’s claim. However, “[c]ontroversies directly affecting the operations of federal programs, although governed by federal law, do not inevitably require resort to uniform federal rules.” State law can sometimes control such controversies, either because Congress intends courts to look to state law, or because the incorporation of state law into the federal common law is “appropriate as a matter of judicial policy under the three-part test established by *Kimbell Foods*.”²⁸¹

While the debate between federal and state law did not ultimately become an issue in *Kunin*, this consideration is a backdrop to the intricate web of acquiring health care access that is only further complicated by the uniqueness of autism.²⁸² Instead, *Kunin* relied on the contract principle of *contra proferentem*, which requires an ambiguity to be read in favor of the insured based on the reasoning that an insurer has expertise in drafting coverage, and thus, should be aware of any limitations or exclusions in coverage and set them forth accordingly.²⁸³ While not discussed in *Kunin*, mental health parity laws were later passed

281. *Id.* (citations omitted).

282. *Id.* at 539-40.

283. *Id.*

There is room for disagreement as to whether a uniform federal rule of construction applies when we construe an ambiguous provision in an ERISA insurance contract or whether the applicable state rule of construction is incorporated into federal law for that purpose. However, we need not decide that question here, because the rule of *contra proferentem* would control in either event. As we noted above, the *contra proferentem* rule is followed in all fifty states and the District of Columbia, and with good reason. Insurance policies are almost always drafted by specialists employed by the insurer. In light of the drafters’ expertise and experience, the insurer should be expected to set forth any limitations on its liability clearly enough for a common layperson to understand; if it fails to do this, it should not be allowed to take advantage of the very ambiguities that it could have prevented with greater diligence. Moreover, once the policy language has been drafted, it is not usually subject to amendment by the insured, even if he sees an ambiguity; an insurer’s practice of forcing the insured to guess and hope regarding the scope of coverage requires that any doubts be resolved in favor of the party who has been placed in such a predicament. Were we to promulgate a federal rule, we would find these common-sense rationales sound. Indeed, it would take a certain degree of arrogance to controvert an opinion held with such unanimity in the various states and to adopt a contrary view as the federal rule. We hold, therefore, that the rule of *contra proferentem* applies to the case at bar, regardless of whether it applies as a matter of uniform federal law or because federal law incorporates state law on this point.

Id. (footnotes omitted).

and their impact on autism will be considered later.

2. *Muratore v. United States Office of Personnel Management*

A considerable amount of time passed before another effort to gain insurance coverage for individuals with autism made its way through the legal system. The Eleventh Circuit's decision in *Muratore v. U.S. Office of Personnel Management* involved another issue of contract interpretation in determining how treatment was categorized under an insurance plan.²⁸⁴ After being granted summary judgment on the issue of whether a parent's employee benefits would cover his autistic child's occupational and speech therapies under the Federal Employees Health Benefits Act (FEHBA), 5 U.S.C. §§ 8901-9014, the plaintiff-parents appealed the district court's denial of their request for attorneys' fees under the Equal Access to Justice Act, 28 U.S.C. § 2412.²⁸⁵ The defendant, U.S. Office of Personnel Management (OPM), appealed the award of benefits for these therapies.²⁸⁶ According to the Eleventh Circuit, "Congress enacted the FEHBA to create a comprehensive program of subsidized health care benefits for federal employees and retirees."²⁸⁷

The primary debate over the interpretation of the insurance plan as a contract involves determining which category of services speech therapy falls under in terms of coverage.²⁸⁸ Applying the arbitrary and capricious standard, the court held that the agency had not acted in an arbitrary or capricious manner in determining that speech therapy was considered a "medical benefit," and thus, subject to the limitations of the plan for those services.²⁸⁹ In reaching this conclusion, the court stated that the agency had reasonably interpreted that speech therapy fell under "medical benefits" rather than as part of "individual therapy" as determined by the type of coverage rather than the type of medical professional prescribing the therapy.²⁹⁰

The debate over classifying coverage will prove critical to future discussions regarding whether or not certain treatments should be covered by insurance plans for individuals with autism. A question that looms from this decision is whether or not a condition such as autism, when classified as a "mental health condition," as was the case in *Muratore*, should be excluded from

284. *Muratore v. U.S. Office of Pers. Mgmt.*, 222 F.3d 918 (11th Cir. 2000).

285. *Id.* at 919.

286. *Id.*

287. *Id.* at 920; *see also* *Kobleur v. Grp. Hospitalization & Med. Servs.*, 954 F.2d 705, 709 (11th Cir. 1992) (finding that the FEHBA grants significant authority to OPM).

288. *Muratore*, 222 F.3d at 923-24.

289. *Id.*

290. *Id.* at 924.

coverage for speech therapy because speech therapy is included under “medical benefits.”²⁹¹ This essentially leaves someone with a condition that falls under “mental health” without access to this therapy other than for a limited period.²⁹²

Another interesting issue that emerges from this decision that has also been pivotal to the discussion of insurance coverage for individuals with autism is the debate over “rehabilitative” versus “habilitative” services.²⁹³

3. Wheeler v. Aetna Life Insurance Co.

In 2003, an Illinois federal district court examined a denial of insurance coverage to an autistic child in *Wheeler v. Aetna Life Insurance Co.*²⁹⁴ In that case, it was argued that the denial of medical treatment to the autistic child violated the Employment Retirement Income Security Act (ERISA)²⁹⁵²⁹⁶ The insurance company responded that the denial of coverage was consistent with the respective insurance plan and a reasonable denial of benefits.²⁹⁷ Payment for therapies past and present were sought for the autistic child as well as attorneys’ fees and costs incurred.²⁹⁸ The insurance company sought summary judgment.²⁹⁹ The court applied the “arbitrary and capricious” standard in reviewing the insurance company’s denial of coverage.³⁰⁰ In applying that standard, the court stated:

Although the arbitrary and capricious standard grants significant deference to the plan’s determination of eligibility, our review is not simply a “rubber stamp”: “[I]f fiduciaries or administrators of an ERISA plan controvert the plain meaning of a plan, their actions are arbitrary and capricious.” The arbitrary and capricious standard, though deferential, nonetheless requires “a ‘rational’ connection between the issue to be decided, the evidence in the case, the text under consideration, and the conclusion reached.”³⁰¹

291. *Id.*

292. UNUMB & UNUMB, *supra* note 270, at 25.

293. *Mutadore*, 222 F.3d at 924; *see also id.* at n.7 (regarding arguments of parents of autistic child distinguishing between “rehabilitative” and “habilitative” services).

294. *Wheeler v. Aetna Life Ins. Co.*, No. 01 C 6064, 2003 WL 21789029, at *1 (N.D. Ill. July 23, 2003).

295. Employment Retirement Income Security Act, 29 U.S.C. §§ 1001-1461 (1974).

296. *Wheeler*, 2003 WL 21789029, at *1.

297. *Id.*

298. *Id.* at *6.

299. *Id.*

300. *Id.*

301. *Id.* (citations omitted).

The court explained that the insurer was required to give a reason for every time benefits were denied for the autistic child.³⁰² In reviewing a group of denial letters by the insurer, the court first acknowledged that the insurer failed to take into proper consideration the actual language of the insurance plan.³⁰³ It also criticized the insurer for not appropriately applying the denial of benefits to the case of the particular autistic child's situation at issue.³⁰⁴ Several of the therapies being sought were denied because of the child's diagnosis of autism, even though autism was a covered condition under the plan.³⁰⁵ In another instance, the insurer indicated denial of coverage because there was an exclusion of certain medical treatments deemed "not necessary,"³⁰⁶ but never specified that any of the therapies sought for the autistic child were considered "not necessary."³⁰⁷

In a rather lengthy discussion, the *Wheeler* court considered whether or not the denial of speech therapy by the insurer for the child with autism was reasonable.³⁰⁸ In analyzing the insurer's denial of coverage for speech therapy, the court noted that the insurer distinguished between chronic and non-chronic conditions³⁰⁹—a distinction that is not even part of the language of the insurance plan.³¹⁰ In reaching the decision to deny coverage for speech therapy, the court determined that the insurer had improperly evaluated the autistic child's medical records to reach its conclusion.³¹¹ The insurer also failed to conduct an independent medical examination of the autistic child while rejecting the examination that was put forward.³¹² The court ultimately concluded the following regarding the insurer's rejection of speech therapy: "Because Aetna failed to make a rational connection between the evidence, the plan language, and its conclusion to terminate speech therapy benefits, its termination of benefits was

302. *Id.* at *7.

303. *Id.* at *9.

304. *Id.*

305. *Id.*

306. *Id.*

307. *Id.*

308. *See id.* at *9-11 (reasoning that Aetna's termination of speech therapy benefits was not reasonable because there was no rational connection between the plan's language, the evidence, and the ultimate decision to terminate).

309. *Id.* at *9; *see generally A History of Autism, supra* note 8 (describing different types of chronic or non-chronic autism and the best treatments for those conditions).

310. *Wheeler*, 2003 WL 21789029, at *9.

311. *See id.* at *11 (asserting that "there is support in the medical history from which to conclude that autism caused Bryce to lose previously existing speech skills . . . Aetna has offered no reasoned explanation for why it ignored this support").

312. *Id.*

arbitrary and capricious.”³¹³

Next, the court examined the denial of coverage for sensory integration therapy for the autistic child.³¹⁴ In denying coverage for this therapy, the basis of the insurer’s denial was that the effectiveness of the therapy was “unproven.”³¹⁵ However, in reviewing the plain language of the insurance plan, the court concluded that nothing in the plan addressed denying coverage of treatment on the basis of its “unproven” effectiveness.³¹⁶ Although it could be implied by the denial of this therapy in that the language of the denial letter showed that the insurer believed the therapy was “unnecessary”³¹⁷ for the child’s treatment, the court determined that the insurer acted arbitrarily in denying coverage for the therapy.³¹⁸

The next category of therapies examined by the *Wheeler* court was occupational.³¹⁹ The denial of coverage for occupational therapy by the insurer was based on the notion that they are not required to cover therapies for chronic conditions that will not restore an individual’s functioning.³²⁰ However, the court determined this denial of the occupational therapy to be arbitrary.³²¹

Dr. Hellmann’s first reason for denying benefits for occupational therapy is that Aetna does not cover “long term occupational therapy” for patients with “chronic diseases.” This conclusion evidently is based on a Coverage Policy Bulletin, but it is not based on any language of the plan. There is no language in the plan carving out a “chronic disease” or a “long-term therapy” exception to coverage. Accordingly, this reasoning is wholly arbitrary.³²²

In addition, the insurer’s occupational therapy denial was based on the contention that the use of these therapies resulted from the child’s diagnosis of developmental delays rather than autism.³²³ The doctors that served as experts for the insurer were split on whether autism was implicated in this but agreed that because of this diagnosis of developmental delays, the insurer was not responsible for providing coverage for therapies that were only being used on the basis of that specific diagnosis.³²⁴ While the

313. *Id.*

314. *Id.* at *11-12.

315. *Id.* at *11.

316. *Id.*

317. *Id.*

318. *Id.*

319. *Id.* at *12.

320. *Id.*

321. *Id.*

322. *Id.*

323. *Id.* at *13.

324. *Id.*

insurance plan covered treatment for autism, the inconsistency created by the physicians for the insurer created doubt for the court resulting in another finding of arbitrary action.³²⁵

Aetna's position in its briefs is somewhat unclear-it seems to want to have it both ways and relies on both versions of the developmental delay argument. Dr. Reed's position appears to be that the therapies are not covered benefits because they relate to developmental delays and not autism. There is no explanation for how Dr. Reed or Aetna came to this conclusion, and it is arbitrary given the records. The diagnosis of autism is primary and pervasive throughout Bryce's medical records. Dr. Hellmann, on the other hand, states that the developmental delays in his opinion are likely due to the autism. Aetna admits that autism is a covered condition under the plan. Thus, there is a tension here, unless Aetna's position is that developmental delays are not covered even if they are caused by autism.³²⁶

Wheeler presents a number of interesting issues for consideration regarding these questions of insuring individuals with autism and determinations of coverage.³²⁷ One of the issues is how autism is categorized.³²⁸ The way autism is actually categorized by an insurance company compared to how autism is categorized medically may differ, and such categorizations can be significant for the purpose of insurance coverage determinations.³²⁹ Another crucial consideration in this case involved the determination of the insurance company's medical director for the treatment of the autistic individual.³³⁰ The question then becomes what, if any, role or weight should the insurer's medical personnel have in such determinations against the treating physician of the autistic individual.³³¹

B. Coverage for Autism Treatment as a Matter of Statutory Interpretation and Contract Law

1. *Micheletti v. State Health Benefits Commission*

The New Jersey Supreme Court addressed insurance coverage for treatment for autistic children in *Micheletti v. State Health Benefits Commission*,³³² which was decided by way of

325. *Id.*

326. *Id.*

327. *See generally id.* at *1-14 (discussing whether termination of an autistic child's medical coverage is arbitrary or appropriate, given the plan's language, the reasons for denial, and the evidence of autistic tendencies).

328. UNUMB & UNUMB, *supra* note 270, at 39.

329. *Id.*

330. *Id.*

331. *Id.* at 39-40.

332. *Micheletti v. State Health Benefits Comm'n*, 389 N.J. Super. 510 (2007).

statutory interpretation. The question before the N.J. Supreme Court in *Micheletti* was “whether coverage for medically necessary treatment may be declined to an autistic child as a dependent under the State Health Benefits Program (Program).”³³³ In New Jersey, the State Health Benefits Program is governed by New Jersey statutory law through the State Health Benefits Program Act of 1961.³³⁴ Under the law, authority was given to the State Health Benefits Commission (SHBC) to establish the State Health Benefits Program for the well-being of the State and its employees.³³⁵ The SHBC was also provided with jurisdiction to handle disputes involving benefits under the program.³³⁶ Additionally, SHBC was given the authority to determine when other “eligible medical services” will be granted under the plan beyond basic services already identified.³³⁷ Thus, the SBHC has the authority to exclude or limit coverage for services under the plan as it sees fit.³³⁸ Finally, rulemaking authority is also granted to SBHC to create rules or regulations to apply to those covered by the plans including dependents.³³⁹

Micheletti involved Jake Micheletti, a three year old who was diagnosed with autism.³⁴⁰ After diagnosis, treatment involving speech and occupational therapy were prescribed for Jake and deemed medically necessary.³⁴¹ As a state employee, Jake’s father, Joseph Micheletti, filed for a family coverage plan (New Jersey Plus—“NJPLUS”) as part of the State Health Benefits Program.³⁴² Mr. Micheletti filed claims for coverage for both the speech and occupational therapies for his son Jake pursuant to the NJPLUS.³⁴³ The claim was reviewed by Horizon Blue Cross Blue Shield (“Horizon”), which granted coverage for Jake’s speech therapy but denied coverage for occupational therapy.³⁴⁴ The Horizon Handbook, which set out the policy regarding coverage, provided two exceptions where coverage may be denied: (1) “[t]raining in the activities of daily living. This does not include services directly related to treatment of an illness or injury that resulted in a loss of a previously demonstrated ability to perform those activities.” And (2) “[t]o promote development beyond any

333. *Id.* at 513.

334. N.J. State Health Benefits Program Act, N.J.S.A. 52:14-17.25 (2012).

335. *Micheletti*, 389 N.J. Super. at 513.

336. *Id.*

337. *Id.*

338. *Id.* at 513-14.

339. *Id.* at 514.

340. *Id.*

341. *Id.* at 515.

342. *Id.*

343. *Id.*

344. *Id.*

level of function previously demonstrated.”³⁴⁵

Mr. Micheletti appealed Horizon’s denial of occupational therapy for Jack to which Horizon responded that the denial of occupational therapy was based on the second exception since Jack had not demonstrated the ability to perform at the level occupational therapy attempted to address.³⁴⁶ A petition was then filed with SBHC over the denial of occupational therapy.³⁴⁷ On the basis of this petition, SBHC requested Horizon to review the entire case.³⁴⁸ Horizon returned not only with a reaffirmation of its denial of occupational therapy but went back on its previous decision regarding speech therapy to also deny such treatment.³⁴⁹ The SBHC affirmed both denials of therapies, and the case before the New Jersey Supreme Court was the result of an appeal of the SBHC’s decision.³⁵⁰

The New Jersey Supreme Court began its analysis by explaining the history of New Jersey statutory law regarding coverage of mental health services.³⁵¹ In examining the Mental Health Parity Law and the Insurance Acts of New Jersey, the court noted that the SBHC was not considered to be a “carrier” for the purpose of insurance coverage and therefore, is not subject to those statutes and regulations because of this.³⁵² However, the law passed later, the State Health Benefits Program Act, which governs the State Health Benefits Program and the authority of the SBHC, was required to follow the same definition of “biologically-based mental illness” as the New Jersey Health Parity Law, and would also provide the same extent of coverage.³⁵³ Because SBHC fell outside of the definition for “carrier,” it was given authority to restrict medical services:

Since the State Health Benefits Program is not a carrier, the SHBC, not the DOBI, has the responsibility to administer the Program. As the SHBC points out, its statutory mandate for maintenance of the largely publicly funded Program requires fiscal and administrative restraints in the allocation of limited resources, which may limit or exclude some benefits afforded under private medical health benefit plans.³⁵⁴

In denying coverage for Jake’s therapy, the SBHC argued that it had followed the discretion it is provided statutorily to limit

345. *Id.*

346. *Id.* at 515-16.

347. *Id.*

348. *Id.* at 516.

349. *Id.*

350. *Id.*

351. *Id.*

352. *Id.*

353. *Id.* at 517.

354. *Id.* at 517-18.

or exclude coverage when treatment is considered non-restorative and that such a denial of treatment(s) is therefore, permissible.³⁵⁵ Further, other medical conditions are not given any greater coverage for treatments that are classified as non-restorative, nor is there a contractual obligation for the SBHC to provide a minimum level of coverage for individuals like Jake who are considered as having a biologically-based mental illness.³⁵⁶

Moving forward with analysis, the court recognized that because competing agency views had existed in reaching a decision on Jake's treatment, the matter of interpretation necessary in the case came down to the statutory language on which these determinations were based.³⁵⁷ The court made the following observation regarding the statutory language and interpretation:

In interpreting whether N.J.S.A. 52:14-17.29e mandates the treatment sought for autism, we must consider that the Legislature included identical language in both of the parity statutes, including an identical definition of BBMI specifically identifying autism. Passed within seven months of each other in the same legislative session with the same Senate and Assembly sponsors, the parity statutes have a common purpose, and therefore, should be read in harmony, not in conflict. Furthermore, the statements to the identical Senate and Assembly bills stated that the purpose of the legislation governing the State Health Benefits Program was 'to require that the [SHBC] provide the same coverage for biologically-based mental illnesses to persons covered under [the Program] as required for other health insurers and health maintenance organizations' under the legislation applicable to carriers.

However, the court determined that the SHBC had interpreted the statute too narrowly: "The SHBC's restrictive literal reading conflicts with the legislative intent and purpose of the act."³⁵⁸ The court continued by recognizing that if the SHBC interpreted the N.J. statute as it had, children with autism would be left with no treatment options:

N.J.S.A. 52:14-17.29d specifically denotes autism as a BBMI, and the following subsection of 17.29e seeks to remedy unfairness and inequality in its treatment when compared with coverage for physical conditions or sickness. Yet the SHBC excludes coverage for the only accepted treatment of autism, thereby excluding autism from coverage despite the legislative directive to the contrary in N.J.S.A. 52:14-17.29e. If the SHBC is correct in its reading, the statute would appear to promise much, but it really grants little or nothing for an autistic child. We cannot infer such a cruel intent by

355. *Id.* at 518.

356. *Id.*

357. *Id.* at 518-19.

358. *Id.* at 521.

the Legislature.³⁵⁹

In considering statutory interpretation, the court analyzed the relationship between “the spirit of the law” and a law’s interpretation.³⁶⁰ In this case, the court found that the interpretation was contrary to the law’s “design and purpose” or “spirit” by excluding medically necessary treatment for autistic children.³⁶¹ The court continued by acknowledging that the State was failing to provide adequate coverage through the State Health Benefits Program that should be comparable to the available coverage in the private sector.³⁶² Additionally, the court emphasized that even prior to the passage of the health parity laws, it had been determined that the SHBC had not been given the authority to determine what categories of individuals would be covered (i.e., autism or mental health as a category), but that it was limited to determinations of limitations or exclusions of coverage.³⁶³ The court argued that while the SHBC tried to make an argument based on contractual terms, the SBHC ultimately denied categorical coverage:

In this case the denial of coverage for Jake’s prescribed treatment is couched in terms of the contractual exclusion of benefits for non-restorative speech, physical and occupational therapy, but the medical evaluations of Jake indicate that the therapy is the only treatment modality for an autistic child. Denial of the treatment amounts to exclusion from coverage of a class of dependents, notably afflicted children, based on the nature of their mental illness, which is beyond the limits of the statutory authority of the SHBC.³⁶⁴

Furthermore, the court even articulated that looking at the contractual terms, the legislative intent must be at the forefront of analysis and its role in dictating the extent of coverage:

The SHBC maintains that the medical benefits contract in the Member’s Handbook clearly and unambiguously state that speech and other therapy treatments for development of skills and functions not yet realized are excluded, and, as a result, State employees are bound to its terms. The Program language is not to be read in the same light as a commercial insurance policy as a contract of adhesion, but is to be interpreted and applied with its legislative intent and purpose as well as the reasonable expectation of the State employees for whom it provides medical benefits. In this regard, the insurance market is a guidepost for interpretation of benefits coverage since the Program was established with the intention of putting State employees on an equal footing with those

359. *Id.*

360. *Id.* at 521-22.

361. *Id.* at 522.

362. *Id.*

363. *Id.* at 522-23.

364. *Id.* at 523.

covered by commercial medical benefits policies.³⁶⁵

The court placed heavy emphasis on the relationship between State insurance contracts and commercial insurance contracts, indicating that courts should interpret those contracts similarly. In construing the actual contractual language, the court indicated that interpretations should err on the side of coverage: “As with other insurance contracts, terms of the State benefits contracts excluding or limiting coverage are to be scrutinized with care. If the language supports two interpretations, the one favoring coverage is to be adopted.”³⁶⁶ The court then spent some time analyzing the contractual language for ambiguity specifically with regard to the exclusionary language.³⁶⁷ The court ultimately determined that the denial of insurance coverage for speech and occupational therapy treatments was improper based on the interpretation of the exclusionary language of the contract due to its ambiguity as demonstrated by the inconsistent interpretations of coverage.³⁶⁸ It also found that reliance on the Handbook that failed to provide a definition of “developmental” was futile in light of making determinations of classifying treatment as being “restorative” or “non-restorative” when children are considered to be in a stage of development essentially giving these words no meaning in this context.³⁶⁹ Because an autistic child was at the center of this controversy, the court determined that it was impossible to find that any treatment could be “non-restorative” in the sense that even an autistic child—just as any child—was in a period of development and would, in fact, have some development, even if minimal, rather than none.³⁷⁰ The court articulated that the autistic child does not lose the essence of being a child that is endowed with potential for development:

Autistic children and other children afflicted with BBMI are hindered from achieving that potential. The treatment for Jake can restore some of his potential. Even with the therapies described, Jake’s prognosis is uncertain, but there is no claim that the treatment is futile. To the contrary, there is the expectation that, to some degree, he will share the skills and functions of more fortunate children, including his siblings.³⁷¹

The court also relied on the standard of treatment for autistic children in reaching this decision for occupational and speech therapy for Jake, recognizing such treatments as “traditional.”³⁷²

365. *Id.* at 524 (citation omitted).

366. *Id.* at 525.

367. *Id.*

368. *Id.*

369. *Id.* at 525-26.

370. *Id.*

371. *Id.*

372. *Id.* at 526.

Additionally, the court indicated that for coverage by this State plan to include such treatments for autistic children were not a “waste of resources,” and that the minimal number of autistic children being covered by such plans would not significantly burden the State’s resources.³⁷³ Because the SHBC lacked the authority to deny coverage for autistic children for treatment as dependents, the court reasoned that treatment of occupational and speech therapy for Jake Micheletti was to be reinstated immediately.³⁷⁴

*C. Cases Challenging Coverage Decisions for ABA Therapy
Domestically and Internationally*

1. *Tappert v. Anthem Blue Cross Blue Shield*

There have been several cases that involve legal challenges specifically for what has been deemed a controversial treatment for autism involving children called ABA therapy. In *Tappert v. Anthem Blue Cross Blue Shield*,³⁷⁵ an arbiter ruled that an insurance company was required to provide a child with autism with ABA therapy as a form of treatment even though it ultimately concluded the insurer had not acted in “bad faith” in denying coverage for benefits.³⁷⁶ The arbitration decision highlighted the debate that is discussed later regarding ABA.

First, in determining whether or not to cover the ABA therapy, a determination needed to be made of whether the therapy is considered “medically necessary” by the insurer.³⁷⁷ In this case, a description was provided of how Anthem determined whether something is medically necessary as follows:

Anthem determines if services, procedures, supplies or visits are medically necessary. Only medically necessary services (except as otherwise provided in this certificate), procedures, supplies or visits are covered services. Anthem uses medical policy, medical practice guidelines, professional standards and outside medical peer review to determine medical necessity. Anthem’s medical policy reflects current standards of practice and evaluates medical equipment, treatment and interventions according to an evidence-based review of scientific literature. Medical technology is constantly changing, and Anthem reserves the right to periodically review and update medical policies. Providers and members may go to our website to view a list of services considered medically necessary. The benefits, exclusions and limitations of a member’s coverage take precedence

373. *Id.*

374. *Id.*

375. *Tappert v. Anthem Blue Cross Blue Shield*, JAG Case No. 270779 (Nov. 20, 2007), *available* *at* <http://www.nasddd.org/pdf/ColoradoTappertArbitrationAward.pdf>.

376. *Id.* at 1.

377. *Id.* at 2.

over medical policy.³⁷⁸

The arbitration decision goes on to explain the insurer (Anthem's) definition of "medically necessary."³⁷⁹ It is important to note that an insurer will specify that a physician ordering a particular treatment does not automatically ensure that it will be accepted as medically necessary by the insurer.³⁸⁰ Because of this determination of medical necessity on the part of an insurer, Anthem drafted a policy regarding autism as explained below:

Pursuant to this provision, Anthem promulgated a medical policy on autism. The policy was drafted by a non-physician, using medically accepted and scientifically reliable data bases. The policy was then reviewed by physicians before its adoption and utilization by Anthem. No evidence was presented that the physician reviewers had any experience in the diagnosis and treatment of autism. In fact, the doctors testifying for Anthem on the validity of the policy acknowledged that they had no experience treating autism. See for example, *Kunin v. Benefit Trust*, 910 F.3d 534 (9th Cir. 1990) (failure to consult with expert in autism was abuse of discretion when labeling autism a mental illness instead of an organic disorder).³⁸¹

Based on the evidence presented to the arbiter, a determination was made that the scientific evidence presented demonstrated that ABA was an effective and accepted treatment for autism in children.³⁸² In particular, it was determined that ABA therapy could be considered "medically necessary" in this case because "it controls Abby's self-destructive behaviors and outward aggressions directed towards others."³⁸³

The second part of the analysis was a determination of whether or not ABA therapy is a covered benefit.³⁸⁴ It is in making this coverage determination that often a consideration of how autism is characterized (i.e., whether as a mental illness) may impact any exclusions or limitations on coverage for particular treatments.³⁸⁵ Debate can and will also occur between the insurer and the insured over where the services were provided.³⁸⁶

In this case, the insurer challenged compensating for services it considered outside the physician's office settings based on the

378. *Id.*

379. *Id.*

380. *Id.* at 3.

381. *Id.*

382. *Id.* at 4.

383. *Id.* at 5.

384. *Id.*

385. *See id.* at 9 (discussing classification of the claimant's autism as a congenital or birth abnormality, developmental disorder, or neurological disorder present at birth in order to determine coverage).

386. *See e.g., id.* at 6-7 (debating claimant versus respondent's contentions about where services were provided, and which would accordingly qualify).

insurer's policy.³⁸⁷ However, the arbiter pointed to the ambiguity in the language of the insurer's policy that favors the insured: "At the very least, these two conflicting provisions create an ambiguity, or inconsistency in a policy of insurance and, therefore, the provision should be construed in favor of coverage."³⁸⁸ The arbiter also agreed that ABA therapy could be covered under the insurer's policy that provided for "Other Outpatient Therapy Protections."³⁸⁹ The insurer attempted to argue that the exceptions applied to prevent coverage, but the arbiter sided with the insured based on the language of the policy as contract law governs in this area.³⁹⁰ At one point, the insurer attempted to contradict its own policy regarding its characterization of autism.³⁹¹ In responding to this flippancy, the arbiter favored the insured: "Given Anthem's inconsistent interpretation of its own policy, the Arbiter must construe the policy to extend coverage."³⁹² Finally, the arbiter found that the insurer had not acted in bad faith.³⁹³ Among the many claims by the insured arguing that the insurer had acted in bad faith was a claim that the insurer's policy toward autism provided an improper description of the disability.³⁹⁴ The arbitration decision stated:

The definitions of autism range from a "developmental abnormality," to an "endpoint of several organic etiologies," to a "neurobehavioral disorder," to a "disorder of brain development with a strong genetic base." The Anthem policy impugns the efficacy of ABA treatment because of its association with Lovaas therapy. While it appears that ABA therapy grew out of research that Lovaas did, they appear to be significantly different approaches with widely disparate results. The Arbiter based his decision on medical necessity on a very narrow ground—self harm and harm to others. The Arbiter will not dictate to Anthem what its medical policy should be and, thus, its contractual obligations on ABA and treatment for autism. Multiple other carriers do not cover ABA therapy. Anthem's policy on medical necessity does not constitute bad faith.³⁹⁵

Ultimately, the arbiter ruled in favor of the insured for the ABA therapy.³⁹⁶ In addition to the insight this case gives regarding consideration of ABA therapy, the case also demonstrates a continued theme in litigation that occurred in both

387. *Id.* at 7.

388. *Id.*

389. *Id.* at 8.

390. *Id.* at 7.

391. *Id.* at 9.

392. *Id.* at 10.

393. *Id.* at 11.

394. *Id.* at 13.

395. *Id.* (citation omitted).

396. *Id.* at 14.

*Kunin*³⁹⁷ and *Wheeler*,³⁹⁸ that of construing insurance policies in favor of the insured where ambiguities exist in a contract.³⁹⁹

2. *Auton v. British Columbia*⁴⁰⁰

The U.S. has not been alone in litigating issues regarding the funding of treatment for autistic children. The controversy over funding autism treatment has also appeared in international courtrooms, most notably, a 2004 case that came before the Supreme Court of Canada.⁴⁰¹ In that case, a question of a right to equality was raised on behalf of autistic children and their parents to receive coverage for ABA treatment by the British Columbian government.⁴⁰² The issue succinctly stated by the Court was “whether the Province of British Columbia’s refusal to fund a particular treatment for preschool-aged autistic children violates the right to equality under the *Canadian Charter of Rights and Freedoms*.”⁴⁰³ The Supreme Court of Canada was quick to distinguish this case by indicating that it is not part of the judicial function to determine whether or not the government is to provide coverage for the specific treatment.⁴⁰⁴ Rather, that function is up to the legislature.⁴⁰⁵ Instead, the Court here was making a determination of whether or not denial of coverage amounted to disability discrimination through violation of the *Canadian Charter Equality Clause*.⁴⁰⁶

The Supreme Court of Canada determined that a claim for discrimination on the basis of disability had not been established.⁴⁰⁷ The Court provided two reasons why this claim failed: (1) the petitioners had assumed that both the Canadian Health Act (CHA) and British Columbia legislation provided for the benefits they sought which, in fact, were not guaranteed benefits; and (2) the petitioners had failed to demonstrate children with autism were discriminated against in terms of coverage.⁴⁰⁸

In reviewing the history of the case, the Court provides an overview of ABA therapy and how although it has been advocated as a treatment for autistic children, it has stirred controversy.⁴⁰⁹

397. *Kunin*, 910 F.3d at 539.

398. *Wheeler*, 2003 WL 21789029, at *13.

399. *Tappert*, JAG Case No. 270779, at 7.

400. *Auton (Guardian ad litem of) v. B.C. (Att’y Gen.)*, 2004 CarswellBC 2675 (Can. S.C.C.).

401. *Id.*

402. *Id.* at para. 1.

403. *Id.*

404. *Id.* at para. 2.

405. *Id.*

406. *Id.*

407. *Id.* at para. 3.

408. *Id.*

409. *Id.* at para. 5.

While increasingly accepted, Applied Behavioural Analysis (ABA) or Intensive Behavioural Intervention (IBI) therapy is not uncontroversial. Objections range from its reliance in its early years on crude and arguably painful stimuli, to its goal of changing the child's mind and personality. Indeed one of the interveners in this appeal, herself an autistic person, argues against the therapy.⁴¹⁰

Numerous parents had received funding from Ministry of Children and Families to pay for ABA therapy for their autistic children until the government ended the funding as it pursued researching alternative treatments for autism.⁴¹¹ Parents attempted to persuade three government agencies to provide funding for ABA therapy without success.⁴¹² As a result, they filed a petition in 1995 to try to force the government to provide funding through the judicial system.⁴¹³ The Court listed a number of therapies that had been funded by the Ministry of Children and Families.⁴¹⁴ The Supreme Court of Canada summarized the extent of government funding of ABA treatment as follows:

In a nutshell, at the time of trial the government funded a number of programs for young autistic children, and appeared to be moving toward funding some form of early intervention therapy. However, it had not established funding for intensive, universal ABA/IBI therapy available to all autistic children between the ages of three and six.⁴¹⁵

This international case also demonstrates the unique tension that exists, even currently in the U.S., in determining where services for autistic children should be placed: in the area of health or education. In describing the state of providing treatment for autistic children when the suit was first heard at the trial court level, the Supreme Court of Canada explained how the services for autistic children had transferred between departments from the Ministry of Health to the Ministry of Children and Families, which essentially changed the way treatment for autistic children was viewed.⁴¹⁶ While the Ministry of Health had characterized treatment “medical” terms, the Ministry of Children and Families instead observed treatment as “non-medical.”⁴¹⁷ The trial court only considered the claim in relation to the Ministry of Health and determined that because ABA therapy was a “medically necessary” treatment, the government had engaged in categorical

410. *Id.*

411. *Id.* at para. 6.

412. *Id.*

413. *Id.*

414. *Id.* at para. 7-8.

415. *Id.* at para. 9.

416. *Id.* at para. 10.

417. *Id.*

discrimination by denying this treatment to autistic children.⁴¹⁸ Even though the government maintains decision-making authority for the allocation of resources, this did not remove the government's injustice in denying treatment to autistic children.⁴¹⁹ The trial court did, however, provide the government authority to determine which types of ABA treatment could be covered.⁴²⁰ Agreeing with the trial court, the Court of Appeals also found the government in violation of the Charter pursuant to s. 15 and s. 1.⁴²¹ The Court of Appeals justified the finding by expressing that to deny autistic children the ability to receive this treatment amounts to inequality by deeming their disability "less worthy" than the medical conditions of other individuals.⁴²²

The Supreme Court of Canada, in analyzing this appeal by the government to providing ABA treatment to autistic children, first turned to the language of the Charter regarding equality under section 15(1), which reads: "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."⁴²³ Focusing on the "mental disability" language of this equality provision of the Charter, the Court explained that the analysis used under this provision of the Charter requires two parts: (1) considering "whether there is unequal treatment under the law," and (2) "whether the treatment is discriminatory."⁴²⁴ A later case divided those requirements into three parts.⁴²⁵ In this case, the Court decided to essentially abandon any set test for challenges involving the equality provision of the Charter preferring a case-by-case analysis:

There is no magic in a particular statement of the elements that must be established to prove a claim under s. 15(1). It is the words of the provision that must guide. Different cases will raise different issues. In this case, as will be discussed, an issue arises as to whether the benefit claimed is one provided by the law. The important thing is to ensure that all the requirements of s. 15(1), as they apply to the case at hand, are met.⁴²⁶

The Court went on to emphasize the fluidity of the analysis involving equality: "The Court must look at the reality of the

418. *Id.* at para. 12-13.

419. *Id.* at para. 14.

420. *Id.* at 15.

421. *Id.* at 16.

422. *Id.*

423. *Id.* at 18-19.

424. *Id.* at 20-21.

425. *Id.* at 22.

426. *Id.* at 23.

situation and assess whether there has been discriminatory treatment having regard to the purpose of s. 15(1), which is to prevent the perpetuation of pre-existing disadvantage through unequal treatment.”⁴²⁷ The Court’s first task in that analysis was to consider whether or not unequal treatment occurred due to the denial of a benefit or burden under the law to autistic children.⁴²⁸ “The unequal treatment is said to lie in funding medically required treatments for non-disabled Canadian children or adults with mental illness, while refusing to fund medically required ABA/IBI therapy to autistic children.”⁴²⁹ The Court turned to the procedural history of the case, and they claimed unequal treatment found in both cases of autistic children who were denied “all medically required treatment.”⁴³⁰ In considering such a proposed benefit, the Supreme Court of Canada evaluated whether everyone is entitled to all “medically required treatment.”⁴³¹ The Court recognized that the CHA provided for two distinct categories for providing coverage between core and non-core treatments that result in a lack of all treatment including ABA treatment for autistic children.⁴³² Similarly, the Medicare Protection Act, R.S.B.C. 1996, c. 286 (MPA), only provided “medically required services” when such services were determined to be necessary by certain classes of medical professionals.⁴³³ As the Court stated: “In summary, the legislative scheme does not promise that any Canadian will receive funding for all medically required treatment.”⁴³⁴ Also, legislation failed to provide funding for ABA therapy by failing to include those authorized to recommend the treatment under the provisions of the legislation.⁴³⁵

The Court ultimately determined that because the legislative scheme did not amount to providing for all medically required services, it could not be the case that denying coverage for ABA treatment for autistic children could be discriminatory:

The legislative scheme in the case at bar, namely the CHA and the MPA, does not have as its purpose the meeting of all medical needs. As discussed, its only promise is to provide full funding for core services, defined as physician-delivered services. Beyond this, the provinces may, within their discretion, offer specified non-core services. It is, by its very terms, a partial health plan. It follows that exclusion of particular non-core services cannot without more be viewed as an adverse distinction based on an enumerated ground.

427. *Id.* at 25.

428. *Id.* at 27-29.

429. *Id.* at 30.

430. *Id.*

431. *Id.* at 31.

432. *Id.* at 32-33.

433. *Id.* at 34.

434. *Id.* at 35.

435. *Id.* at 36.

Rather, it is an anticipated feature of the legislative scheme. It follows that one cannot infer from the fact of exclusion of ABA/IBI therapy for autistic children from non-core benefits that this amounts to discrimination. There is no discrimination by effect.⁴³⁶

The Court suggested that the petitioners in this case would have been wiser to have framed their legal claim differently in terms of procedural protection “equal application of the law” for a benefit rather than the funding for particular medical services such as ABA therapy.⁴³⁷ A claim that does not depend on a benefit protected by law is implausible and essentially inadequate according to the court.⁴³⁸

The Court took it one step further by providing what the analysis would be for such a case where there was a recognized legal benefit for ABA therapy as a non-core treatment under the law for autistic children.⁴³⁹ In making such a comparison, the Court determined it would need to compare the denial of ABA therapy as a non-core service for autistic children that is not yet well established to the denial of a similar service to the non-disabled or those disabled but not by mental disability.⁴⁴⁰ The Court determined:

On the evidence adduced here, differential treatment either directly or by effect is not established. There was no evidence of how the Province had responded to requests for new therapies or treatments by non-disabled or otherwise disabled people. We know that it was slow in responding to the demands for ABA/IBI funding for autistic children. But we do not know whether it acted in a similar manner with respect to other new therapies.⁴⁴¹

Although the Court said the government did not necessarily move as swiftly as it should have, the Court, nonetheless, believed that the services the government provided for autistic children were not inadequate enough to amount to discrimination.⁴⁴² While ABA therapy had been acknowledged as the “gold standard,” the government was not required to provide that standard:

The issue, however, is not whether the government met the gold standard of scientific methodology, but whether it denied autistic people benefits it accorded to others in the same situation, save for mental disability. There is no evidence suggesting that the government’s approach to ABA/IBI therapy was different than its approach to other comparable, novel therapies for non-disabled persons or persons with a different type of disability. In the absence

436. *Id.* at 43.

437. *Id.* at 45.

438. *Id.* at 46.

439. *Id.* at 47.

440. *Id.* at 58.

441. *Id.*

442. *Id.* at 62.

of such evidence, a finding of discrimination cannot be sustained.⁴⁴³

Finally, the petitioners raised a claim under Section 7 of the Canadian Charter, which had been denied on previous reviews, which states: “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”⁴⁴⁴ The Court decided the petitioners had not provided enough evidence to raise this claim: “The petitioners do not clearly identify the principle of fundamental justice which they allege to have been breached by the denial of funding for Lovaas or other ABA/IBI-based therapy. Nor do they argue that the denial of funding or the statutory scheme violate the prohibition against arbitrariness or requirements for procedural safeguards.”⁴⁴⁵ *Auton* is certainly valuable and thought-provoking for its discussion of ABA therapy and considering legal challenges based on equality principles for autistic children.

Auton provides an interesting perspective on analyzing the judiciary’s role in making determinations regarding insurance coverage for autistic children. Unlike *Micheletti* in the U.S., the Court in *Auton* was making distinctions between the extent of authority the judiciary has in such cases and the legislature’s role in setting out coverage determinations through law in which the judiciary should not get involved. In *Micheletti*, the court was willing to reinstate some treatments for an autistic child under a state plan, determining that the state authority denying coverage for particular treatments under the state plan had acted improperly. While the U.S. cases described in this Article primarily focused on issues of interpretation of insurance contracts and policies, as well as statutory interpretation, the *Auton* case provides another legal avenue to consider by looking at issues of equality for autistic children and disability discrimination. Finally, both *Auton* and the U.S. cases demonstrate that scientific evidence will always play a significant role in trying to prove the necessity of particular treatments for autistic children, such as ABA therapy, as both countries considered ABA therapy in terms of whether the treatment has been proven to be “medically necessary.” As more children continue to be diagnosed with autism, debates over the role of the judiciary versus the legislature, the understanding of what equality means in terms of treatments for autistic children and their medical care, and what treatments and services constitute those that are “medically necessary” will become even more vital to coverage determinations domestically and abroad.

443. *Id.*

444. *Id.* at 64.

445. *Id.* at 66.

The U.S. has also attempted to develop some way to provide relief for autistic children and their families by creating a mechanism outside the traditional course of litigation through the Vaccine Court as discussed below.

D. Creation of the Vaccine Court

While this Article does not cover the role of vaccines in the autism debate, it is important to acknowledge that a litigation framework has been established in the United States for parents of autistic children who may seek to claim that a vaccine was the cause of a child's autism and that compensation should be granted to them on that basis.⁴⁴⁶ The U.S. Congress enacted the National Childhood Vaccine Injury Act of 1986, which included the National Vaccine Injury Compensation Program ("Vaccine Program"), which went into effect in 1988.⁴⁴⁷ The Office of Special Masters oversees the Vaccine Program through the U.S. Court of Federal Claims.⁴⁴⁸ The U.S. Court of Federal Claims describes the role of the Vaccine Act as follows:

The Vaccine Act became effective October 1, 1988. It establishes the Vaccine Program as a no-fault compensation scheme whereby persons allegedly suffering injury or death as a result of the administration of certain compulsory childhood vaccines may petition the federal government for monetary damages. Congress intended that the Vaccine Program provide individuals a swift, flexible, and less adversarial alternative to the often costly and lengthy civil arena of traditional tort litigation.⁴⁴⁹

Additionally, the U.S. Court of Federal Claims provides guidance on the role of the Office of Special Masters in its adjudicatory function of these vaccine claims.⁴⁵⁰ The U.S. Court of Federal Claims explains the function of the Office of Special Masters and the process involved in vaccine claims:

All vaccine claims are managed and adjudicated by the congressionally-created Office of Special Masters, which currently consists of one chief special master and seven associate special masters who are appointed to serve for four year terms. The Office of Special Masters is established within the U.S. Court of Federal Claims which appoints and removes the special masters and to which the special masters' decisions are appealed. The special master has two primary functions: case management, which involves overseeing the collection of information and setting time

446. U.S. Ct. of Fed. Claims, *Vaccine Program/Office of Special Masters*, USCFC.USCOURTS.GOV, <http://www.uscfc.uscourts.gov/vaccine-programoffice-special-masters> (last visited Oct. 28, 2012).

447. *Id.*

448. *Id.*

449. *Id.*

450. *Id.*

frames for its submission; and decision making, which involves determining the types of proceedings necessary for presenting the relevant evidence and ultimately weighing the evidence in rendering a final, enforceable decision. In each case, the special master actively and frequently interacts with the parties, generally through counsel representing petitioner and a Department of Justice attorney representing the Secretary of Health and Human Services, to ensure that the case progresses effectively and efficiently. The parties are also given several opportunities early on in the case to ask questions, raise concerns, discuss generally how the system works, and, if appropriate, learn the special master's tentative conclusions and findings. Throughout the entire process, the special masters make every effort to balance Congress's vision of streamlined proceedings with the parties' right to a fair opportunity to present their cases. The special masters' rules, orders, and other published communications, such as the special masters' Guidelines for Practice Under the National Vaccine Injury Compensation Program, likewise evoke a philosophy of guidance, cooperative effort, informality, and reasonable speed in presenting and deciding the case.⁴⁵¹

While not all the cases that come before the Vaccine Court involve autism, the statistics show a significant portion of the cases do.⁴⁵² "As of March 1, 2010, 13,330 cases have been filed, 5,617 representing autism cases. Of the total, 7,397 have been adjudicated, with 2,409 being compensated."⁴⁵³ Although this Article does not attempt to provide exhaustive coverage of the cases involving autism that have come through the Office of Special Masters, a few cases deserve mention due to their national prominence in this area.

A 2008 case that went through the vaccine court system involving nine-year-old Hannah Poling gained national attention when the government decided to compensate her family, as many claimed this victory was evidence that the government acknowledged a connection between autism and vaccines.⁴⁵⁴ However, large government players in the autism debates, including the CDC, made statements against making such assumptions.⁴⁵⁵ The two theories offered during the case as to whether or not Hannah was essentially damaged as a result of the vaccinations, were (1) that Hannah had an underlying condition that was aggravated after vaccinations, and (2) that the

451. *Id.*

452. U.S. Ct. of Fed. Claims, *Vaccine Program Background 2* (2010), <http://www.uscfc.uscourts.gov/sites/default/files/vaccine.background.2010.pdf>.

453. *Id.*

454. Gardiner Harris, *Deal in an Autism Case Fuels Debate on Vaccine Case*, N.Y. TIMES (Mar. 8, 2008), <http://www.nytimes.com/2008/03/08/us/08vaccine.html>.

455. *Id.*

vaccinations themselves caused Hannah's disorder.⁴⁵⁶ The court ultimately determined that the vaccinations aggravated an underlying condition.⁴⁵⁷ In covering the case, the New York Times made the following commentary over the Poling case: "The Poling case has become a flashpoint in the long-running controversy over thimerosal, a vaccine preservative containing mercury. Some people believe that thimerosal is behind the rising number of autism diagnoses."⁴⁵⁸ Despite this categorization, it was pointed out that several major governmental entities have dismissed a connection between autism and thimerosal, including the Food and Drug Administration (FDA), the Institute of Medicine (IOM), the World Health Organization (WHO), and the AAP.⁴⁵⁹ "Five major studies have found no link, and since thimerosal's removal from all routinely administered childhood vaccines in 2001, there has been no apparent effect on autism rates."⁴⁶⁰

However, *Poling* was not the last case to gain national attention involving autism and vaccines. In 2010, a set of rulings by the U.S. Court of Federal Claims constituting a set of theories testing the link between autism and vaccines struck a blow to those advocating for the autism-vaccine link.⁴⁶¹ The authority of the Vaccine Court and its role in compensating families for vaccine injuries made its way up to the U.S. Supreme Court in 2010 in the case of *Bruesewitz v. Wyeth LLC*.⁴⁶² In *Bruesewitz*, the Court affirmed the authority of the Vaccine Court under the National Childhood Vaccine Injury Act (NCVIA), which preempts all other claims on the basis of design-defect of a vaccination.⁴⁶³ Despite these recent developments, which advocates of an autism-vaccine link may view as setbacks, cases continue to be brought to the vaccine court and advocates and parents continue to insist on the existence of a link between autism and vaccinations.⁴⁶⁴

456. *Id.*

457. *Id.*

458. *Id.*

459. *Id.*

460. *Id.*

461. *Vaccine Court Finds No Link to Autism*, CNN (Mar. 8, 2012), http://articles.cnn.com/2010-03-12/health/vaccine.court.ruling.autism_1_vaccine-autism-federal-claims?_s=PM:HEALTH; see also U.S. Ct. of Fed. Claims, *The Autism Proceedings* (2010), <http://www.uscfc.uscourts.gov/sites/default/files/autism.background.2010.pdf> (outlining a series of cases testing the theories on the link between autism and vaccines).

462. *Bruesewitz v. Wyeth LLC*, 131 S. Ct. 1068 (2011).

463. *Id.* at 1082.

464. Press Release, PR Newswire, 83 Cases of Autism Associated with Childhood Vaccine Injury Compensated in Federal Vaccine Court (May 10, 2011), <http://www.prnewswire.com/news-releases/83-cases-of-autism-associated-with-childhood-vaccine-injury-compensated-in-federal-vaccine-court-121570673.html>.

E. Final Thoughts on Litigation as a Means of Accessing Treatment for Autism for Children

The success of litigation for securing insurance coverage for treatment for autism has been largely individualized.⁴⁶⁵ The Vaccine Court offers another option, although it has seen similar results to traditional litigation and may or may not have major future implications for autism unless new research and evidence finds new support for an autism-vaccine link. Even when one case was successful against an insurer, the following case could easily be found in favor of the same insurer.⁴⁶⁶

However, one instance of more widespread litigation success did occur in a 2000 case in Minnesota:

One litigation effort in Minnesota, on the other hand, did result in widespread change. In 2000, the Attorney General of Minnesota sued the state's major insurer, BlueCross BlueShield of Minnesota, for failure to cover autism therapies, among other things. The parties settled the lawsuit in a manner that resulted in coverage, including ABA benefits, for individuals with autism of all ages.⁴⁶⁷

Recent news has also suggested that this may not be the end of litigation in cases involving autism and insurance coverage.⁴⁶⁸ A number of military families are joining forces to try to secure coverage for ABA therapy for their children in a suit against the U.S. Department of Defense.⁴⁶⁹

Another contemporary case explores another litigation approach that has to date not been used but remains a volatile option in litigation: class action suits.⁴⁷⁰ A Philadelphia federal judge has ordered class action status on behalf of individuals with autism who were denied insurance coverage for ABA therapy by CIGNA Insurance on the basis of the determination that ABA

465. See *Auton*, 2004 CarswellBC at para. 48 (analyzing claims based on individual petitioner's situation).

466. *Id.*

467. *Id.*

468. Press Release, PR Newswire, Nationwide Class Action Status Is Granted in Case Filed Against CIGNA Insurance for Denying ABA Therapy to Treat Autism (Aug. 15, 2011), <http://www.prnewswire.com/news-releases/nationwide-class-action-status-is-granted-in-case-filed-against-cigna-insurance-for-denying-aba-therapy-to-treat-autism-127739853.html>.

469. Press Release, PR Newswire, Military Families File Lawsuit Against Department of Defense for Refusing to Pay for Applied Behavior Analysis Therapy for Children with Autism (July 6, 2012), <http://www.prnewswire.com/news-releases/military-families-file-lawsuit-against-department-of-defense-for-refusing-to-pay-for-applied-behavior-analysis-therapy-for-children-with-autism-97849624.html>.

470. *Id.*

therapy was “experimental.”⁴⁷¹ However, other relatively new developments suggest the class action suit may very soon become an antiquated legal option or, at least largely minimized, due to latest jurisprudence of the U.S. Supreme Court and other alternatives that have developed from a number of issues facing lawyers in trying to bring class action lawsuits that ultimately favors individual adjudication.⁴⁷² Time will tell if newer developments, including the Vaccine Court and the class action approach, will be successful in providing more individuals with autism the health services they are seeking.

V. LEGISLATING SOLUTIONS TO ACCESS TO HEALTH CARE FOR AUTISTIC CHILDREN

It became clear that while litigation was a mechanism for trying to secure access to health care for an autistic individual, a greater approach was necessary in an attempt to secure coverage more broadly for people with autism as a group.⁴⁷³ Because of this, advocates for individuals with autism began to explore legislative approaches:

Notwithstanding that some early litigation efforts aimed at obtaining insurance coverage in isolated individual cases were successful, for a variety of reasons broad-based coverage remained largely unavailable at the turn of the millennium. Thus, advocates turned to legislative action. Tactically, this approach followed in the path of the civil rights movement of the 1960s. Although civil rights litigators such as Thurgood Marshall obtained several favorable and

471. *Id.*

472. Alexandra D. Lahav, *The Case for “Trial by Formula”*, 90 TEX. L. REV. 571, 572 (2012).

The Supreme Court has consistently favored the liberty of individual adjudication over equality. For example, in his opinion in *Wal-Mart Stores, Inc. v. Dukes* last term, Justice Scalia disparaged the idea of “Trial by Formula” because it does not provide individualized adjudication. In *AT&T Mobility LLC v. Concepcion*, the majority assumed that the baseline of adjudication is individualized suits, leading Justice Breyer to ask, “Where does the majority get its contrary idea—that individual, rather than class, arbitration is a ‘fundamental attribut[e]’ of arbitration?” Similarly, the Court has limited the availability of class actions to resolve mass tort cases in the interest of protecting individual litigants, especially persons whose injuries have not yet manifested. In *Taylor v. Sturgell*, the Court held that individuals cannot be precluded from bringing their own suits even if those suits are completely duplicative and brought by parties who are virtually identical. And in *Martin v. Wilks*, the Court held that individuals who failed to intervene in an earlier employment discrimination suit in which consent decrees were entered could challenge employment decisions made pursuant to those decrees. Each of these decisions stressed the importance of individualized adjudication.

Id.

473. UNUMB & UNUMB, *supra* note 270, at 49-50.

groundbreaking court rulings in the 1950s, effects were not widespread until passage of the major civil rights legislation of the 1960s, such as the Civil Rights Act of 1964 and the Voting Rights Act. Similarly, autism advocates now sought not to merely prevail in individual actions, but to change the entire health care structure related to autism.⁴⁷⁴

There is no doubt that determining the availability of legislative protections for individuals with autism, including children, is complex. The complexity in navigating the availability of these protections is elaborated on as follows:

In any given jurisdiction, numerous local, state, and federal programs touch the lives of affected individuals. This fragmentation not only drives variation in policy but also flows to the organization, financing, and delivery of care. While screening and diagnostic services may be funded by Title XIX of the Social Security Act (Act) under state Medicaid programs and delivered by pediatric or primary medical care practitioners, for example, prevention and early intervention services may be funded by Title V/Maternal and Child Health under the aegis of departments of public health. Other early treatment services may involve funds and programs from departments of mental health and/or developmental disabilities services and by departments of education implementing the Individuals with Disabilities Education Act (IDEA) mandates and child welfare agency services.⁴⁷⁵

In moving into legislation, it is important to recognize that laws exist both federally and at the state level. Because of this, what services are available to children with autism and their families can differ drastically depending on their geographical location. In order to understand the breakdown of legislative approaches currently being used, this Article divides areas of legislation into three primary categories: (1) federal legislation, (2) mixed (legislation that involves cooperation between federal and state government, and (3) state legislation. The federal legislation includes federal mental health parity law, ERISA plans, the Federal Employee Health Benefit Plan (FEHBP) and TRICARE, autism and federal research, and PPACA. The category of legislation involving coordination between the federal government and the state governments includes the IDEA and Medicaid focusing on the availability of Medicaid waivers. Finally, the state legislation explores state mental health parity laws, movement to autism-specific state legislation, and the expansion of autism insurance mandates. While this Article does not attempt to provide an exhaustive list of every legislative approach taken, the following is intended to provide a broad overview and understanding of the current legislative framework that exists at

474. *Id.*

475. Mauch et al., *supra* note 260, at 10.

both the federal and state levels to provide access to health care services for children with autism.

A. Federal Legislation

1. Federal Mental Health Parity

In turning to a legislative approach, the earliest attempts at such legislation categorized autism within the schemes of mental health parity laws.⁴⁷⁶

Parity, as it relates to mental health and substance abuse, prohibits insurers or health care service plans from discriminating between coverage offered for mental illness, serious mental illness, substance abuse, and other physical disorders and diseases. In short, parity requires insurers to provide the same level of benefits for mental illness, serious mental illness or substance abuse as for other physical disorders and diseases. These benefits include visit limits, deductibles, copayments, and lifetime and annual limits.⁴⁷⁷

In 1996, the U.S. federal government passed its own health parity law known as the Mental Health Parity Act of 1996.⁴⁷⁸ The passage of this federal legislation is described as follows:

Like most states, Congress also made efforts to secure appropriate mental health benefits for insured individuals across the country. On September 26, 1996, Congress enacted the Mental Health Parity Act (“MHPA”), which required that annual or lifetime dollar limits on mental health benefits be no lower than any dollar limits for medical and surgical benefits offered by a group health plan or health insurance issuer offering coverage in connection with a group health plan. MHPA requirements applied beginning in 1998 and had an original sunset provision of September 30, 2001. Congress extended the MHPA several times.⁴⁷⁹

It also soon became clear that the MHPA was not as extensive as it could be and it was later supplemented by other federal legislation:

The MHPA offered limited protections. Although insurers had to provide equal annual or lifetime dollar limits for mental health benefits, they could still impose a maximum number of provider visits and caps on the number of days an insurer would cover for inpatient psychiatric hospitalizations. Furthermore, the MHPA did not cover substance abuse or chemical dependency. To address these deficiencies, in 2008, through a rider on the Troubled Asset Relief

476. UNUMB & UNUMB, *supra* note 270, at 50.

477. Nat’l Conference of St. Legislatures, *State Laws Mandating or Regulating Mental Health Benefits*, NCSL.ORG (Dec. 2011), <http://www.ncsl.org/issues-research/health/mental-health-benefits-state-laws-mandating-or-re.aspx>.

478. UNUMB & UNUMB, *supra* note 270, at 265.

479. *Id.*

Program (TARP), Congress enacted the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (Pub. L. 110-343).⁴⁸⁰

Federal mental health parity is never discussed as a significant source for obtaining services for people with autism.⁴⁸¹ While many states developed mental health parity laws (and there have even been recent examples involving coverage for autism), state insurance mandates soon developed in an effort to fill significant gaps in coverage of mental health parity laws. State mental health parity laws and insurance mandates are covered later in this Article under state legislation.

2. ERISA Plans

“The American population receives its health care coverage from a variety of sources. Some people have private health insurance arranged and paid for (perhaps partially) by their employers.”⁴⁸² It is in some health insurance coverage provided by employers that a federal law regulates coverage.⁴⁸³ “The federal law that governs self-funded plans is the Employee Retirement Income Security Act of 1974, commonly known as ERISA. ERISA establishes minimum standards for health, retirement and other welfare benefit plans that are voluntarily established by an employer.”⁴⁸⁴ ERISA covers an array of plans based on the statutory criteria.⁴⁸⁵ Most ERISA plans are self-funded as demonstrated by a 2011 Kaiser Family Foundation report: “Sixty percent of covered workers are in a self-funded plan. The percentage of covered workers who are in a plan that is completely or partially self-funded has increased over time from 49% in 2000 to 54% in 2005.”⁴⁸⁶ When an employer self-funds a plan, meaning that it actually pays for the insurance coverage for its employee, ERISA will be enforced and preempt state law requirements.⁴⁸⁷ The enforcement of ERISA is the responsibility of a federal agency called the Employee Benefits Security Administration (EBSA) that is a part of the U.S. Department of Labor.⁴⁸⁸ There are several

480. *Id.*

481. Nat'l Conference of St. Legislatures, *Autism*, NCSL.ORG (Jan. 2012), <http://www.ncsl.org/issues-research/health/autism-policy-issues-overview.aspx>.

482. UNUMB & UNUMB, *supra* note 270, at 161.

483. *Id.*

484. *Id.*

485. *Health Plans and Benefits: Employee Retirement Income Security Act — ERISA*, U.S. DEPT OF LABOR, <http://www.dol.gov/dol/topic/health-plans/erisa.htm> (last visited Oct. 28, 2012).

486. *Employer Health Benefits 2011 Annual Survey, Section 10: Plan Funding*, KAISER FAMILY FOUND. (Sept. 27, 2011), <http://ehbs.kff.org/?page=charts&id=2&sn=25 &p=1> (citation omitted).

487. UNUMB & UNUMB, *supra* note 270, at 161.

488. *Id.* at 161-62.

limitations on the extent of coverage that ERISA provides: “ERISA does not cover group health plans established by governmental entities, nor does it cover health plans established by churches for their employees, or plans that are maintained solely to comply with applicable workers compensation, unemployment, or disability laws.”⁴⁸⁹

One other thing that it is important to remember about self-insured plans that are outside the realm of state law is that they are not required to follow any state mandates.⁴⁹⁰ Because of this, it is an easy way for employers to avoid covering autism treatment:

Individuals who obtain health coverage through their employer’s self-funded plans do not receive the benefits of state laws that require autism benefits. As such, health insurance coverage for individuals with autism will likely never be universal unless Congress passes an autism insurance mandate. In the meantime, individuals in self-funded plans may choose to litigate coverage claims in an effort to secure autism benefits.⁴⁹¹

Even though exempt from any requirements of state mandates that would offer health services for individuals with autism, self-insured employers needed to change their approach in order to compete with other employers offering benefits for those with autism.⁴⁹² Because of this, many self-insured employers began to offer health benefits that included those with autism:

Some self-funded companies, including governmental entities, voluntarily offer benefits for autism, even if not required to do so by state law. In fact, the presence of a legislatively-mandated benefit within a state often serves as a catalyst for self-funded companies to establish a similar benefit, so as to remain competitive in the workplace with employers who are required to offer benefits. Numerous self-funded companies offer benefits for autism, including coverage for ABA therapy; prominent examples include Microsoft, Home Depot, Time Warner, Children’s Mercy Health Systems, and Ohio State University.⁴⁹³

At the federal level, there have been some attempts to mandate coverage for health benefits but these have been few:

Notwithstanding a significant trend among large, self-funded companies to voluntarily offer autism benefits, health care coverage for autism is unlikely to become universal unless Congress passes an autism mandate. Federally-enacted health benefit mandates are few and far between; they include the Newborns and Mother’s Health Protection Act of 1996, the Women’s Health and Cancer Rights Act, and mental health parity laws. Congress has also

489. *Id.* at 162.

490. *Id.*

491. *Id.*

492. *Id.* at 207.

493. *Id.*

amended ERISA with protections in the Comprehensive Omnibus Budget Reconciliation Act of 1985 (COBRA), which requires continuation of health-care provisions, and the Health Insurance Portability and Accountability Act (HIPAA), which requires certain health care portability in group plans.⁴⁹⁴

While these federal health benefit mandates have not included autism to date, they still suggest that there is the possibility for a federal mandate for autism coverage.

3. *Federal Employee Health Benefit Plan (FEHBP) and TRICARE*

The federal government provides options for insurance coverage benefits plans to federal employees and their family members.⁴⁹⁵ Federal employees and their families may have insurance through the FEHBP.⁴⁹⁶ The FEHBP is overseen by the U.S. Office of Personnel Management.⁴⁹⁷ FEHBP includes insurance coverage options for children of federal employees in the following ways:

Family members eligible for coverage under your Self and Family enrollment are your spouse (including a valid common law marriage) and children under age 26, including legally adopted children, stepchildren, and recognized natural (born out of wedlock) children. Foster children are included if they live with you in a regular parent-child relationship. A child age 26 or over who is incapable of self-support because of a mental or physical disability that existed before age 26 is also an eligible family member. Your employing office will look at the child's relationship to you as the enrollee to determine whether the child is a covered family member. In determining whether the child is a covered family member, your employing office will look at the child's relationship to you as the enrollee.⁴⁹⁸

The extension of insurance coverage for children to age twenty-six under the Federal Health Employees Health Benefit Program occurred through the passage of the PPACA in March 2010.⁴⁹⁹ The Federal Employees Health Benefits Programs Handbook specifies the diseases and conditions under which

494. *Id.*

495. See *Healthcare and Insurance: Quality Benefits for the Federal Family*, U.S. OFFICE OF PERS. MGMT., <http://www.opm.gov/insure/index.aspx> (last visited Nov. 3, 2012) (providing health insurance options for federal employees and their families).

496. *Id.*

497. *Id.*

498. *FEHB Eligibility*, U.S. OFFICE OF PERS. MGMT., <http://www.opm.gov/insure/health/eligibility/index.asp> (last visited Nov. 3, 2012).

499. U.S. Office of Pers. Mgmt., *Federal Benefits: Fast Facts 1*, <http://www.opm.gov/insure/fastfacts/reform.pdf>.

federal employees may be able to continue to claim a child with a disability as an adult past the age of twenty-six.⁵⁰⁰ Although the list of conditions is not exhaustive, it does include “severe autism.”⁵⁰¹ There are various types of plans for coverage of health benefits available through the federal government.⁵⁰² Because of this, it is hard to get a reasonable sense of the extent of coverage for autism and how autism is defined as the plans differ in type and by state.⁵⁰³ However, it is known that ABA therapy is not provided across the board through FEHBP, as a federal bill known as the Autism Acceleration Act of 2009 included a provision under its proposed insurance coverage for ABA therapy in the bill’s House version.⁵⁰⁴

Another major source of providing insurance coverage through the federal government occurs through TRICARE, which is available to members of the military, retired military personnel, and their families.⁵⁰⁵ “More than 23,000 military children have been diagnosed on the autism spectrum.”⁵⁰⁶ TRICARE does offer limited coverage for autism treatments.⁵⁰⁷ The challenges are especially unique for children with autism from military families:

Military families face obstacles that impact the growth and development of an autistic child. Progress made is often lost with the stress of a move. New states mean new laws to learn and new school districts to navigate. With each move, services are identified and sought after, and these children are once again on the bottom of a long waiting list.⁵⁰⁸

500. *Federal Employees Health Benefits Program Handbook*, U.S. OFFICE OF PERS. MGMT., <http://www.opm.gov/insure/health/reference/handbook/fehb30.asp> (last visited Nov. 3, 2012).

501. *Id.*

502. *Types of Plans*, U.S. OFFICE OF PERS. MGMT., <http://www.opm.gov/insure/health/planinfo/types.asp> (last visited Nov. 3, 2012).

503. *Plan Information*, U.S. OFFICE OF PERS. MGMT., <http://www.opm.gov/insure/health/planinfo/index.asp> (last visited Nov. 3, 2012).

504. Autism Treatment Acceleration Act of 2009, S. 819, 111th Cong. (2009), available at <http://www.govtrack.us/congress/bills/111/s819>; Autism Treatment Acceleration Act of 2009, H.R. 2413, 111th Cong. (2009), available at <http://www.govtrack.us/congress/bills/111/s819>.

505. *Welcome TRICARE Beneficiaries!*, TRICARE, <http://www.tricare.mil/> (last visited Nov. 3, 2012).

506. Anne Woods, *Military Parents with Special Needs Kids: Who Makes the Real Sacrifice?*, HUFFINGTON POST (Apr. 13, 2012), http://www.huffingtonpost.com/anne-woods/military-parents-special-needs_b_1420433.html.

507. *Covered Services: Autism Services*, TRICARE, <http://www.tricare.mil/mybenefit/jsp/Medical/IsItCovered.do?kw=Autism+Services&x=22&y=9> (last modified Aug. 30, 2012).

508. Woods, *supra* note 506.

TRICARE coverage is administered through the Extended Care Health Option (ECHO) that provides health benefits for the families of active duty military members.⁵⁰⁹ Under ECHO, health benefits may include special education as well as early intervention through a special program of early intervention for autistic children.⁵¹⁰ The extent of services that may be covered under ECHO include: “[T]raining, rehabilitation, special education, assistive technology devices, institutional care in private nonprofit, public and State institutions and facilities and, if appropriate, transportation to and from such institutions and facilities, and respite care for the primary caregiver of the ECHO-registered beneficiary.”⁵¹¹ Additionally, “the total TRICARE cost share for all ECHO benefits combined, excluding the ECHO Home Health Care (EHHC) benefit, is \$36,000 per fiscal year.”⁵¹² However, TRICARE makes clear that all options for public assistance must first be utilized before coverage begins under ECHO:

Many communities offer public funds or programs for persons with disabilities. You must use these resources first to the extent they are available and adequate for ECHO benefits related to training, rehabilitation, special education, assistive technology devices and institutional care in private nonprofit, public and state institutions/facilities and, if appropriate, transportation to and from such institutions and facilities.⁵¹³

The Enhanced Access to Autism Services Demonstration is available if eligibility requirements⁵¹⁴ are met to provide what TRICARE calls Educational Interventions for Autism Spectrum Disorders, or EIA.⁵¹⁵ TRICARE makes the following statement regarding why early intervention education services are available

509. *Extended Care Health Option*, TRICARE, <http://www.tricare.mil/mybenefit/ProfileFilter.do?purI=%2Fhome%2Foverview%2FSpecialPrograms%2FECHO> (last modified Mar. 10, 2010).

510. *Benefits*, TRICARE, <http://www.tricare.mil/mybenefit/home/overview/SpecialPrograms/ECHO/Benefits?> (last modified Mar. 10, 2010).

511. *Costs and Coverage Limits*, TRICARE, <http://www.tricare.mil/mybenefit/home/overview/SpecialPrograms/ECHO/Costs> (last modified Dec. 30, 2010).

512. *Id.*

513. *Id.*

514. *Autism Services Demonstration*, TRICARE, <http://www.tricare.mil/mybenefit/home/overview/SpecialPrograms/ECHO/AutismServicesDemonstration> (last modified May 22, 2012) (“The demonstration is available to beneficiaries who are [a]ge 18 months and older, [r]egistered in the Extended Care Health Option (ECHO), [and] [d]iagnosed with one of the following: Autistic Disorder (AD), Childhood Disintegrative Disorder (CDD), Asperger’s Syndrome (AS), [or] Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS).”).

515. *Id.*

under its coverage for autism: “[H]ave been shown to reduce or eliminate specific problem behaviors and teach new skills to individuals with autism.”⁵¹⁶ It is also noted that the available EIA services available are “evidence-based.”⁵¹⁷ There are also a number of other requirements for the EIA services.⁵¹⁸ While there is no specific provision listed for ABA therapy, the requirements for EIA services state that coverage for EIA services includes the following: “Implement basic principles of Applied Behavior Analysis and target behaviors associated with the core deficits of ASD.”⁵¹⁹ TRICARE defines Applied Behavior Analysis as follows:

The design, implementation, and evaluation of systematic environmental changes to produce socially significant change in human behavior through skill acquisition and the reduction of problematic behavior. ABA includes direct observation and measurement of behavior and the identification of functional relations between behavior and the environment. Contextual factors; establishing operations, antecedent stimuli, positive reinforcers, and other consequences are used to produce the desired behavior change.⁵²⁰

But many are unaware of the limitations of TRICARE involving ABA therapy. ABA therapy can potentially utilize the entire \$36,000 annual limit for benefits:

Military families receive their medical benefits through Tricare, which is an entitlement, not insurance. Coverage for treatment, such as Applied Behavior Analysis (ABA), is capped at \$3,000 per month. Laws eliminating dollar caps apply to insurance coverage, not entitlements. To date, 30 states have passed laws mandating the coverage of ABA. However, Tricare is a federal entitlement, and not

516. *Id.*

517. *Id.*

518. *Id.*

The demonstration covers EIA services that:

Implement basic principles of Applied Behavior Analysis and target behaviors associated with the core deficits of ASD

Focus on changing the child’s behavior by observing and measuring the behavior in real-life environments

Use scientific behavioral data to identify functional relationships between environmental events and behavior

Gather behavioral data to track progress in reaching behavioral objectives identified in the Behavior Plan and periodically modifies the plan to adapt to the child’s response to the intervention.

Incorporate parent training so family members/caregivers can teach and support skills during typical family activities

Require meetings between family members/caregivers and those designing and implementing the intervention program.

Id.

519. *Id.*

520. *Glossary*, TRICARE, <http://www.tricare.mil/mybenefit/Glossary.do?F=A> (last visited Nov. 3, 2012).

subject to state laws.⁵²¹

The Enhanced Access to Autism Services Demonstration was also only scheduled to be in operation under TRICARE until March 12, 2012.⁵²² It is also important to note that the costs associated to the beneficiary through the Demonstration program for autism are a part of the ECHO benefit, and thus would be capped by the \$36,000 annual limit.⁵²³ Additionally, medically retired military members do not have the availability of treatment for autism: “Those who are medically retired due to their injuries face a larger roadblock. Once retired, the military family is entitled to no services for the treatment of autism.”⁵²⁴

Recalling the earlier section of this Article discussing litigation, one of the recent efforts against TRICARE is a class action lawsuit involving coverage for autism treatments and services is against TRICARE.⁵²⁵ The debate over TRICARE’s classification of ABA therapy as being non-medically necessary echoes the litigation previously discussed in whether or not ABA therapy can and should be considered “medically necessary.”

4. *Change Coming for Federal Health Care and ABA Therapy?*

Health care protections available under ERISA, FEHBP, and TRICARE have all previously signaled the federal government’s skepticism for ABA therapy by its often limited coverage, if coverage exists at all. However, there is new evidence suggesting the federal government has begun to rethink this longstanding policy.⁵²⁶ “In a major shift, the U.S. Office of Personnel Management said that it has determined there is enough evidence behind the use of ABA therapy to deem it a medical rather than an educational service.”⁵²⁷ As the OPM is responsible for oversight of health benefits for federal employees, this change in policy on ABA

521. Woods, *supra* note 506.

522. *Costs and Coverage Limits*, *supra* note 511.

523. *Id.*

524. Woods, *supra* note 506.

525. See Kimberly Johnson, *Military Families Advance Lawsuit to Force DOD to Provide Autism Care*, CARE.COM (May 26, 2011), <http://www.care.com/child-care-military-families-advance-lawsuit-to-force-dod-to-provide-autism-care-p1017-q6593033.html> (discussing the administration of military medical benefits, including a pending lawsuit against TRICARE for issues about coverage).

526. Diament, *supra* note 228 (quoting Peter Bell, Executive Vice President for programs and services at Autism Speaks, stating, “The OPM decision directly contradicts a long-standing insurance industry claim that ABA therapy is not ‘medical,’ but rather ‘educational’—provided by the schools at taxpayer expense. Now, tens of thousands of families will have better access to more affordable, critical ABA treatment”).

527. *Id.*

therapy is seen by disability advocates as monumental.⁵²⁸ As the U.S. government serves as the nation's largest employer, it is believed that this policy change that goes into effect in 2013 to allow federal government health plans to offer ABA therapy may create a significant policy shift that will encourage greater health care coverage for ABA therapy for health care plans outside of the federal government. Such a policy shift by the federal government to view ABA therapy as a medical treatment as opposed to a non-medical or educational treatment may assist in ushering a nationwide movement toward greater coverage for ABA therapy.

5. *Autism and Federal Research*

Perhaps the greatest way that federal legislation has attempted to assist individuals with autism has come through research initiatives.⁵²⁹ The first major federal legislation to include research initiatives involving autism was the Children's Health Act of 2000.⁵³⁰

The 2000 Children's Health Act established the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC) and authorized the establishment of Centers of Excellence at both CDC and the National Institutes of Health (NIH) to promote research and monitoring efforts related to the causes, diagnosis, early detection, prevention, and treatment of autism.⁵³¹

The Children's Health Act was also instrumental in establishing a committee to be known as the Interagency Autism Coordinating Committee (IACC) under section 104.⁵³² In 2006, monumental developments were made at the federal level when President George W. Bush signed the Combating Autism Act into law.⁵³³ The Combating Autism Act was designed to inject substantial federal funding into autism research, prevention,

528. *Id.*

529. Nat'l Conference of St. Legislatures, *supra* note 477.

530. Children's Health Act of 2000, Pub. L. No. 106-310, 114 Stat. 1101 (2000), available at <http://www.gpo.gov/fdsys/pkg/PLAW-106publ310/pdf/PLAW-106publ310.pdf>.

531. *Id.*

532. U.S. Dep't of Health & Human Servs., *Report to Congress on Autism Activities Under the Children's Health Act of 2000 (Fiscal Year 2005)*, <http://iacc.hhs.gov/reports/reports-to-congress/FY2005.shtml> (last visited Nov. 3, 2012).

533. Combating Autism Act of 2006, Pub. L. No. 109-416, 120 Stat. 2821 (2006), available at <http://www.gpo.gov/fdsys/pkg/PLAW-109publ416/pdf/PLAW-109publ416.pdf>; see also Fact Sheet: Combatting Autism Act of 2006, WHITE HOUSE: PRESIDENT GEORGE W. BUSH (Oct. 19, 2012), <http://georgewbush-whitehouse.archives.gov/news/releases/2006/12/20061219-3.html> (describing the expansion in autism research, prevention, and treatment authorized by the Act).

treatment, and education through 2011.⁵³⁴ Another important component of the Combating Autism Act was the continuance of IACC and its role in directing the federal government's activities regarding autism.⁵³⁵ Under the Combating Autism Act, the IACC is charged with the responsibility of creating a strategic plan annually for autism research:

The Plan provides a blueprint for autism research that is advisory to the Department of Health and Human Services and serves as a basis for partnerships with other agencies and private organizations involved in autism research and services. Under the Combating Autism Act of 2006 it must be updated on an annual basis. To this end, the 2011 Plan has been updated by the IACC to reflect important new scientific advances in the field over the past year, emerging areas of opportunity, and areas where more research is necessary. Input from the ASD community, advocacy groups, research funding organizations, and the scientific community has continued to be a critical aspect of the updating process.⁵³⁶

According to the IACC, the 2011 Plan has the following implications:

The 2011 Plan includes an additional 16 objectives and newly developed addendum sections for each chapter describing what has recently been learned, what gap areas have emerged, and what progress is being made in fulfilling the objectives. The Committee has identified several important new areas of focus, including the need for additional research on the use of alternative and augmentative communication (AAC) to facilitate communication for nonverbal individuals with ASD. The Committee recognized the need for more research to determine which types of AAC are most effective for particular subpopulations and how best to improve access. In addition, the 2011 Plan now calls for studies focusing on health promotion and the prevention of secondary conditions in people with ASD such as injury, obesity, and other co-occurring medical and psychiatric conditions. Also included is a new focus on understanding potential biological causes of wandering/elopement behavior, an issue that was brought to the Committee's attention through compelling public testimony at an IACC meeting in 2010. Throughout the year, the Committee heard and discussed reports of people with ASD being at increased risk for injury or premature death, and recognizing the urgent need to fully understand the reasons for this and how it can be prevented, added a new objective to the Plan exploring a range of issues related to safety and

534. *Id.*

535. *About IACC*, U.S. DEPT OF HEALTH & HUMAN SERVS., <http://iacc.hhs.gov/about/> (last visited Nov. 3, 2012).

536. *The 2011 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research – January 18, 2011*, U.S. DEPT OF HEALTH & HUMAN SERVS., <http://iacc.hhs.gov/strategic-plan/2011/index.shtml> (last visited Nov. 3, 2012).

mortality for people on the spectrum.⁵³⁷

As the Combating Autism Act of 2006 would run out in 2011, debate over the reauthorization of the Act occurred.⁵³⁸ However, on September 30, 2011, President Barack Obama reauthorized the Combating Autism Reauthorization Act (CARA).⁵³⁹ While the majority of tasks delegated to the IACC have remained the same under the CARA, the Act does provide a new change to the composition of membership to the IACC that will begin to include “public membership”:

Nominations for public members to serve on the IACC under CARA are currently being accepted. Those eligible for nomination include leaders or representatives of major autism spectrum disorder (ASD) research, advocacy and service organizations, parents or guardians of individuals with ASD, individuals on the autism spectrum, providers, educators, researchers and other individuals with professional or personal experience with ASD. Nominations of new public members are encouraged, but current members may also be re-nominated to continue to serve.⁵⁴⁰

The IACC is authorized through the Combating Autism Reauthorization Act of 2011.⁵⁴¹ The future of federal autism research may be highly dependent on the final outcomes of the DSM’s changes to the definition of autism.

537. *Id.*

538. See Jordan E. Otero, *Standoff Threatens Autism Research Funding: GOP Senators Object to Limits*, WASH. TIMES (Sept. 21, 2011), <http://www.washingtontimes.com/news/2011/sep/21/standoff-threatens-autism-research-funding/?page=all> (discussing the debate over whether Congress should dictate how research should spend federal funds); see also *Press Room: Dr. Coburn Speaking on the Objection to the Combating Autism Reauthorization Act, Requesting Waste & Duplication Be Addressed*, TOM COBURN, M.D. (Oct. 19, 2012), http://www.coburn.senate.gov/public/index.cfm/floorstatements?ContentRecord_id=ab78a023-5629-41c7-a128-f752f17d6627&ContentType_id=471b9448-fc4b-4070-8bea-982855edf000&Group_id=67474547-0768-4e95-8562-83add78d80a7 (opposing the notion of telling researchers what they must research).

539. Combating Autism Reauthorization Act of 2011, Pub. L. No. 112-32, 125 Stat. 361 (2011), available at <http://www.gpo.gov/fdsys/pkg/PLAW-112publ32/pdf/PLAW-112publ32.pdf>; see also U.S. Dep’t of Health & Human Servs., *Interagency Autism Coordinating Committee to Continue into 2014; HHS Seeks Nominations for Public Membership*, IACC.HHS.GOV (Oct. 28, 2011), http://iacc.hhs.gov/news/news_updates/2011/news_2011_iacc_call_for_nominations.shtml (asserting that the Act ensured that all federal autism research and services would continue without disruption).

540. U.S. Dep’t of Health & Human Servs., *supra* note 539.

541. *Id.*

6. *What Does Federal Health Care Reform Mean for Individuals with Autism?*

a. PPACA Coverage for Autism

Recent legislative action through the PPACA⁵⁴² and a pending federal bill specific to providing services for individuals with autism (discussed later in legislative solutions) demonstrate the inadequacies of the current federal options. The involvement of the federal government in helping individuals with autism to secure access to health care coverage was a campaign promise of Barack Obama: “President Obama even made a campaign pledge during the 2008 election that he would support a federal mandate requiring coverage of autism treatments.”⁵⁴³ The passage of the PPACA was considered a landmark in federal health care reform:

In March 2010, Congress passed the Patient Protection and Affordable Care Act, P.L. 111-148 (HR 3590), and shortly thereafter the Health Care and Education Reconciliation Act of 2010, P.L. 111-152 (HR 4872). Together, these acts became known as the “Affordable Care Act” and represented a major overhaul of the health insurance system in America.⁵⁴⁴

Despite the extensiveness of this sweeping legislative reform for health care, PPACA does not include any reference to “autism.”⁵⁴⁵ Because of this, the question remains as to what PPACA means for insurance coverage for individuals with autism.⁵⁴⁶ Generally there remains many questions as to the extent of the coverage of autism treatment.⁵⁴⁷ During April 2011, as part of National Autism Awareness Month, HHS Secretary Kathleen Sebelius addressed the issue of coverage under PPACA involving children with autism:

The Affordable Care Act, the health care law signed a year ago by President Obama, will help ease the financial burden that often comes with treating and caring for people with ASD. The law requires new plans to cover autism screening and developmental assessments for children at no cost to parents, and allows parents to keep their children on their family health insurance until they turn

542. Patient Protection and Affordable Care Act, H.R. 3590, 111th Cong. (2009), *available at* http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111_cong_bills&docid=f:h3590enr.txt.pdf.

543. *Health Care Reform: What Does It Mean for the Autism Community?*, AUTISM SPEAKS OFFICIAL BLOG (Mar. 23, 2010), <http://blog.autismspeaks.org/2010/03/23/health-care-reform/>.

544. UNUMB & UNUMB, *supra* note 270, at 280.

545. *Id.* at 285.

546. *Id.*

547. *Mandate Insurance Coverage of Autism Treatment*, TAMPA BAY TIMES, <http://www.politifact.com/truth-o-meter/promises/obameter/promise/80/mandate-insurance-coverage-of-autism-treatment/>.

26. Insurers will also no longer be allowed to deny children coverage for a pre-existing condition such as ASD or to set arbitrary lifetime or annual limits on benefits.⁵⁴⁸

But it has been known since PPACA's passage that it is not going to cover all health plans for individuals with autism, leaving open the possibility that many autistic individuals will not have access to the services they need:

While the new health care reform law will extend autism insurance reform to some families, not all insurance plans will be required to cover behavioral health treatment. That's because only certain types of health plans will be required, beginning in 2014, to cover the list of essential benefits, including behavioral health treatment. The types of plans included under this provision are: (1) plans offered by state-based exchanges, through which individuals and businesses can purchase coverage; and (2) plans offered in the individual and small group markets outside the exchange. Existing coverage, plans offered in the large group market outside exchanges, and self-insured plans (plans under which an employer assumes direct financial responsibility for the costs of enrollees' medical claims, or sometimes referred to as "ERISA plans") will not be required to provide the essential benefits package. This last exception is especially significant because 57% of workers who are currently covered by their employers' health benefits are enrolled in a plan self-insured by the employer.⁵⁴⁹

Even with the plans that will be covered, defining "essential health benefits" is going to be a critical moment for people with autism as the Department of Health and Human Services (HHS) is charged with the responsibility of putting forward the definition of this term.⁵⁵⁰ "To ensure a more consistent level of benefits, the ACA requires that certain insurance plans—including those participating in the state purchasing exchanges—cover a package of diagnostic, preventive, and therapeutic services and products that have been defined as 'essential' by the Department of Health

548. News Release, *Statement by Secretary Sebelius on National Autism Awareness Month*, <http://www.autism-society.org/news/president-and-secretary.html> (released Apr. 1, 2011).

549. *Health Care Reform: What Does It Mean for the Autism Community?*, *supra* note 543; see also Kathleen Sebelius, *Meeting the Needs of People with Autism*, WHITE HOUSE BLOG (Apr. 25, 2011, 12:27 PM), <http://www.whitehouse.gov/blog/2011/04/25/meeting-needs-people-autism> (asserting that the Affordable Care Act provided greater assistance for those with autism by requiring new insurance plans to cover autism screenings and developmental assessments and allowing young adults to remain on their family health insurance under age twenty-six).

550. News Release, *Statement by HHS Secretary Kathleen Sebelius Regarding Selected Medical Benefits: A Report from the Department of Labor to the Department of Health and Human Services*, <http://www.hhs.gov/news/press/2011pres/04/20110415b.html> (released Apr. 15, 2011).

and Human Services (HHS).⁵⁵¹ “Essential health benefits” refers to

a set of essential health benefits (EHB)—constitutes a minimum set of benefits that the plans must cover, but insurers may offer additional benefits. The ACA requires that the EHB include at least 10 general categories of health services, and have benefits similar to those currently provided by a typical employer.⁵⁵²

What is often not as talked about in the government’s role of creating regulations is that there are many advocates for conditions, diseases, etc.—including autism—that will be trying to get the federal government’s attention as worthy of coverage.⁵⁵³ In making the determination of what constitutes “essential health benefits,” HHS has sought the help of the IOM⁵⁵⁴ in making this determination.⁵⁵⁵ The IOM was expected to conclude its recommendation regarding “essential health benefits” by September 2011.⁵⁵⁶ The official report on “essential health benefits” was released by IOM on October 6, 2011.⁵⁵⁷ It is important to understand the distinction that was made in IOM’s role in defining “essential health benefits”: “The task of the IOM was not to decide what is covered in the EHB, but rather to propose a set of criteria and methods that should be used in deciding what benefits are most important for coverage.”⁵⁵⁸ The IOM’s role was to assist the federal government in two ways: “1) define the benefits that should be in the EHB, and 2) update the benefits to take into account advances in science, gaps in access, and the impact of any benefit changes on cost.”⁵⁵⁹ According to the

551. *Essential Health Benefits: Balancing Coverage and Cost*, INST. OF MED. OF THE NAT’L ACAD., <http://www.iom.edu/Reports/2011/Essential-Health-Benefits-Balancing-Coverage-and-Cost.aspx> (last visited Nov. 3, 2012).

552. *Id.*

553. Julie Appleby, *Obama Administration’s Balancing Act: Health Insurance Benefits vs. Costs*, KAISER HEALTH NEWS (Jan. 11, 2011), <http://www.kaiserhealthnews.org/Stories/2011/January/10/health-insurance-benefits-package-iom.aspx>; see also Shawn Tully, *How Rich Health Care Mandates Could Bust the Budget*, CNN MONEY (May 4, 2011), <http://finance.fortune.cnn.com/2011/05/04/how-rich-health-care-mandates-could-bust-the-budget/>.

554. *About the IOM*, INST. OF MED. OF THE NAT’L ACADS., <http://www.iom.edu/About-IOM.aspx#> (last visited Nov. 3, 2012).

555. News Release, *supra* note 550; see also *Project Information*, NAT’L ACADS., <http://www8.nationalacademies.org/cp/projectview.aspx?key=IOM-HCS-10-04> (last visited Nov. 3, 2012).

556. *Mandate Insurance Coverage of Autism Treatment*, *supra* note 547.

557. *Id.*

558. *Essential Health Benefits: Balancing Coverage and Cost*, *supra* note 551.

559. INST. OF MED. OF THE NAT’L ACADS., *ESSENTIAL HEALTH BENEFITS: BALANCING COVERAGE AND COST 1* (Oct. 2011), available at <http://www.iom.edu/~media/Files/Report%20Files/2011/Essential-Health->

IOM:

The committee recognized that the benefits included in the EHB must be sufficiently inclusive to enable access to essential services but must also be affordable so that as many as possible can purchase the coverage. The committee saw its primary task as finding the right balance between making a breadth of coverage available for individuals at a cost they could afford. This balance will help ensure that an estimated 68 million people have access to care covered by the EHB.⁵⁶⁰

IOM came to the following conclusion regarding its recommendation for strategically how the EHB package would be determined:

One way to think about the EHB package is to compare HHS's task to going grocery shopping. One option is to go shopping, fill up your cart with the groceries you want, and then find out what it costs. The other option is to walk into store with a firm idea of what you can spend and to fill the cart carefully, with only enough food to fit within your budget. The committee recommends that HHS take the latter approach to developing the EHB package and to keep in mind what small employers and their employees can afford. Employers who offer insurance packages make such choices now.⁵⁶¹

The committee recommended that HHS consider the following in creating strategies for the EHB packages: “consider the population’s health needs as a whole,” “encourage better care by ensuring good science,” “emphasize the judicious use of resources,” and “carefully use economic tools to improve value and performance is used to inform coverage decisions.”⁵⁶² The IOM report acknowledged that PPACA requires, at the minimum, the following ten categories of included services for EHB plans: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; pediatric services, including oral and vision care.⁵⁶³ The IOM committee noted in this report that despite the existence of current state insurance mandates, those mandates should not result in automatically guaranteeing services as part of EHB plans in light of the new guidance being provided in this

Benefits-Balancing-Coverage-and-Cost/essentialhealthbenefitsreportbrief4.pdf.

560. *Essential Health Benefits: Balancing Coverage and Cost*, *supra* note 551.

561. INST. OF MED. OF THE NAT'L ACADS., *supra* note 559, at 2.

562. *Id.*

563. *Id.*

area.⁵⁶⁴ This could be seen as a major blow to state insurance mandates that have been created for insurance coverage for autism that is discussed in greater detail in a later section.

The IOM also emphasized the importance of “public involvement” in determinations of EHB by HHS.⁵⁶⁵ According to IOM: “As envisioned by the committee, the public deliberation process would enable individuals—working in small group meetings around the country—to participate in a prioritization process, where different elements of coverage-specific services, types of cost-sharing, degree of provider choice, approval requirements, etc.—are discussed and debated.”⁵⁶⁶

Additionally, IOM recognized the importance of involving all parties in the improvement of health care. Specifically, IOM recommended that determinations of “medically necessary” services be made on a case-by-case basis: “Only medically necessary services should be covered, and decisions by insurers about what is ‘medically necessary’ should depend on the circumstances of an individual case. Under the ACA, when patients are denied care by their insurer, they have the right to appeal to an external review by experts.”⁵⁶⁷

The IOM report also supports flexibility in creating EHBs to promote state innovations. IOM stated: “Proposed state-specific variations should be consistent with the ACA statute, abide by the selection criteria in this report, produce a benefits package that is equivalent in value to the EHB, and utilize meaningful public input.”⁵⁶⁸

Finally, the IOM makes recommendations to HHS regarding the actual process of updating EHBs.⁵⁶⁹ “HHS should update the EHB package annually, beginning in 2016, to promote better health outcomes for both individuals and the broader population.”⁵⁷⁰ IOM also indicated that the EHB packages must be on the basis of “credible evidence” for effectiveness, and that a National Benefits Advisory Council should be established to assist in this continual process.⁵⁷¹

Since the IOM recommendation to HHS regarding the definition of “essential health benefits,” the HHS released an information bulletin on essential health: benefits on December 16, 2011.⁵⁷² According to HHS: “This bulletin describes a

564. *Id.*

565. *Id.*

566. *Id.*

567. *Id.* at 3.

568. *Id.*

569. *Id.*

570. *Id.*

571. *Id.*

572. U.S. Dep’t of Health & Human Servs., *Essential Health Benefits: HHS Informational Bulletin*, HEALTHCARE.GOV (Dec. 16, 2011),

comprehensive, affordable and flexible proposal and informs the public about the approach that HHS intends to pursue in rulemaking to define essential health benefits.”⁵⁷³ It is important to understand the difference between the release of a bulletin and an actual proposed regulation:

Rather than issue a proposed regulation, the administration chose to advise the states through a bulletin. That does not have the force of law, but neither can it be quashed by Congress, as could a rule. By putting out the choices as a form of guidance, the administration also does not have to provide definitive economic estimates of the proposal or determine its regulatory impact on small businesses.⁵⁷⁴

The bulletin also indicates that HHS has pursued those policies in order to provide greater flexibility to states.⁵⁷⁵ Additionally, HHS explained that this guidance was designed to allow for planning for implementation of those policies: “HHS is releasing this intended approach to give consumers, states, employers and issuers timely information as they work towards establishing Affordable Insurance Exchanges and making decisions for 2014.”⁵⁷⁶ Like the IOM report, HHS listed the same ten categories for essential health benefits.⁵⁷⁷ Rather than providing any more specific meaning to these categories in terms of national guidance, HHS instead leaves it to the states to make such determinations:

HHS intends to propose that essential health benefits are defined using a benchmark approach. Under the department’s intended approach announced today, states would have the flexibility to select a benchmark plan that reflects the scope of services offered by a “typical employer plan.” This approach would give states the flexibility to select a plan that would best meet the needs of their citizens.⁵⁷⁸

States would then have the ability to make decisions regarding essential health benefits within their selected benchmark: “The benefits and services included in the benchmark health insurance plan selected by the state would be the essential health benefits package. Plans could modify coverage within a benefit category so long as they do not reduce the value of

<http://www.healthcare.gov/news/factsheets/2011/12/essential-health-benefits12162011a.html> (last updated Feb. 24, 2012).

573. *Id.*

574. Julie Appleby, *HHS Gives States Flexibility on Health Law’s ‘Essential Benefits’*, KAISER HEALTH NEWS (Dec. 16, 2011), <http://www.kaiserhealthnews.org/Stories/2011/December/16/essential-benefits-guidance.aspx>.

575. U.S. Dep’t of Health & Human Servs., *supra* note 572.

576. *Id.*

577. *Id.*

578. *Id.*

coverage.”⁵⁷⁹ HHS also indicated that states that opted for certain benchmark plans that did not include all ten categories would have other guidance for essential health benefits:

If a state selects a benchmark plan that does not cover all 10 categories of care, the state will have the option to examine other insurance plans, including the Federal Employee Health Benefits Plan, to determine the type of benefits that must be included in the essential health benefits package.⁵⁸⁰

However, the strategy of such plans is to prevent unnecessary spending of federal money on state mandates:

To prevent federal dollars going to state benefit mandates, the health reform law requires states to defray the cost of benefits required by state law in excess of essential health benefits for individuals enrolled in any plan offered through an Exchange. However, as a transition in 2014 and 2015, some of the benchmark options will include health plans in the state’s small group market and state employee health benefit plans.⁵⁸¹

Despite this strong language suggesting state mandates may be in danger under the new HHS guidance, HHS offers that state mandate coverage will not be lost if states opt for particular benchmark plans:

These benchmarks are generally regulated by the state and would be subject to state mandates applicable to the small group market. Thus, those mandates would be included in the state essential health benefits package if the state elected one of the three largest small group plans in that state as its benchmark.⁵⁸²

One of the major points of emphasis in the bulletin is the flexibility this strategy creates for states.⁵⁸³ In order to succeed in providing EHB packages, HHS offered the following guidance to states: “To meet the EHB coverage standard, HHS intends to require that a health plan offer benefits that are ‘substantially equal’ to the benchmark plan selected by the state and modified as necessary to reflect the 10 coverage categories.”⁵⁸⁴ According to HHS, flexibility will ultimately benefit the consumer by creating options for health care services: “Permitting flexibility will provide greater choice to consumers, promoting plan innovation through coverage and design options, while ensuring that plans providing EHBs offer a certain level of benefits.”⁵⁸⁵

579. *Id.*

580. *Id.*

581. *Id.*

582. *Id.*

583. *Id.*

584. *Id.*

585. *Id.*

Finally, the HHS bulletin offers plans for the future of this strategy:

The department intends to propose that benchmarks will be updated in the future, and that state mandates outside the definition of essential health benefits may not be included in future years. The Bulletin also notes that updating the benchmark will allow benefits to reflect the most up-to-date medical and market practices.⁵⁸⁶

“HHS also conducted a series of listening sessions to collect public comments.”⁵⁸⁷ While this is not the final rule promulgated by HHS on essential health benefits, it sets the stage for what can be expected for the final rule that has no set date for determination.⁵⁸⁸

The HHS bulletin pre-rule is not seen by all as a positive approach as the federal government has, in the eyes of many, avoided defining a critical part of PPACA:

Defining “essential health benefits” is among the most important steps in implementing the Affordable Care Act. The law lists 10 broad categories of benefits that every plan sold to individuals and small businesses will have to cover, beginning in 2014. It leaves the specifics of that mandate to HHS. And HHS said it intends to pass the job down to states.⁵⁸⁹

The debate over essential health benefits was surely one that it was hoped the federal government would step in to provide national standards for and resolve the issue:

Essential benefits, which must be offered by insurers in most policies sold to individuals and small businesses, are one of the key flash points in the federal health law. Patient advocates have called for a broad national standard covering a wide range of treatments, while business groups have said affordability must be a top consideration, even if it means a more limited package.⁵⁹⁰

According to the Kaiser Family Foundation, states will now have to wrestle with such difficult decisions of essential health benefits:

States need to develop the essential benefit packages as part of their work to establish online insurance marketplaces, called exchanges, set to open in 2014. In addition, states need to know the scope of the

586. *Id.*

587. *Id.*

588. Appleby, *supra* note 574.

589. Sam Baker, *HHS Defers to States, Will Let Them Decide Which Benefits Health Plans Must Cover*, THE HILL'S HEALTHCARE BLOG (Dec. 16, 2011, 2:29 PM), <http://thehill.com/blogs/healthwatch/health-reform-implementation/199981-hhs-will-defer-to-states-on-mandates-for-health-benefits>.

590. Appleby, *supra* note 574.

coverage because they must pay the cost of any medical services their laws mandate that go beyond the essential benefits called for in the federal law. That provision has led advocates to fear that state-mandated services such as autism treatments, acupuncture or chiropractic care, might be rolled back in some states.⁵⁹¹

“The guidance may well please states, which wanted maximum flexibility, but it disappointed some patient advocates. And it continues the uncertainty faced by insurers, consumers and employers over exactly what will be covered in the essential benefit package.”⁵⁹² The big question the HHS guidance on essential health benefits raises for autism is what it means for certain behavioral health treatments, in particular, ABA therapy. As is discussed later, not all state mandates for insurance coverage related to autism include behavioral health treatment. Even those that do are not necessarily including ABA therapy. Will the behavior health treatments being utilized for children with autism be covered under this new formula?

It has been no secret that autism advocates are heavily pursuing the inclusion of autism treatment in “essential health benefits.”⁵⁹³ Of particular concern for people with autism is whether or not “behavioral health” will be included in “essential benefits” to provide coverage for treatment of autism.⁵⁹⁴ Because the IOM report really does not offer any concrete definition for EHB, there is no guarantee the services those with autism are seeking will be covered. This is especially true as even state mandates are viewed by the recommendation as not an automatic guarantee of services and that all services are subjected to scrutiny. It is also critical that the IOM’s recommendations suggest an individualized approach to determining “medically necessary” services that has been a hot area of debate concerning behavioral health treatments for autism, as shown through the cases litigated for such treatments.

Another component of PPACA that will impact the health care of individuals with autism is the elimination of annual and lifetime caps that will also be phased in.⁵⁹⁵ Several other benefits

591. *Id.*

592. *Id.*

593. See, e.g., Stuart Spielman, *Autism and the Determination of Essential Health Benefits*, AUTISM SPEAKS (Jan. 14, 2011), <http://www.iom.edu/~media/Files/Activity%20Files/HealthServices/EssentialHealthBenefits/2011-JAN-12/1235%201%20Spielman.pdf>.

594. Alex Wayne, *Chiropractic, Autism Care May Be Essential Under Obama Law*, BLOOMBERG NEWS (Oct. 22, 2010), <http://www.moneynews.com/Headline/Chiropractic-Autism-Care-Essential/2010/10/22/id/374611>.

595. Ass’n of Univ. Ctrs. On Disabilities, *Federal Legislative Activity Related to Autism* 3 (Sept. 27, 2010), <http://autismlawcenter.com/wp-content/uploads/2010/09/AUCD-Legislative-Update.pdf>.

provided by the Act include training to medical professionals on disabilities and programs designed to provide better medical care for the disabled by focusing on data collection on disability disparities and prevention programming.⁵⁹⁶

b. U.S. Supreme Court Upholds Federal Health Care Reform

On June 28, 2012, the U.S. Supreme Court upheld the constitutionality of PPACA signaling a victory to many for the benefits of federal health care reform.⁵⁹⁷ Even after the initial passage of federal health care reform, there has been skepticism over the extent of assistance provided to individuals with autism and their families:

While passage of health care reform will bring some relief to families caring for a child with autism, there is still much work to be done in state legislatures and in Congress to make effective health care coverage a reality for the autism community and to bring about an end to discrimination of individuals with autism by the insurance industry.⁵⁹⁸

Despite the ruling of the U.S. Supreme Court upholding the constitutionality of the PPACA, challenges may still exist to the Act's movement due to congressional action to try to repeal the Act and the implementation of the Act that must now occur. A number of disability organizations have released statements since the U.S. Supreme Court's upholding of the PPACA again suggesting that the autism population will need more than federal health care reform. Perhaps one of the most well-known yet controversial organizations advocating for those with autism, Autism Speaks, responded with praise for upholding the PPACA, yet voiced concern that the law's implementation could still be problematic to secure treatments for individuals with autism:

For the past several months, Autism Speaks has raised concerns with the U.S. Department of Health and Human Services (HHS), which is overseeing the implementation of the ACA, that the requirement for behavioral health treatment coverage is not being pursued. Congress required such treatment be included as an essential health benefit and the U.S. Supreme Court has held the act constitutional. It is now the obligation of HHS to respect the intent of Congress by insisting all states include behavioral health treatment, such as ABA for autism.⁵⁹⁹

596. *Id.* at 4.

597. Nat'l Fed'n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566 (2012).

598. *Health Care Reform: What Does It Mean for the Autism Community?*, *supra* at 543.

599. Autism Votes, *Autism Speaks Response to U.S. Supreme Court Ruling on the Affordable Care Act*, AUTISMSPEAKS.ORG (June 28, 2012), <http://www.autismspeaks.org/advocacy/advocacy-news/autism-speaks-response-us-supreme-court-ruling-affordable-care-act>.

Another national organization dedicated to improving the lives of those with autism, the Autism Society of America, also advocated the necessity of greater legal reform for access to health care for those with autism and their families:

Regardless of today's decision, the reality is that the problems faced by individuals living with autism and their families remain unsolved. We are continuing to struggle to access the services we need. Never mind that more than 30 states have recently required insurance providers to cover certain autism-related treatments and services. In many of these same states, individuals with autism are denied basic coverage. In fact, with ongoing cutbacks in government funding, more and more of us are using limited funds to pay for therapies, personal assistance or other necessities, and often times we cannot afford basic insurance for preventative care.⁶⁰⁰

Further into its statement, the Autism Society of America expresses concern over treatment coverage, similar to the comments of Autism Speaks, and the need for continued work to ensure that necessary treatments are provided through health care coverage:

The Autism Society believes all governmental and non-governmental entities must understand that any health-care reform must not preclude individuals with developmental disabilities from life-changing therapies. In addition, for health-care to be effective, autism must be viewed as a whole-body condition that requires medical and non-medical treatments. While we applaud the federal and state continued support of Medicaid and Medicare, we need to do more.⁶⁰¹

The Arc, which advocates for a number of different groups of individuals with disabilities including those with autism, stated its concern over the ruling regarding Medicaid.⁶⁰² The Arc stated:

But the ruling is not perfect for people with I/DD. The Arc is concerned that disallowing the federal government the ability to withhold Medicaid dollars from states that don't expand their program to cover more of the uninsured might mean that people with I/DD who would have benefitted from the expansion could be left behind. Medicaid is an incredibly important lifeline for people with I/DD, providing health care and long term services and supports.⁶⁰³

600. Autism Soc'y, *Supreme Court Upholds Affordable Care Act*, AUTISM-SOCIETY.ORG (June 28, 2012), <http://www.autism-society.org/news/supreme-court-upholds.html>.

601. *Id.*

602. *The Arc Reacts to the U.S. Supreme Court's Decision on the Affordable Care Act*, S.F. CHRON. (June 28, 2012), <http://www.sfgate.com/business/prweb/article/The-Arc-React-to-the-U-S-Supreme-Court-s-3671182.php>.

603. *Id.*

The verdict is still out on exactly how much PPACA will benefit people with autism and how such provisions will be implemented if the legislation stands. In a later section, this Article turns to an attempt at the state level to help alleviate the financial burden to families of individuals with autism—state insurance mandates for autism.

7. Analyzing Federal Legislation for Autism: Significant Gaps

The federal legislation discussed above demonstrates a patchwork of federal law that leaves significant gaps. Although this Article has not yet discussed the largest provider of services for individuals with autism through a joint effort of the federal and state governments through Medicaid, the other federal legislation, even in consideration of federal health reform, must leave any autism advocate questioning: is that all? Federal health parity was expected to provide greater services for those identified as having a mental illness, but this has never been a major source of support to those with autism, as autism has moved largely outside the categorization of mental illness into either the category of developmental disability or its own definition. Access to health care under ERISA has serious holes.

ERISA is problematic for several reasons. One, as the majority of plans are self-funded by the employer and most people utilizing ERISA plans involve self-funded plans, employers are not required to provide insurance coverage for specific treatments such as ABA therapy. Additionally, ERISA preempts state laws, which means employees will not get the benefit of insurance coverage available through state law by insurance mandates. Although some employers who are self-funding plans are starting to provide coverage for autism treatments, there is no requirement for them to do so, and ERISA leaves a huge gap to allow employers the ability not to cover such treatments. Federal employees, as well as both active and retired members of the military, are additionally lacking protection through federal law to provide access to health care for autism. General insurance coverage was expanded under PPACA for the FEHBP for children up to age twenty-six, and includes coverage for children who fall under the definition of “severe autism.” While there are a number of different plan options through FEHBP, it is known that ABA therapy is not provided as federal legislation proposed in 2009, advocating for insurance coverage for ABA therapy under FEHBP.

Similarly, insurance coverage for active and retired military personnel and their families has, through TRICARE, developed a special program for early intervention services for autistic children, but this program expired in March 2012. ABA therapy is available under TRICARE, however, its availability is limited by an annual \$36,000 cap on benefits. It is unknown at this point how

the federal government's change in position on ABA therapy will actually be implemented into health care coverage for federal employees, despite the fact that it does represent a dramatic shift in policy position that could eventually have a ripple effect into the private sector.

Federal health care reform promises to bring major change in terms of autism, most significantly by access for diagnosis and screenings for the disorder. However, even with the U.S. Supreme Court upholding federal health care reform, it is still uncertain the extent of coverage for behavioral treatments for autism, including ABA therapy, as the federal government, thus far, has punted defining "essential health benefits" to the states.

In totality, the federal efforts for health care services for autism provide a minimum that leaves the autistic child largely at the mercy of the state for coverage for services. Perhaps the most promising part of the current federal framework for autism is the research being done through the CARA that has recently been reauthorized. However, unless this research is in some way designed to tackle the difficulties that currently lie in this federal framework, the research in itself does nothing to push forward policy at this crucial time for finding solutions to providing access to health services for children with autism and their families. Such research cannot be performed in a vacuum that does not tie it to the significant questions that may be plaguing federal legislators and policymakers in how best to craft federal policy to come to the aid of autistic children and their families. The IACC is charged with the responsibility under CARA of advising the government on issues regarding autism, but it seems that there needs to be coordination between the IACC and our legislative branch that is charged with developing legislative solutions. In particular, this would include examining the cost of health care for children with autism, and how that will be impacted by the changing of the definition of autism in the DSM, the effectiveness of ABA therapy, and looking to states for their solutions in providing health care that has developed in the absence of any greater federal assistance to autistic children and their families, and the gaps that have been discussed in current federal legislation.

Having the background of the extent of protections in place for access to health care services for individuals with autism that are federally based, the next section explores two programs for services which rely on cooperation between the federal and state governments for the implementation of such programs—early intervention services and Medicaid.

B. *Joint Efforts at Providing Services for Autism: Mixed Federal and State Legislation*

1. *IDEA and Early Intervention Services*

The availability of early intervention services has been among the most prominent discussions for the treatment of children with autism.⁶⁰⁴ “Increasingly, the benefits of early identification and treatment on child health outcomes are being proven.”⁶⁰⁵ According to the CDC, “[r]esearch shows that early intervention treatment services can greatly improve a child’s development. Early intervention services help children from birth to 3 years old (36 months) learn important skills. Services include therapy to help the child talk, walk, and interact with others.”⁶⁰⁶

In fact, the CDC even encourages the consideration of early intervention services when a child does not have an actual diagnosis of autism: “Even if your child has not been diagnosed with an ASD, he or she may be eligible for early intervention treatment services.”⁶⁰⁷ This demonstrates a strong commitment by the federal government in prevention and detection. Such commitment has led to the development of the CDC’s campaign beginning in 2004 to help parents monitor child development through its National Center on Birth Defects and Developmental Disabilities (NCBDDD) called “Learn the Signs. Act Early.”⁶⁰⁸ Through this campaign, the CDC provides valuable information and resources to unite parents, health care providers, and educators in identifying signs of a child’s developmental difficulties or delays.⁶⁰⁹ The campaign also includes the involvement of national partners such as private organizations committed to issues important to individuals with autism as well as state and local entities.⁶¹⁰ One significant issue in the identification of children with developmental difficulties is that often the difficulties are being missed because of the lack of use of appropriate tools:

One of the primary goals of routine preventive health care is to ensure that a child is developing normally. Although pediatric clinicians choose to monitor development in various ways, studies

604. Ctrs. for Disease Control & Prevention, *supra* note 7.

605. Am. Acad. of Pediatrics, *The Medical Home and Early Intervention Services* 3, <http://www.medicalhomeinfo.org/downloads/pdfs/eibrochuref.pdf>.

606. Ctrs. for Disease Control & Prevention, *supra* note 7.

607. *Id.*

608. Ctrs. for Disease Control & Prevention, *About the Program*, CDC.GOV <http://www.cdc.gov/ncbddd/actearly/about.html> (last updated July 12, 2012).

609. Ctrs. for Disease Control & Prevention, *CDC’s “Learn the Signs. Act Early.” Program*, No. CS231436, http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/LTSAE-factsheet_508.pdf.

610. *Id.*

have shown that the most effective method is through the utilization of formal, validated screening tools. Unfortunately, recent evidence indicates that most pediatric clinicians continue to rely on informal measures of development. This technique has been shown to identify only 30% of children who have developmental delays. The American Academy of Pediatrics (AAP) recommends the use of formal, validated tools to screen for developmental delays.⁶¹¹

As critical as the CDC's campaign may be in helping to educate society about child development to ensure prevention, the question becomes: Where can parents turn in order to secure early education services for a child who has been diagnosed as autistic or a child who demonstrates the potential risk for developmental delays as recommended by the CDC? The National Dissemination Center for Children with Disabilities (NICHCY), which serves as the nation's leading resource of information regarding children with disabilities, describes early intervention services as follows:

Broadly speaking, early intervention services are specialized health, educational, and therapeutic services designed to meet the needs of infants and toddlers, from birth through age two, who have a developmental delay or disability, and their families. At the discretion of each State, services can also be provided to children who are considered to be at-risk of developing substantial delays if services are not provided.⁶¹²

NICHCY is funded through the Office of Special Education Programs (OSEP) in U.S. Department of Education, and is operated by the Academy for Educational Development (AED).⁶¹³ Children's eligibility for early intervention services is determined at the state level.⁶¹⁴ NICHCY provides access to contact information for places to contact for each state's services on their website.⁶¹⁵ While early intervention services are described and addressed regarding a child's health and well-being, the provisions of federal law addressing early intervention services are found through federal special education law through the IDEA.⁶¹⁶ Since

611. Am. Acad. of Pediatrics, *supra* note 605, at 3.

611. *Id.*

611. *Id.*

612. *Q&A Corner – Issue #26*, NAT'L ASS'N OF SPECIAL ED. TEACHERS, <http://www.naset.org/3023.0.html> (last visited Nov. 3, 2012).

613. Nat'l Dissemination Ctr. for Child. With Disabilities, *About the National Dissemination Center*, NICHCY.ORG, <http://nichcy.org/about> (last visited Nov. 30, 2012).

614. Nat'l Dissemination Ctr. for Child. with Disabilities, *State Organizations – Search by State*, NICHCY.ORG, <http://nichcy.org/state-organization-search-by-state> (last visited Nov. 30, 2012).

615. *Id.*

616. *Part C. of IDEA: Early Intervention for Babies and Toddlers*, NAT'L DISSEMINATION CTR. FOR CHILD. WITH DISABILITIES, <http://nichcy.org/laws/idea/partc> (last visited Nov. 30, 2012).

1986, Part C of IDEA has addressed providing early intervention services to children with disabilities from birth to age three.⁶¹⁷ The primary reasons that early intervention services were incorporated into the framework of IDEA were to: “enhance the development of infants and toddlers with disabilities,” “reduce educational costs by minimizing the need for special education through early intervention,” “minimize the likelihood of institutionalization, and maximize independent living;” and, “enhance the capacity of families to meet their child’s needs.”⁶¹⁸ The general setup of early intervention services to infants with disabilities through IDEA involves an ongoing relationship between the federal and state governments:

The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth through age 2 years, and their families. In order for a state to participate in the program it must assure that early intervention will be available to every eligible child and its family. Also, the governor must designate a lead agency to receive the grant and administer the program, and appoint an Interagency Coordinating Council (ICC), including parents of young children with disabilities, to advise and assist the lead agency. Currently, all states and eligible territories are participating in the Part C program. Annual funding to each state is based upon census figures of the number of children, birth through 2, in the general population.⁶¹⁹

As previously mentioned, states vary in terms of their determinations of eligibility of children for early intervention services. The regulations to IDEA define children who are eligible for early intervention services as follows:

Sec. 303.16 Infants and toddlers with disabilities.

(a) As used in this part, infants and toddlers with disabilities means individuals from birth through age two who need early intervention services because they—

(1) Are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas:

- (i) Cognitive development.
- (ii) Physical development, including vision and hearing.
- (iii) Communication development.
- (iv) Social or emotional development.

617. *Id.*

618. *Early Intervention (Part C of IDEA)*, WRIGHTSLAW, <http://www.wrightslaw.com/info/ei.index.htm> (last updated July 17, 2012).

619. *Id.*

(v) Adaptive development; or

(2) Have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

(b) The term may also include, at a State's discretion, children from birth through age two who are at risk of having substantial developmental delays if early intervention services are not provided.⁶²⁰

But even with this federal guidance under the IDEA in eligibility, great discretion is given to states to determine whether or not a child is eligible for such services:

Part C eligibility is determined by each state's definition of developmental delay and whether it includes children at risk for disabilities in the eligibility formula. An important part of the evaluation process for infants and toddlers (ages 0 - 36 months) includes informed clinical opinion of professionals experienced with the development of very young children. States have been given a lot of discretion for determining eligibility for entry into their programs.⁶²¹

But the extent of a state's discretion is actually far greater than just eligibility determinations:

Part C programs (commonly referred to as early intervention programs) are state-based. This means that although the statute for Part C contains many requirements, including sixteen minimum components of a comprehensive statewide early intervention system, every state has the flexibility to determine certain aspects of these components. For example, each state determines which state agency will administer the early intervention program. In most states, this is either the Department of Education or the Department of Health and Human Services. Another important example is that although the IDEA statute for Part C specifies the developmental areas that are to be included in states' definitions of developmental delay, states must identify appropriate diagnostic instruments, procedures (including the use of informed clinical opinion), and levels of functioning or other criteria that will be used to determine eligibility. As a result, definitions of eligibility differ significantly from state to state, as well as the types of services that are provided to these children.⁶²²

Another complication in the process of securing early intervention services is that there is a lack of communication and coordination between the child's primary care provider, who

620. *Full Text of the Federal Regulations for 34 CFR Part 303, Early Intervention Program for Infants and Toddlers with Disabilities*, OSSE.DC.GOV, <http://osse.dc.gov/sites/default/files/dc/sites/osse/publication/attachments/Individuals%20with%20Disabilities%20Education%20Act%20Part%20C.pdf>.

621. *Early Intervention (Part C of IDEA)*, *supra* note 618.

622. *Am. Acad. of Pediatrics*, *supra* note 605, at 4.

constitutes the child's "medical home," and those providing early intervention services:

Early intervention programs funded under Part C of the Individuals with Disabilities Education Act (IDEA) are one place where young children (birth to age 3) with disabilities or at risk for disabilities should be referred. Optimally, there should be a seamless referral system in place, as well as firmly established lines of communication between the early intervention program and the medical home. However, historically, communication has been limited between medical homes and early intervention programs.⁶²³

The initial step in the process of determining a child's eligibility for early intervention services is the evaluation of the child for the presence of a disability. If it is determined that the child has a developmental disability or delay that warrants early intervention services, the child will be referred for early intervention services. The referral process works as follows:

A referral to early intervention services can be made by anyone, including social workers, physicians, parents, childcare providers, teachers, other pediatric clinicians, etc. The early intervention program typically acts on referrals quickly, assigning a service coordinator as soon as possible. The service coordinator then contacts the family to set up an evaluation to determine program eligibility.⁶²⁴

Part C of IDEA mandates a "child find and identification" by every state, which involves the coordination of various health and education entities in locating children who may be in need of early intervention services. That coordination effort is described as follows:

For Part C, the lead agency with the advice and assistance of the state interagency coordinating council ensures that the system is coordinated with all other major efforts to locate and identify young children by other state health, education, tribes, and social service organizations. This comprehensive system addresses referral procedures and timelines for agencies to act on referrals. It targets primary referral sources including hospitals, physicians, parents, child care programs, local education agencies, public health facilities, other social service agencies and other pediatric clinicians.⁶²⁵

Once a child has been suspected of having a disability that may require early intervention services, a state has forty-five days to determine a child's eligibility for early intervention services. The evaluation of the child for early intervention services must include the following:

623. *Id.* at 3.

624. *Id.* at 5.

625. *Id.*

Each child who is suspected of having a disability is entitled to receive a comprehensive, multidisciplinary evaluation to determine his/her needs and strengths, and to identify the needs of each child's family to appropriately assist in the development of the child. Multidisciplinary means the involvement of two or more disciplines or professions in the provision of integrated and coordinated services, including evaluation and assessment activities in Sec. 303.3229 and development of the Individual Family Service Plan (IFSP) in Sec. 303.342.10 If necessary, medical services to determine a child's developmental status and need for early intervention services may also be provided.⁶²⁶

Early intervention services have become a starting point for the parents of children with autism. However, as it has been demonstrated, the availability of those services will differ substantially by state because of the latitude given to states under IDEA over providing early intervention services.

2. Medicaid

CMS and HRSA also support services for people with autism, generally as part of broader programs to provide services or enhance the delivery of health care to people with developmental disabilities. For example, CMS supports community-based services to meet the needs of people with autism through Medicaid programs targeted to people with developmental disabilities. However, many people with autism may be unable to obtain services through these Medicaid programs because they do not meet the programs' eligibility rules or because states limit enrollment.⁶²⁷

The primary source of access to health care services for individuals with autism, including children, is a joint effort by both the federal and state governments through the Medicaid program.⁶²⁸ Medicaid was established as a companion to Medicare⁶²⁹ through Title XIX of the Social Security Act.⁶³⁰ Medicaid provides the following coverage regarding children: "Medicaid and the Children's Health Insurance Program (CHIP)

626. *Id.* at 6.

627. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-06-700, FEDERAL AUTISM ACTIVITIES: FUNDING FOR RESEARCH HAS INCREASED, BUT AGENCIES NEED TO RESOLVE SURVEILLANCE CHALLENGES 3-4 (2006), available at <http://www.gao.gov/new.items/d06700.pdf>.

628. Wendy Taormina-Weiss, *People with Autism and the Budget Crisis*, DISABLED WORLD (Aug. 21, 2012), <http://www.disabled-world.com/editorials/budget-crisis.php>.

629. Ctrs. for Medicare & Medicaid Servs., *Is My Test, Item, or Service Covered?*, MEDICARE.GOV, <http://www.medicare.gov/> (last visited Nov. 3, 2012).

630. S.S. Admin., *Title XIX – Grants to States for Medical Assistance Programs*, SSA.GOV, http://www.ssa.gov/OP_Home/ssact/title19/1900.htm (last visited Nov. 30, 2012).

provide health coverage to more than 43 million children, including half of all low-income children in the United States. The federal government sets minimum guidelines for Medicaid eligibility but states can choose to expand coverage beyond the minimum threshold.”⁶³¹

Eligibility for Medicaid is primarily income-based, however, there are exceptions for certain groups of children who receive mandatory coverage:

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. In many states, families with higher incomes can still qualify for coverage for their children. This includes children in mandatory Medicaid eligibility groups, which states must cover in order to participate in Medicaid, as well as children in optional eligibility groups that a state may elect to cover. 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. Other eligible children include infants born to women covered by Medicaid (known as “deemed newborns”), certain children in foster care or an adoption assistance program and certain children with disabilities.⁶³²

Additionally, the PPACA expanded Medicaid eligibility beginning in 2014.⁶³³ However, states have the ability to expand such coverage earlier if they choose.⁶³⁴

Furthermore, children may gain coverage for services if they are not eligible for Medicaid through the Children’s Health Insurance Program (CHIP).⁶³⁵ “The Children’s Health Insurance

631. Ctrs. for Medicare & Medicaid Servs., *Children*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Population/Children/Children.html> (last visited Nov. 3, 2012).

632. *Id.*

633. Ctrs. for Medicare & Medicaid Servs., *Eligibility*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Eligibility/Eligibility.html> (last visited Nov. 3, 2012)

(The Affordable Care Act of 2010, signed by President Obama on March 23, 2010, creates a national Medicaid minimum eligibility level of 133% of the federal poverty level (\$29,700 for a family of four in 2011) for nearly all Americans under age 65. This Medicaid eligibility expansion goes into effect on January 1, 2014 but states can choose to expand coverage with Federal support anytime before this date-see related Federal Policy Guidance and states that have expanded Medicaid prior to 2014.)

634. *Id.*

635. Ctrs. for Medicare & Medicaid Servs., *Children’s Health Insurance Program (CHIP)*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Childrens-Health-Insurance-Program-CHIP/Childrens-Health-Insurance-Program-CHIP.html> (last visited Nov. 3, 2012) (“Like Medicaid, CHIP is administered by the states, but is jointly funded by the federal government and states. The Federal matching rate for

Program (CHIP) provides health coverage to nearly 8 million children in families with incomes too high to qualify for Medicaid, but can't afford private coverage. Signed into law in 1997, CHIP provides federal matching funds to states to provide this coverage."⁶³⁶ States are permitted to use one of three different approaches to setting up their CHIP: (1) Medicaid expansion (seven states, DC, and five territories), (2) separate child health insurance program (seventeen states), and (3) combination of the two approaches (twenty-six states).⁶³⁷ Similar to Medicaid, CHIP will vary across states in its eligibility standards.⁶³⁸ The PPACA has also expanded coverage under CHIP to include children of public employees.⁶³⁹

a. Medicaid Waivers—Source of Help or Source of Distress?

“States can apply to the Centers for Medicare & Medicaid Services for waivers to provide Medicaid to populations beyond what traditionally can be covered under the state plan.”⁶⁴⁰ “Waivers are vehicles states can use to test new or existing ways to deliver and pay for health care services in Medicaid and the Children’s Health Insurance Program (CHIP).”⁶⁴¹ Medicaid waivers have become an important mechanism for the federal government’s implementation of the U.S. Supreme Court’s landmark decision in *Olmstead v. L.C.*, which interpreted the original Americans with Disabilities Act (ADA)⁶⁴² to require the removal of individuals with disabilities from institutional settings whenever possible and into communities. In *Olmstead*, mentally disabled individuals challenged their confinement to institutions by Georgia health officials under the ADA under Title II for Public Services.⁶⁴³ Title II provides: “Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such

state CHIP programs is typically about 15 percentage points higher than the Medicaid matching rate for that state (i.e. a State with a 50% Medicaid FMAP has an ‘enhanced’ CHIP matching rate of 65%). Every state administers its own CHIP program with broad guidance from CMS.”)

636. *Id.*

637. *Id.*

638. *Id.*

639. Ctrs. for Medicare & Medicaid Servs., *CHIP Eligibility Standards*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Childrens-Health-Insurance-Program-CHIP/CHIP-Eligibility-Standards-.html> (last visited Nov. 3, 2012).

640. Ctrs. for Medicare & Medicaid Servs., *supra* note 633.

641. *Id.*

642. Americans with Disabilities Act (ADA), 42 U.S.C. § 12101 (1990).

643. *Olmstead v. L.C.*, 527 U.S. 581, 588-90 (1999).

entity.”⁶⁴⁴ Writing the majority opinion for the Court, Justice O’Connor stated:

This case concerns the proper construction of the anti-discrimination provision contained in the public services portion (Title II) of the Americans with Disabilities Act of 1990 (ADA), 104 Stat. 337, 42 U.S.C. § 12132. Specifically, we confront the question whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes. Such action is in order when the State’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.⁶⁴⁵

In reaching this conclusion, the Court initially highlighted the significance of the passage of the ADA in breaking down the barriers of people with disabilities of being fully integrated into society: “The ADA stepped up earlier measures to secure opportunities for people with developmental disabilities to enjoy the benefits of community living.”⁶⁴⁶ The Court also noted that the findings of the ADA required the prevention of discrimination that included the segregation of individuals with disabilities.⁶⁴⁷ The Court acknowledged two reasons why institutionalization is contrary to the ADA’s purpose by creating unreasonable assumptions about individuals with disabilities.⁶⁴⁸ “First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”⁶⁴⁹ “Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”⁶⁵⁰ Specifically regarding access to health care services and the institutionalization of those with mental disabilities, the Court stated:

Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable

644. ADA, § 201, 42 U.S.C. § 12132.

645. *Olmstead*, 527 U.S. at 587.

646. *Id.* at 599.

647. *Id.* at 600.

648. *Id.*

649. *Id.*

650. *Id.* at 601.

accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.⁶⁵¹

Although *Olmstead* was decided in 1999, significant action on its implementation was not at the forefront as a government priority until 2009:

In 2009, the Civil Rights Division launched an aggressive effort to enforce the Supreme Court's decision in *Olmstead v. L.C.*, a ruling that requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs.⁶⁵²

President Obama proclaimed 2009 “The Year of Community Living” in recognition of the tenth anniversary of the U.S. Supreme Court ruling in *Olmstead* and the need to continue efforts to ensure people with disabilities were further integrated into community living.⁶⁵³ This initiated a movement by the federal government to assist states in providing support to ensure people with disabilities—including those with autism—would have access to the critical services they require such as those for health care.

Waivers will fall into one of the four following categories: Section 1115 Research & Demonstration Projects,⁶⁵⁴ Section 1915(b) Managed Care Waivers,⁶⁵⁵ Section 1915(c) Home and Community-Based Services Waivers,⁶⁵⁶ and Concurrent Section 1915(b) and 1915(c) Waivers.⁶⁵⁷ “Among the optional services that

651. *Id.*

652. U.S. Dep't of Justice, *Olmstead: Community Integration for Everyone*, ADA.GOV, <http://www.ada.gov/olmstead/index.htm> (last updated Sept. 27, 2012).

653. Press Release, The White House, Pres. Obama Commemorates Anniversary of *Olmstead* and Announces New Initiatives to Assist Ams. with Disabilities (June 22, 2009), *available at* http://www.whitehouse.gov/the_press_office/President-Obama-Commemorates-Anniversary-of-Olmstead-and-Announces-New-Initiatives-to-Assist-Americans-with-Disabilities/

(To help remedy that problem, the Obama Administration provided over \$140 million in the Recovery Act funding for independent living centers across the country. The Administration acknowledges that strides have been made, and knows and accepts that there is much work to do in order to maximize the choices and opportunities for individuals to receive long-term services and supports in institutional and community settings.).

654. Ctrs. for Medicare & Medicaid Servs., *Waivers*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html> (last visited Nov. 3, 2012) (“States can apply for program flexibility to test new or existing approaches to financing and delivering Medicaid and CHIP.”).

655. *Id.* (“States can apply for waivers to provide services through managed care delivery systems or otherwise limit people's choice of providers.”).

656. *Id.* (“States can apply for waivers to provide long-term care services in home and community settings rather than institutional settings.”).

657. *Id.* (“States can apply to simultaneously implement two types of

can be provided are Medicaid Home and Community-Based Services ('HCBS') waivers.⁶⁵⁸ The most used of these waivers involving individuals with autism is the HCSB waiver because of its availability in providing long-term health care:

The 1915(c) waivers are one of many options available to states to allow the provision of long term care services in home and community based settings under the Medicaid Program. States can offer a variety of services under an HCBS Waiver program. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.⁶⁵⁹

Because states have significant authority in crafting these waivers with federal approval, they can and will differ substantially from state to state.

b. Examples of Different State Medicaid Waivers

To understand how much Medicaid waivers will differ between states, it is helpful to look at a few examples from different states that emphasize this phenomenon. Wisconsin has established a set of waivers known as Children's Long-Term Support (CLTS) Waivers.⁶⁶⁰ CLTS waivers are described as follows:

The Children's Long-Term Support Home and Community-Based Medicaid Waivers (CLTS Waivers) provide a structure within which Medicaid funding is available to support children who are living at home or in the community and who have substantial limitations in multiple daily activities as a result of one or more of the following disabilities: developmental disabilities, severe emotional disturbances, and physical disabilities. Funding can be used to support a range of different services that are identified based on an individual assessment of the child and his or her needs.⁶⁶¹

wavers to provide a continuum of services to the elderly and people with disabilities, as long as all Federal requirements for both programs are met.").

658. Ctr. for Medicare & Medicaid Servs., *Home & Community-Based Services 1915(c)*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services-1915-c.html> (last visited Nov. 3, 2012).

659. *Id.*

660. *Children's Long-Term Support Waivers*, WIS. DEP'T OF HEALTH SERVS., <http://www.dhs.wisconsin.gov/children/clts/index.htm> (last updated Mar. 22, 2012).

661. *Id.*

The CLTS waivers are broken down into three separate waivers based on different categories of disability (developmental disabilities, severe emotional disturbances, and disabilities), but a child may be eligible for more than one waiver.⁶⁶² In the event a child is eligible for more than one waiver, a determination will be made between the family and service coordinator of which waiver will be most effective in providing needed services for the child.⁶⁶³ All CLTS Waivers have a set of eligibility requirements that must be met for any child or young adult.⁶⁶⁴ However, there are additional eligibility requirements that have been established for children with autism for those children in need of intensive in-home treatment.⁶⁶⁵ Among the extra requirements for the eligibility for intensive in-home treatment for an autistic include that the child must be diagnosed with autism before age eight, the family must agree to intensive in-home treatment for twelve months, the family must have already reached an agreement with a provider for the intensive in-home treatment, and the child must not have already received two years or more of intensive in-home treatment, regardless of the funding source, to name a few.⁶⁶⁶ The program for intensive in-home treatment is described as follows:

The CLTS Waivers provide funding for some specific services that are not covered by the Wisconsin Forward Health Medicaid card. For young children diagnosed with an Autism Spectrum Disorder (ASD), intensive in-home treatment using intense behavioral methods, this CLTS Waiver service aims to help reduce the challenging behaviors often found in children with ASD. Eligible children may participate in this intensive program for up to three years, after which the child may qualify for ongoing waiver services at a less intensive level that address the more diverse needs of the growing child. The goal of the program is for the child to have fewer needs in the future and to make significant gains towards normal development, including an increase in social, behavioral and communication skills that the child can use at home and in their community.⁶⁶⁷

662. *Id.*

663. *Id.*

664. *Children's Long-Term Support Waviers: Who Is Eligible?*, WIS. DEP'T OF HEALTH SERVS., <http://www.dhs.wisconsin.gov/children/clts/waiver/family/eligibility.htm> (last updated Sept. 26, 2011).

665. *Intensive Treatment Services for Children with Autism: Who Is Eligible?*, WIS. DEP'T OF HEALTH SERVS., <http://www.dhs.wisconsin.gov/children/clts/waiver/family/autism/eligibility.htm> (last updated Sept. 21, 2011).

666. *Id.*

667. *Intensive Treatment Services for Children with Autism*, WIS. DEP'T OF HEALTH SERVS., <http://www.dhs.wisconsin.gov/children/clts/waiver/family/autism/> (Sept. 21,

The intensive in-home treatment that is provided through the CLTS waiver includes the following parameters:

Intensive treatment is provided on a one-to-one basis in the child's home. A team, including a Lead and Senior Therapist as well as Line Therapists, develops and implements a treatment plan that is individualized to each child's developmental needs. This intensive approach addresses specific skills for each child that are clearly defined in observable terms and are measured carefully by direct observation throughout each treatment session. Intensive treatment services involve up to 35 hours per week of face-to-face service in the family's home.⁶⁶⁸

What is even more interesting about the Wisconsin CLTS waiver program is a recent approval to allow for an online program known as Rethink Autism⁶⁶⁹ to be an available treatment when children are no longer eligible for intensive treatment.⁶⁷⁰ The program "seeks to ensure every child on the autism spectrum has access to effective and affordable science-based treatment tools."⁶⁷¹ While Rethink Autism offers several types of treatment, its primary focus is ABA therapy.⁶⁷² "The CLTS Medicaid Waiver covers the Rethink Autism program for children and youth with autism under the age of 22 who have an autism diagnosis, and is available in all counties across Wisconsin."⁶⁷³ It is believed that the online program will be utilized as an option for children who are waiting for access to intensive in-home treatment or that the online program will be used in conjunction with the intensive in-home treatment a child is using.⁶⁷⁴ Wisconsin will be the second state to use Rethink Autism (it is already currently being used in Montana) and may lead a trend toward more Medicaid Waivers offering this option.⁶⁷⁵ The Council for Affordable Health Insurance praised this Wisconsin Medicaid waiver back in 2009 for

2011).

668. *Id.*

669. *Web-based Educational Treatment Solutions for Autism Assessment, Training, Curriculum & Data Tracking*, RETHINK AUTISM, <http://www.rethinkautism.com/> (last visited Nov. 3, 2012).

670. Press Release, PR Newswire, Wisconsin Extends Medicaid Waiver to Cover Innovative Web-Based Autism Treatment (June 15, 2011), <http://www.prnewswire.com/news-releases/wisconsin-extends-medicaid-waiver-to-cover-innovative-web-based-autism-treatment-program-96366019.html>.

671. *How It Works*, RETHINK AUTISM, <http://www.rethinkautism.com/parents/intro.aspx> (last visited Nov. 3, 2012).

672. *Applied Behavior Analysis*, RETHINK AUTISM, <http://www.rethinkautism.com/AboutAutism/ABAOverview/> (last visited Nov. 3, 2012).

673. Press Release, *supra* note 670.

674. *Web-based Educational Treatment Solutions for Autism Assessment, Training, Curriculum & Data Tracking*, *supra* note 669.

675. *Id.*

its innovative approach:

We do know these children need significant amounts of care. That's why Wisconsin's approach, which set up the Children's Long-Term Care Community-Based Waiver (or CTLS) to provide a range of services to qualifying individuals, makes the most sense. It provides more integrated care than could possibly be provided by health insurance.⁶⁷⁶

For an example of a much more limited Medicaid waiver, Kansas has an autism waiver based on early intervention services.⁶⁷⁷ The Kansas autism waiver has the following parameters:

The HCBS Autism waiver is an early intensive intervention waiver for children who are 0 through 5 years of age, who has a diagnosis of an Autism Spectrum Disorder and Other Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS), Children are required to meet functionally eligibility guidelines and Kansas' financially eligible guidelines for Medicaid, and utilize two waiver services every month.⁶⁷⁸

Through HCBS waivers, autistic children may benefit from services for three years with a possible additional year of services if approved.⁶⁷⁹ The focus by Kansas on early intervention services is largely due to the recognition of the impact of cost autism will have for the lifetime of the individual on society:

The waiver will provide opportunities for children with Autism to receive intensive early intervention treatment and their primary caregivers to receive needed support through respite services. The program will greatly benefit children with Autism and their families, in the future it may potentially provide dramatic cost savings to the state, as these children are less likely to depend on public services over the course of their lifetime. According to the Autism Society of America, the cost of lifelong care can be reduced by two-thirds with early diagnosis and intervention.⁶⁸⁰

There are four primary areas of services available under the Kansas Autism Waiver: Consultative Clinical and Therapeutic Services,⁶⁸¹ Intensive Individual Support providers,⁶⁸² Respite

676. Bunce & Wieske, *supra* note 231, at 2.

677. *About the Autism Waiver*, KS. DEP'T FOR AGING AND DISABILITY SERVS., <http://kansasearlyautism.org/information/about.aspx> (last visited Nov. 3, 2012).

678. *Kansas Early Autism Services*, KS. DEP'T FOR AGING AND DISABILITY SERVS., <http://www.kansasearlyautism.org/> (last visited Nov. 3, 2012).

679. *Id.*

680. *Id.*

681. *About the Autism Waiver*, *supra* note 677.

Consultative Clinical and Therapeutic Services are intended to assist the family and paid support staff or other professionals in carrying out the Individual Behavioral Program/Plan of Care (IBP/POC) that

Providers,⁶⁸³ and Parent Support and Training providers.⁶⁸⁴

While the Medicaid waivers used in Wisconsin and Kansas have similar goals of providing children with autism with services early, the eligibility for those programs, composition of these programs, and their implementation differ and serve as a small sampling of the many different Medicaid waivers being used at the state level to provide access to health care services and support for children with autism and their families in the U.S.⁶⁸⁵

However, Medicaid Waivers are not without their problems as a way to provide services for individuals with autism. In addition to the differences of mandates by states, evidence suggests that the high demand for such waivers leave many on waiting lists for services, and without services all together.⁶⁸⁶ According to the

supports the child's functional development and inclusion in the community. This is monitored by an Autism Specialist. Autism Specialist will assess the child and family's strengths and needs, develop the IBP/POC, provide training and technical assistance to the family and paid support staff in order to carry out the program, and monitor the child's progress within the program and of the family and/or other providers implementation of the program.

Id.

682. *Id.*

Intensive Individual Support providers assist the child with an ASD in acquiring, retaining, improving, and generalizing the self-help, socialization, and adaptive skills necessary to function successfully in the home and community. Intensive Individual support workers will provide services directly to the child through evidence-based and data driven methodologies. They will be trained and work under the Autism Specialist.

Id.

683. *Id.* ("Respite Providers provide temporary direct care and supervision of the child. The primary purpose is to provide relief to families of a child with an ASD. This can include assistance with normal activities of daily living and support in home and community settings.")

684. *Id.*

Parent Support and Training providers promote engagement and active participation of all family members in all aspects of the treatment process. This involves assisting the family in acquiring the knowledge and skills necessary to understand and address the specific needs of the child in relation to Autism Spectrum Disorder. The services will enhance the family's skills by providing specific problem solving skills, coping mechanisms, and help in developing strategies for the child's maladaptive behaviors and behavior management.

Id.

685. See *Medicaid Waivers*, SPECIAL NEEDS RES. PROJECT, http://www.snrproject.com/Special_Needs/Resources/Insurance/Medicaid+Waivers (last visited Nov. 4, 2012) (explaining that each state has its own Medicaid program while the program titles may vary, most programs are similar).

686. See The Henry J. Kaiser Family Found., *Waiting List for Medicaid 1915(c) Home and Community Based (HCBS) Waivers, 2010*, STATEHEALTHFACTS.ORG, <http://statehealthfacts.org/comparetable.jsp?ind=246&cat=4&sub=62&yr=138>

Kaiser Family Foundation, a 2010 summary of individuals listed as wait listed for different Medicaid 1915(c) HCBS waivers shows that 268,220 individuals are waitlisted for waivers for intellectual and developmental disabilities (this may include autism depending on how the state defines these terms for eligibility).⁶⁸⁷ It also shows that 27,546 children across the U.S. were waitlisted for HCBS waivers in 2010.⁶⁸⁸ While it is uncertain based on these numbers alone exactly how many autistic children are included, the numbers suggest that Medicaid waivers are not without their problems in access to health care services for children with autism.

As the federal government has even stepped in to force states to rectify these situations involving lengthy wait lists for Medicaid waivers, many parents, especially those of children with autism, fear that the wait will be too long to bring much needed assistance even if they manage to move up the wait list.⁶⁸⁹ Another fact that goes unnoticed is not only are individuals being waitlisted for Medicaid waivers, but the wait times are extensive and can be as long as a decade if not more.⁶⁹⁰

c. The Relationship Between Medical Services and Education for Children with Disabilities: Medicaid and IDEA

Another interesting aspect of Medicaid for purposes of examining the funding of medical services for autistic children is its relationship to the IDEA.⁶⁹¹ The origin of that relationship was not existent upon IDEA's initial passage in 1975, but as a result of amendments to federal special education law:

The Individuals with Disabilities Education Act (IDEA) was passed to "assure that all children with disabilities have available to them . . . a free appropriate public education which emphasizes special education and related services designed to meet their individual needs." The IDEA authorizes federal funding to states for medical services provided to children through a child's Individualized Education Program (IEP), including children that are covered under Medicaid. In 1988, section 1903(c) of the Act was amended to permit Medicaid payment for medical services provided to Medicaid eligible

&typ=1 (last visited Nov 4, 2012) (displaying chart for waiting lists for Medicaid 1915(c) Home and Community-Based Waivers for 2010).

687. *Id.*

688. *Id.*

689. Whitney Wild, *Virginia Medicaid Waiver Wait List Continues to Grow*, WJLA.COM (Feb. 17, 2012), <http://www.wjla.com/articles/2012/02/virginia-medicaid-waiver-wait-list-continues-to-grow-72720.html>.

690. Maureen Hayden, *Families with Autistic Children Face Long Wait Time for State Services*, HERALD BULL. ONLINE (Oct. 24, 2011), <http://heraldbulletin.com/local/x1990851379/Families-with-autistic-children-face-long-wait-time-for-state-services>.

691. Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773 (1975) (codified as amended at 20 U.S.C. § 1401).

children under IDEA and included in the child's IEP.⁶⁹²

Because of the complicated nature of these two programs that operate on both the federal and state levels, the U.S. Office of Government Accountability attempted to provide guidance on the interaction of these programs in 1999.⁶⁹³ According to that report, "Medicaid and IDEA interact differently at the federal, state, and local levels, and the extent and nature of coordination continue to evolve."⁶⁹⁴ Much of the dynamics of such funding falls to the local levels: "Local interactions between Medicaid and IDEA are affected by a variety of factors, including the commitment of individual school districts to seek Medicaid reimbursement, as well as specific characteristics and concerns of local communities."⁶⁹⁵ The relationship between education and medical services is described as follows:

Schools can be an appropriate location from which to identify, enroll, and provide Medicaid services to low-income children. In addition to services offered in hospitals, clinics, or other health care locations, states are authorized to use their Medicaid programs to help pay for certain health care services delivered to Medicaid-eligible children in a school-based setting. In some cases, states have identified schools as providers of Medicaid services. The amount and type of services provided in school-based settings vary by state, ranging from services provided by contractors who visit the schools to services offered by fully equipped school-based health clinics with permanent staff. Commonly provided school-based services that qualify for federal funds include physical, occupational, and speech therapy as well as diagnostic, preventive, and rehabilitative services.⁶⁹⁶

Specifically, Medicaid is seen as a viable financial option through which children with disabilities can receive medical services even when IDEA funds are exhausted:

Medicaid can be an important source of funding for schools, particularly because the costs of providing special education can greatly exceed the federal assistance provided under IDEA. Children who qualify for IDEA are frequently eligible for Medicaid

692. Ctrs. for Medicare & Medicaid Servs., *Medicaid School-Based Administrative Claiming Guide* 4 (May 2003), http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and-Reimbursement/Downloads/2003_SBS_Admin_Claiming_Guide.pdf.

693. KATHRYN G. ALLEN, U.S. GOV'T ACCOUNTABILITY OFFICE, GAO/HEHS-00-20, MEDICAID AND SPECIAL EDUCATION: COORDINATION OF SERVICES FOR CHILDREN WITH DISABILITIES IS EVOLVING Cover Page (12/10/1999), available at [http://www.gpo.gov/fdsys/pkg/GAOREPORTS-HEHS-00-20.htm](http://www.gpo.gov/fdsys/pkg/GAOREPORTS-HEHS-00-20/html/GAOREPORTS-HEHS-00-20.htm).

694. *Id.* at 1.

695. *Id.*

696. *Id.* at 2.

services, and although Medicaid is traditionally the payer of last resort for health care services, it is required to reimburse for IDEA-related medically necessary services for eligible children before IDEA funds are used. Because many services required by a child's IEP are health-related or medical in nature, the Medicaid entitlement is an attractive option for funding many IDEA services for low-income children with disabilities. Furthermore, some administrative activities under Medicaid, such as EPSDT outreach, can be relevant for such IDEA activities as child find. Hence, educational entities have both programmatic and financial incentives to ensure that coordination exists between Medicaid and IDEA.⁶⁹⁷

Additionally, children with disabilities who do not qualify for special education services through IDEA may qualify through section 504 of the Rehabilitation Act of 1973. This could become significant with the news that autism will undergo new diagnostic criteria under the DSM and children who were once considered to have a diagnosis of “autism” because of the current use of the spectrum may not under the new criteria. As a result, a new group of children who are not *per se* autistic may need to turn to alternative sources for special education such as 504. Similar to IDEA, section 504 may also work to provide access to important health care services:

Section 504 of the Rehabilitation Act of 1973 requires local school districts to provide or pay for certain services to make education accessible to handicapped children. These services may include health care services similar to those covered by IDEA and Medicaid. These services are typically described in a section 504 plan and are provided free of charge to eligible individuals.⁶⁹⁸

This begs the question then of how much of educational services for autistic children are paid for by Medicaid and what is left for educational providers that still seems to leave autistic children without adequate services in education primarily because of the financial burden. As the lines of medical services and education blur, it is suggested that maybe greater attention needs to be given to how these complicated federal programs can work for one goal—ensuring services for children with disabilities, including those with autism.

3. *Analyzing Joint Efforts for Providing Services for Autism—Largely State-Specific Endeavors*

The aforementioned joint programs for providing services for children with disabilities through the cooperation of the federal and state governments—IDEA and Medicaid—demonstrate that a

697. *Id.*

698. Ctrs. for Medicare & Medicaid Servs., *supra* note 692, at 4.

lot can be done for autistic children through these endeavors due to their flexibility. However, the question becomes whether such flexibility is a blessing or a curse. The federal government initially provided a lot of discretion to state governments in implementing IDEA and Medicaid, believing that states are better equipped to see the realities of the needs, and therefore in a better position to make critical decisions involving things such as eligibility and service availability to serve the individual state population appropriately based on available resources. Instead, such “flexibility” has resulted in a myriad of different IDEA and Medicaid programs by state with children and their families often significantly limited in services because of what a particular state is able to provide. Should an autistic child in Ohio have access to more services than an autistic child in Michigan? It would seem that programs created by our federal government should have more uniformity.

While so much still remains uncertain about autism in general, there is uniformity in the need for services and their absence, even with the current joint efforts, that demands the federal government take legislative action to create greater uniformity and coordination with the states if U.S. children with autism are going to have the same access to services. States have moved in an absence of federal legislation to attempt to alleviate the enormous financial pressure that could otherwise be placed on the parents and families of autistic children. However, as the next section explains, this becomes even more challenging as states are more and more financially strapped for resources.

C. State Legislation and Autism

“While the national economic downturn persists, causing public revenues to decrease, states are challenged to meet the growing demand for publicly financed services to individuals diagnosed with ASD.”⁶⁹⁹ Despite the federal laws that provide ways for access to health care and services for children with autism, states themselves have also become a battlefield for parents and caregivers to try to secure these protections. “In response to the growing number of individuals with autism, states have taken action to address the needs of these individuals.”⁷⁰⁰

1. Early Efforts to Provide Services for Autism at the State Level

The earliest attempt at any legislation designed to provide services for individuals with autism came through state mental health parity laws.⁷⁰¹ “The question of whether autism is a mental

699. Mauch et al., *supra* note 260, at 1.

700. Nat’l Conference of St. Legislatures, *supra* note 481.

701. UNUMB & UNUMB, *supra* note 270, at 51.

health condition covered under health insurance varies from state to state.”⁷⁰² The decision to categorize health care services for individuals with autism in terms of mental health or as habilitative services will significantly impact the way these services are treated for insurance purposes:

A mental health benefit mandate provides for the payment of mental health evaluation and treatment, but sometimes at a higher out-of-pocket cost for the patient, or limitations are imposed on the coverage. Historically, mental health services have higher patient cost-sharing and shorter visit limits than services for physical illness or injury. Mental health parity laws try to minimize or eliminate this difference by requiring the same limitations and cost-sharing for mental health as for traditional medical care.⁷⁰³

When services for autism are categorized as habilitative, such services will be instead viewed in terms of long-term healthcare: “Habilitative services treatments, by contrast, include occupational, physical and speech therapies for children with a congenital or genetic birth defect, including autism. The goal of such services is to enhance the child’s ability to function.”⁷⁰⁴ However, it soon became clear that mental health parity laws were proving ineffective at providing coverage for individuals with autism:

Like Maine and California, multiple states included autism within mental health parity laws, but the coverage that resulted for individuals with autism was less than adequate. Individuals with autism could still be denied coverage altogether, if the policy did not include mental health benefits generally. Or, more commonly, individuals with autism were issued policies that offered mental health benefits, but those benefits failed to include the treatments most commonly prescribed for autism, such as Applied Behavior Analysis therapy. Even the most comprehensive mental health parity statutes failed to offer meaningful coverage to individuals with autism, often forcing the individuals to go without treatment or their families to go deeply out of pocket for medically necessary treatments.⁷⁰⁵

As previously discussed, mental health parity laws were not simply created at the state level, and a federal mental health parity law was passed in 1996.⁷⁰⁶ However, states began looking to alternative options for providing services to those with autism outside the lens of mental health parity.⁷⁰⁷ States considered plans

702. Bunce & Wieske, *supra* note 231, at 1.

703. *Id.*

704. *Id.*

705. *Id.* at 56.

706. UNUMB & UNUMB, *supra* note 270, at 265.

707. Despite the turn away from mental health parity laws at the state level as a means of providing coverage for services for autism, some states do

to fill in gaps for federal programs for services.⁷⁰⁸ “Some states have additional ‘state only’ programs to provide medical assistance for certain low-income people who do not qualify for Medicaid. No federal funds are provided for state only programs.”⁷⁰⁹ What is clear is that states have been at the forefront of trying to develop unique ways to finance services for those with autism: “States have employed a number of strategies to provide funds for therapies to help children with an ASD. No state has found a magic bullet, however, and many parents are left to piece together different funding streams to pay for the treatment their children’s needs.”⁷¹⁰

2. *A Movement Toward Autism-Specific Legislation*

In the wake of the difficulties posed by mental health parity laws in securing access to health care services for individuals with autism, two states emerged with an innovative legislative approach of creating autism specific legislation to provide for access to health care: Georgia⁷¹¹ and Kentucky.⁷¹² The Georgia statute defined autism as follows: “Autism’ means a developmental neurological disorder, usually appearing in the first three years of life, which affects normal brain functions and is manifested by compulsive, ritualistic behavior and severely impaired social interaction and communication skills.”⁷¹³

The Georgia statute also prohibited the exclusion of autism by an insurer in providing benefits:

An insurer that provides benefits for neurological disorders, whether under a group or individual accident and sickness contract, policy, or benefit plan, shall not deny providing benefits in accordance with the conditions, schedule of benefits, limitations as to type and scope of treatment authorized for neurological disorders, exclusions, cost sharing arrangements, or copayment requirements which exist in such contract, policy, or benefit plan for neurological disorders because of a diagnosis of autism. The provisions of this subsection shall not expand the type or scope of treatment beyond that

continue to offer such services through mental health laws: “In addition, some states may require limited coverage for autism under their mental health coverage laws.” See Nat’l Conference of St. Legislatures, *supra* note 481 (discussing options to supplement the minimum requirements of mental health parity laws).

708. Ctrs. for Medicare & Medicaid Servs., *supra* note 633.

709. *Id.*

710. Megan Foreman & Matthew Gever, *States Respond to Rising Rates of Autism*, 28 ST. HEALTH NOTES 1, 4 (2007), available at <http://www.ncsl.org/print/health/shn/shn502.pdf>.

711. GA. CODE ANN. § 33-24-59.10 (West 2001).

712. KY. REV. STAT. ANN. § 304.17A-143 (West 2010).

713. UNUMB & UNUMB, *supra* note 270, at 56-58.

713. GA. CODE ANN. § 33-24-59.10(a)(2).

authorized for any other diagnosed neurological disorder.⁷¹⁴

The Kentucky statute differs from Georgia's first by specifying its protection for children with autism and limitations on that coverage.⁷¹⁵ Compared to the Georgia statute, the Kentucky statute has a much more extensive process in determining whether or not a child is considered autistic.⁷¹⁶ Under this legislative scheme, a determination of autism requires identifying particular characteristics of the child.⁷¹⁷ These characteristics include qualitative impairment in social interaction, qualitative impairments in communication, and restricted repetitive and stereotyped patterns of behavior, interests, and activities.⁷¹⁸ The Kentucky statute also requires the presence of "delays or abnormal functioning" in at least one of the following areas: social interaction, language as used in social communication, or symbolic or imaginative play.⁷¹⁹ With regard to treatment, the statute provides: "All health benefit plans shall provide coverage, including therapeutic, respite, and rehabilitative care, for the treatment of autism of a child covered under the policy."⁷²⁰ This policy for services could prove problematic because, as previously discussed, some treatments commonly used for autistic individuals are considered "habilitative." This Kentucky statute, passed in 1998, allowed for a maximum of only \$500 per autistic child for therapeutic services—a relatively small amount compared to the financial cost of ABA therapy.⁷²¹ ABA therapy, as discussed earlier, is a costly endeavor:

Therapeutic interventions for autism can be needed for a significant period of time, even years. For this reason, and because of the required daily intensity of the intervention, treating autism is expensive. An ABA therapy program can easily run in the \$30,000 to \$100,000 range annually, depending on the severity of the autism, the location of the patient, and other similar factors. It is unlikely that Kentucky legislators were cognizant of the costs of intensive therapeutic interventions at the time they enacted a \$500 per month benefit for autism.⁷²²

The cost involved in ABA therapy brings with it questions of just how much should states require health insurers to cover for this type of treatment, if at all, and should there be any

714. *Id.* § 33-24-59.10(b).

715. KY. REV. STAT. ANN. § 304.17A-143 (West 2010).

716. *Id.* § 304.17A-143(3)(a).

717. *Id.*

718. *Id.* § 304.17A-143 (3)(a)(1)-(3).

719. *Id.* § 304.17A-143(3)(b)(1)-(3).

720. *Id.* § 304.17A-143 (1).

721. *Id.* § 304.17A-143 (2).

722. UNUMB & UNUMB, *supra* note 270, at 58.

limitations imposed.⁷²³ Despite this, insurance has become the place where state legislatures have gravitated toward in providing access to health care services for individuals with autism: “In the past few years, the debate over autism and insurance coverage has heated up in state legislatures. Most of the legislation to provide coverage for autism has been enacted in the last four years.”⁷²⁴ According to the National Conference on State Legislatures (“NCSL”), as of May 2011, “A total of 37 states and the District of Columbia have laws related to autism and insurance coverage.”⁷²⁵ Of those 37 states and the District of Columbia, 31 states have enacted legislation to provide insurance coverage for the treatment of autism.⁷²⁶ The difficulty in crafting legislation related to autism for health services has been a continued lack of understanding of autism and the mystery behind it: “One of the problems is that scientists and doctors are not certain what causes autism, and so historically treatment differs from one person to the next.”⁷²⁷ “Proponents believe that health insurance companies should assume the financial burden—typically in the range of \$50,000 per year per child—for autistic children that families and school districts have borne.”⁷²⁸ But insurers argue they should not be responsible for funding all treatments for autism because they should not all be categorized as medical:

Insurance carriers argue that most medically related treatments are already covered for autism. In addition, they note that autism is an individually based disorder, and so there is often no clear standard of care to determine the appropriate therapy. Further, some see behavioral therapy not as a medical benefit but an educational one.⁷²⁹

While many states have addressed insurance for individuals with autism through specific legislation, other states offer only “limited coverage” and have included individuals with autism in

723. *Id.*

724. Nat’l Conference of St. Legislatures, *supra* note 254.

725. *Id.*

726. *Id.*

At least 31 states—Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, Pennsylvania, Rhode Island, South Carolina, Texas, Vermont, Virginia, West Virginia and Wisconsin—specifically require insurers to provide coverage for the treatment of autism.

Id.; see also *State Insurance Mandates for Autism Spectrum Disorder*, AM. SPEECH-LANGUAGE HEARING ASS’N, <http://www.asha.org/Advocacy/state/States-Specific-Autism-Mandates/> (last visited Nov. 4, 2012) (listing thirty-four states with coverage).

727. Bunce & Wieske, *supra* note 231, at 1.

728. *Id.* at 2.

729. *Id.*

other state laws such as those covering mental health.⁷³⁰

Additionally, the calculations on how many states provide protections through law for autistic individuals for health benefits continues to differ substantially because of how individuals perceive these law and categorize them accordingly: “Plus autism-coverage advocates often vary in how they interpret existing laws.”⁷³¹ Regardless, states have become a force and beacon of hope for many parents and families of those with autism, especially children, in the development and spread of state laws mandating insurance coverage far more extensive in most cases than ever before. This Article relies on information that has been compiled by the NCSL in describing the current framework of legislation at the state level in light of these differences.⁷³²

3. *The Spread of State Autism Insurance Coverage: A Web of Complication and Diversity*

“State legislatures traditionally have grouped autism in the broader category of mental health, but one of the latest state legislative trends is to pass an autism mandate separately from mental health benefit mandates.”⁷³³ First, it is important to understand what exactly an insurance mandate means. A “mandate” is explained by the Council for Affordable Health Insurance as follows:

A health insurance “mandate” is a requirement that an insurance company or health plan cover (or offer coverage for) health care providers, benefits and patient populations. Sometimes states require the mandate to be covered; sometimes they only require it to be offered to employers and/or individuals, who can then choose whether to include it in their policy. Insurers must adjust their premiums accordingly.⁷³⁴

Mandates can include providers, benefits, and populations.⁷³⁵ It is also important to understand the workings of a mandate if one category or another is covered:

It is important to note that mandating providers is similar to mandating a benefit. If a law requires an insurance carrier to add a certain provider to a health insurance policy, then the benefits associated with such care are typically covered. For example, if a state does not mandate chiropractic care coverage, but does

730. Nat'l Conference of St. Legislatures, *supra* note 254.

731. Bunce & Wieske, *supra* note 231, at 1.

732. Nat'l Conference of St. Legislatures, *supra* note 254 (detailing the various state statutes specifically requiring insurance coverage for autism).

733. Bunce & Wieske, *supra* note 231, at 1.

734. Council of Affordable Health Ins., *Mandate Benefit Definition Memo* (Jan. 2009), available at <http://www.distrodocs.com/10496-mandate-benefit-memo-jan-09>.

735. *Id.*

mandate chiropractors as a covered provider, the costs associated with chiropractic care are paid for by insurance.⁷³⁶

As defining “autism” has been critical in determining the extent of coverage, the Council for Affordable Health Insurance has offered the following definition for autism: “Autism is a brain disorder that affects three areas of development: communication, social interaction, and creative or imaginative play. Mandate provides for evaluation and treatment services.”⁷³⁷ However, as greater debate continues over how to define autism (i.e., as a health, behavioral, or educational disorder), not everyone agrees that the burden should be bore to just the system of providing health care to provide access to treatments for autistic individuals:

While health insurance does and should cover health-related aspects of autism, policymakers who want to ensure that families facing the real financial and other challenges posed by autism should develop safety net programs that meet their needs, rather than trying to impose autism related costs on health insurance.⁷³⁸

“However, autism advocates want to require health insurance to cover therapies more accurately described as educational.”⁷³⁹ Despite this opposition, states have still pushed for the insurance industry to bear the burden, especially when it comes to children: “Even so, states are increasingly looking to insurers to cover more—or all—of the costs of caring for autistic children. Not because health insurers have any particular expertise in, or even responsibility for, autism. Legislators want insurers to cover more of the costs simply so the state doesn’t have to.”⁷⁴⁰

Indiana has been said to have the first effective insurance mandate for those with autism:

In 2001, the Indiana legislature passed the first truly effective autism insurance mandate. A health insurance “mandate” is a requirement that an insurance plan cover particular health care providers (such as chiropractors), benefits (such as mammograms or cleft palate), or patient populations (such as adopted children). The purpose of mandated benefit laws is to guarantee that individuals who are insured will have coverage for the service or type of provider that is the subject of the mandate. When a legislature passes a mandate, insurers must modify benefit plan documents, revise premium rates if necessary, and program claims systems to comply with the new law.⁷⁴¹

736. *Id.*

737. *Id.* at 2-3.

738. Bunce & Wieske, *supra* note 231, at 1.

739. *Id.*

740. *Id.* at 2.

741. UNUMB & UNUMB, *supra* note 270, at 58.

The diversity of legislation mandating insurance coverage for people with autism on the state level is an indication of the present instability and inconsistency in the availability of health care for individuals with autism that becomes largely a matter of where the individual resides.⁷⁴² “Autism and treatment for its various complications is becoming one of the most discussed and demanded state benefit mandates.”⁷⁴³ It is also noticeable that this movement for more expansive insurance coverage at the state level is a result of the desire of states not to carry the high financial burden created by services for individuals with autism:

Even so, states are increasingly looking to insurers to cover more—or all—of the costs of caring for autistic children. Not because health insurers have any particular expertise in, or even responsibility for, autism. Legislators want insurers to cover more of the costs simply so the state doesn’t have to.⁷⁴⁴

But even as states have moved to some consistency legislatively in passing insurance mandates, the mandates themselves differ drastically from state to state over a number of issues.⁷⁴⁵ In order to fully understand the complexity that continues to exist for those seeking insurance coverage for their children with autism at the state level, it is critical to know both the differences and similarities that exist in coverage provided at the state level.

a. State Laws and Insurance Coverage for Treatment

While states are providing insurance coverage for treatment, the extent of treatment coverage will differ by state.⁷⁴⁶ This difference in treatment is primarily demonstrated by the types of treatment covered by states providing coverage for treatment.⁷⁴⁷ Limitation on treatments is often done by requiring that the therapies provided for treatment are “medically necessary.”⁷⁴⁸ The issue of whether or not a therapy is believed to be “medically necessary” is prevalent in cases of behavioral therapy that includes ABA therapy. Suffice it to say that determinations of whether therapies are “medically necessary” are reflected in the law as, for example, Arizona does provide insurance coverage for behavioral therapies, premised on the therapies being “medically

742. See Nat’l Conference of St. Legislatures, *supra* note 254 (listing the different state statutes specifically requiring insurance coverage of autism noting the entire lack of such a state in some states).

743. Bunce & Wieske, *supra* note 231, at 1.

744. *Id.* at 2.

745. Nat’l Conference of St. Legislatures, *supra* note 254.

746. *Id.*

747. *Id.*

748. *Id.*

necessary.”⁷⁴⁹ Some states such as Colorado have more specific legislation on the types of treatment that are covered:

Treatment for autism spectrum disorders is defined to include treatments that are medically necessary, appropriate, effective or efficient and shall include evaluation and assessment services; behavior training and management and applied behavior analysis; habilitative or rehabilitative care, including occupational, physical or speech therapy; pharmacy care and medication; psychiatric care; psychological care; and therapeutic care.⁷⁵⁰

Habilitative or rehabilitative services are available in laws in Alaska, Colorado, Louisiana, Maine, Massachusetts, Missouri, and Montana.⁷⁵¹ Illinois only offers coverage for “habilitative services.”⁷⁵² Nevada also provides for habilitative or rehabilitative services, but also specifies these services must be “medically necessary.”⁷⁵³ Several states specifically include applied behavioral analysis or ABA therapy as a covered treatment within the coverage limits, while a few states including Connecticut and Nevada provide for “behavior therapy” but do not include language specific for ABA therapy.⁷⁵⁴ Several other categories of services have been adopted as treatments available under state laws.⁷⁵⁵ States that offer coverage for occupational therapy include Colorado, Connecticut, Florida, Illinois, Maine, Maryland, New Hampshire, New Jersey, New Mexico, Oregon, Rhode Island, and Texas.⁷⁵⁶ Coverage for speech therapy is available in Colorado, Connecticut, Florida, Illinois, Maine, New Hampshire, New Jersey, New Mexico, Oregon, Rhode Island, and Texas.⁷⁵⁷ Physical therapy receives insurance coverage in Colorado, Connecticut, Florida, Illinois, Maine, Maryland, New Hampshire, New Jersey, New Mexico, Oregon, Rhode Island, and Texas.⁷⁵⁸ Coverage for psychiatric services can be found in Colorado, Connecticut, Iowa, Kentucky, Louisiana, Massachusetts, Michigan, Missouri, Montana, Nevada, New York, Rhode Island, Vermont, and Virginia.⁷⁵⁹ Several states provide coverage for psychological services, including Colorado, Connecticut, Iowa, Kentucky, Louisiana, Massachusetts, Michigan, Missouri, Montana, Nevada, New York, Rhode Island, Vermont, and Virginia.⁷⁶⁰ Additionally,

749. *Id.*

750. *Id.*

751. *Id.*

752. *Id.*

753. *Id.*

754. *Id.*

755. *Id.*

756. *Id.*

757. *Id.*

758. *Id.*

759. *Id.*

760. *Id.*

some states have a provision for therapeutics, including Colorado, Iowa, Connecticut, Kentucky, Louisiana, Massachusetts, Michigan, Missouri, Montana, New York, Vermont, and Virginia.⁷⁶¹ Several states also have coverage for medications, prescriptions, and pharmacy care.⁷⁶² Medications are covered in Colorado, Montana, and Texas while prescriptions are covered in Connecticut and Nevada.⁷⁶³ Pharmacy care coverage is available in Colorado, Kentucky, Louisiana, Massachusetts, Michigan, Missouri, New York, Vermont, and Virginia.⁷⁶⁴ New Hampshire defines their coverage in this area as “prescribed pharmaceuticals”.⁷⁶⁵ Texas also offers coverage for nutritional supplements.⁷⁶⁶

b. Differences in Cost Limitations on Coverage for ABA Therapy

Another difference that may occur between statutes is the amount of coverage provided and how that coverage is applied.⁷⁶⁷ Arizona provides coverage up to \$50,000 for a child up to the age nine and only \$25,000 for a child between age nine and sixteen.⁷⁶⁸ One of the most recent mandates in Virginia provides \$35,000 annually without any age limitation and that an insurer may offer a greater amount than this \$35,000.⁷⁶⁹ Kansas also uses a tiered system by age for coverage amount with a \$36,000 maximum for children up to age seven and a \$27,000 limit for children between ages seven and nineteen.⁷⁷⁰ However, the maximums on various age categories can be drastic as evidenced by the categories established in Kentucky law that provides a \$50,000 maximum limit for children up to age seven while the maximum benefit limit is a mere \$1,000 for children between ages seven and nineteen.⁷⁷¹ Montana also has a fairly large drop in coverage provided between age categories with a maximum benefit of \$50,000 for children eight and younger and children between ages nine and nineteen only having a maximum benefit available of \$20,000.⁷⁷² Meanwhile, while categorizing differences in maximum benefit amounts by age in New Hampshire, the state law’s difference in amount is not as severe as others with a maximum benefit of \$36,000 for children as old as twelve and \$27,000 for children

761. *Id.*

762. *Id.*

763. *Id.*

764. *Id.*

765. *Id.*

766. *Id.*

767. *Id.*

768. *Id.*

769. *Id.*

770. *Id.*

771. *Id.*

772. *Id.*

between ages thirteen and twenty-one.⁷⁷³ Similarly, one of the newest laws enacted in West Virginia provides for \$30,000 for the first three years of treatment with a reduction to \$2,000 per month after those three years (total \$24,000 for a year).⁷⁷⁴ In Florida and New Mexico, an annual coverage limit exists of \$36,000 and a lifetime limit is also imposed of \$200,000.⁷⁷⁵ Similarly, Louisiana's maximum coverage limit is \$36,000, however, Louisiana no longer has a lifetime limit.⁷⁷⁶ The mandates in Illinois, Iowa, and Pennsylvania have an annual cap of \$36,000.⁷⁷⁷ The State of Maine also has a \$36,000 maximum coverage limit but this limit is described only in terms of ABA treatment.⁷⁷⁸ Missouri's law creates limits on the maximum coverage for ABA therapy at \$40,000 for children up to age eighteen.⁷⁷⁹ However, the Missouri law does provide the opportunity for this coverage for ABA therapy to be expanded if it is determined that ABA therapy is "medically necessary."⁷⁸⁰ Under the Massachusetts mandate, limitations may not be imposed on autism treatment that is less than any limits placed on treatments for physical conditions.⁷⁸¹

c. Age Limitations in Coverage for Autistic Children

There have also been differences shown in state insurance mandates in terms of the ages of children covered.⁷⁸² The most extensive coverage has been up to the age twenty-two.⁷⁸³ Nevada provides for coverage up to age twenty-two if the child is enrolled in high school up to that age.⁷⁸⁴ New Mexico offers the same coverage based on school enrollment.⁷⁸⁵ Several states provide for coverage up to age twenty-one including Iowa, Kentucky, New Hampshire, New Jersey, and Pennsylvania.⁷⁸⁶ Three states allow for coverage up to age nineteen: Illinois, Kansas, and New Mexico in the event that the child is not enrolled in school (which would then allow up to twenty-two).⁷⁸⁷ Missouri, Montana, and West Virginia provide coverage up to age eighteen.⁷⁸⁸ The State of

773. *Id.*

774. *Id.*

775. *Id.*

776. *Id.*

777. *Id.*

778. *Id.*

779. *Id.*

780. *Id.*

781. *Id.*

782. *Id.*

783. *Id.*

784. *Id.*

785. *Id.*

786. *Id.*

787. *Id.*

788. *Id.*

Louisiana provides coverage if a child is under age twenty-one.⁷⁸⁹ South Carolina provides coverage up to age sixteen, which is dependent on a child having been diagnosed with autism by age eight.⁷⁹⁰ Several other states have much more limited insurance coverage for children with autism by age. Texas only provides coverage for children with autism up to age nine.⁷⁹¹ Vermont's coverage is limited to between the ages of eighteen months and six years old unless the child enters first grade before six and coverage would end at that time.⁷⁹² One of the most recent state insurance mandates to surface in Virginia limits the age range for coverage between two and six.⁷⁹³ It is clear from this examination of coverage by age of numerous states that the extensiveness of mandates with regard to age is quite substantive and may even force the parents of children with autism to relocate in a different area in order to have the availability of coverage for a longer duration of the child's life.

d. Emerging Issues of State Mandates

Although this Article includes a relatively new state mandate originally passed in Virginia in 2011 among the above discussions in differences between state mandates, it should be observed that this mandate was not put into effect as anticipated due to a problem with language in the original mandate regarding state licensure of ABA therapists.⁷⁹⁴ The legislation, as originally passed, failed to give licensing authority over behavioral analysts in Virginia to the Board of Medicine: "McDonnell amended last year's bill to require the state to license the analysts. But Cuccinelli spokeswoman Caroline Gibson said McDonnell's amendment, which was not reviewed until after the legislation was approved, failed to give the Board of Medicine express authority to license them."⁷⁹⁵ Legislation is now moving through both houses of the Virginia legislature to try to correct this problem.⁷⁹⁶ Utah is one of the newest states to be considering a

789. *Id.*

790. *Id.*

791. *Id.*

792. *Id.*

793. Autism Votes, *Virginia Becomes the 26th State to Enact Autism Insurance Reform Legislation*, AUTISMSPEAKS.ORG (May 6, 2011), <http://www.autismvotes.org/site/c.frKNI3PCImE/b.4445103/k.D5E8/Virginia.htm>.

794. Anita Kumar, *Va. Families of Autistic Children Still Waiting for Coverage*, WASH. POST (Jan. 22, 2012), http://www.washingtonpost.com/local/dc-politics/va-families-of-autistic-children-still-waiting-for-coverage/2012/01/18/gIQA_rQH_WJQ_story.html?wpisrc=emailtoafriend.

795. *Id.*

796. *Id.*

mandate in 2012.⁷⁹⁷ Efforts are also strong in Michigan to pass a mandate.⁷⁹⁸ Attempts have also been made within the past year to eliminate state mandates that were already passed.⁷⁹⁹ As states become increasingly challenged to find ways to make cuts, and work with even more limited resources, autism insurance mandates are a place that may be targeted and that is even truer with the most recent development on the federal level with the failure thus far by HHS to specify “essential health benefits” any more than broad categorizations.⁸⁰⁰

4. *State Commissions, Task Forces, and Councils on Autism*

Another development at the state level has been the creation of commissions, task forces, and councils to provide some unified and comprehensive approach at the state level to the unique challenges of providing different services utilizing a variety of resources, agencies, etc.⁸⁰¹ According to the NCSL:

Some states have created task forces, commissions and councils to study autism issues. Several initiatives have been created to make recommendations for coordinating autism services across many government or private agencies and organizations that may provide health, education or other services. Other initiatives aim to gain a better understanding of the services available in the state or to develop a strategic plan to better serve individuals with autism in the state.⁸⁰²

Those entities can be created through state legislation, a Governor, or another state entity.⁸⁰³ NCSL offers a list of some innovative examples of these bodies last updated May 2011.⁸⁰⁴

797. Laud Brubaker, *Battling Autism: Lawmaker Wants to Require Insurance Coverage*, DESERT NEWS (Jan. 20, 2012), http://www.deseretnews.com/article/700217192/Battling-autism-Lawmaker-wants-to-require-insurance-coverage.html?s_cid=s10.

798. Laura Weber, *Autism Legislation in Michigan Could Gain Momentum in 2012*, MICH. RADIO (Jan. 13, 2012), <http://www.michiganradio.org/post/autism-legislation-michigan-could-gain-momentum-2012>.

799. Michelle Diament, *State May Repeal Autism Insurance Mandate*, DISABILITY SCOOP (Apr. 19, 2011), <http://www.disabilityscoop.com/2011/04/19/state-repeal-autism/12944/>.

800. Phill Galewitz, *Uncertainty Surrounds Autism Insurance Mandates*, DISABILITY SCOOP (Sept. 26, 2011), <http://www.disabilityscoop.com/2011/09/26/uncertainty-autism-mandates/14113/>.

801. *States with an Active Autism Task Force, Commission or Council, 2009*, NAT'L CONFERENCE OF ST. LEGISLATURES, <http://www.ncsl.org/issues-research/health/autism-task-forces-commissions-and-councils.aspx> (last visited Nov. 4, 2012).

802. *Id.*

803. *Id.*

804. *Id.*

5. *Analyzing State Solutions to Health Care for Autistic Children*

If any area of government has really pushed forward the movement for autism and access to health care, it has been the states. While the states offer an array of options for autism, one only needs to likely cross the border of the next state to discover the availability of services for autistic children will be drastically different. However, the legislative efforts of the states, while highlighting diversity, emphasize the challenge of how to provide services for a group of children where much of what is known about the disorder and treating it can differ. This in fact, is the wake-up call to the federal government that it needs to step in and be the place to do the research and policy work to create uniformity in access to health care for autistic children. States can also be a bastion of valuable research that the federal government should explore in its efforts to create federal policy on securing health care services for children with autism.

VI. EXPLORING SOLUTIONS

A. *The Autism Treatment and Acceleration Act of 2009*

A federal attempt to provide a solution for many legal issues for individuals with autism including health care was proposed in the spring of 2009 through the Autism Treatment Acceleration Act of 2009 (ATAA).⁸⁰⁵ President Barack Obama began this endeavor as an effort to fulfill his commitment to improving the lives of people with autism on a national level.⁸⁰⁶ The history of this federal legislative attempt is as follows:

On April 2, 2009, Senator Durbin of Illinois, Senator Casey of Pennsylvania, and Senator Menendez of New Jersey introduced the Autism Treatment Acceleration Act. A companion bill was introduced in the House (H.R. 2413) by Representative Doyle of Pennsylvania and Representative Smith of New Jersey. This bill mandates health insurance autism benefits in ERISA plans and accelerates the development of a service system to meet the needs of individuals with autism.⁸⁰⁷

The primary purpose identified for this bill is “[t]o provide for enhanced treatment, support, services, and research for

805. Autism Treatment Acceleration Act of 2009, S. 819, 111th Cong. (2009), available at <http://www.govtrack.us/congress/bills/111/s819>.

806. Autism Speaks, *Autism Speaks Hails the Introduction of the Landmark Autism Treatment Acceleration Act*, AUTISMSPEAKS.ORG, <http://www.autismspeaks.org/about-us/press-releases/autism-speaks-hails-introduction-landmark-autism-treatment-acceleration-act> (last visited Nov. 30, 2012).

807. UNUMB & UNUMB, *supra* note 270, at 207-08.

individuals with autism spectrum disorders and their families.”⁸⁰⁸ Several findings of this proposal identify the complexity of health care needs for individuals with autism.⁸⁰⁹ The first provides the following description of the concerns:

Individuals with autism spectrum disorders and their families experience a wide range of medical issues. Few common standards exist for the diagnosis and management of many aspects of clinical care. Behavioral difficulties may be attributed to the overarching disorder rather than to the pain and discomfort of a medical condition, which may go undetected and untreated. The health care and other treatments available in different communities can vary widely. Many families, lacking access to comprehensive and coordinated health care, must fend for themselves to find the best health care, treatments, and services in a complex clinical world.⁸¹⁰

The bill also acknowledges that people with autism have frequently been denied access to health insurance.⁸¹¹ While that issue has been addressed through the federal health reform by providing health care coverage for those with pre-existing conditions such as autism, the recognition in ATAA reaffirms that health care access has historically been a problem for individuals with autism. One of the reasons for the push for legislation of this nature comes in part by recognition that children with autism can only acquire educational supports under IDEA until age twenty-one, leaving adults with autism with little access to services essential to their ability to function daily, and would present the potential prevention of their active participation in society.⁸¹² Section 12 of ATAA includes amendments for health care coverage for individuals with autism.

The first set of amendments provided by ATAA concerning health care seeks to amend ERISA. Those amendments provide that group health plans and health insurers supplying health care coverage under these group plans are required to provide coverage for individuals with autism both in terms of diagnosis and treatment.⁸¹³ However, the amendments would not prevent group plans provided under ERISA from establishing requirements or limitations with regards to benefits to people with autism so long as those requirements or limits are essentially no different than

808. Autism Treatment Acceleration Act of 2009, S. 819, 111th Cong. (2009), available at <http://www.govtrack.us/congress/bills/111/s819>.

809. *Id.* § 2(12)(13).

810. *Id.* § 2(12).

811. *Id.* § 2(16).

812. Autism Soc’y, *Autism Treatment Acceleration Act of 2009 (ATAA)*, <https://secure2.convio.net/asa/site/Advocacy?cmd=display&page=UserActionInActive&id=259> (last visited Nov. 4, 2012).

813. Autism Treatment Acceleration Act of 2009, S. 819, 111th Cong. (2009), § 12(a)(1), available at <http://www.govtrack.us/congress/bills/111/s819>.

those placed on the rest of the population.⁸¹⁴ In terms of treatment, ATAA would require coverage for treatment including ABA therapy, among other treatments.⁸¹⁵ As it will be further discussed at the state level, ABA is the current treatment option which is frequently sought by parents of children with autism and its coverage varies by state making this possibility of a national mandate requiring its coverage a welcome option to pursue by advocates for individuals with autism.

B. The Autism Services and Workforce Acceleration Act of 2011

Congress never passed ATAA, and an alternative bill was proposed called Senate Bill 850, the Autism Services and Workforce Acceleration Act of 2011.⁸¹⁶ The findings of the new bill do acknowledge the critical difficulties of access to health care for autistic individuals: “The health care and other treatments available in different communities can vary widely. Many families, lacking access to comprehensive and coordinated health care, must fend for themselves to find the best health care, treatments, and services in a complex clinical world.”⁸¹⁷ The findings also recognize the importance of continuing research to ensure the use of the most appropriate strategies for health care:

Effective health care, treatment, and services for individuals with autism spectrum disorders depends upon a continuous exchange among researchers and caregivers. Evidence-based and promising autism practices should move quickly into communities, allowing individuals with autism spectrum disorders and their families to benefit from the newest research and enabling researchers to learn from the life experiences of the people whom their work most directly affects.⁸¹⁸

The findings also make clear that the goals found in the ADA for protecting the rights of individuals with disabilities generally are the same as for those with autism.⁸¹⁹ That statement in the findings begs the question of why or if it is believed from the start that there are things unique about autism spectrum disorders that essentially dictate that the law crafts out a completely separate area for autism from the more generalized protections already found in disability law such as the ADA. The findings also emphasize that autistic individuals have frequently been denied

814. *Id.*

815. Autism Soc’y, *supra* note 812.

816. Autism Services and Workforce Acceleration Act of 2011, S. 850, 112th Cong. (2011), *available at* <http://www.gpo.gov/fdsys/pkg/BILLS-112s850is/pdf/BILLS-112s850is.pdf>.

817. *Id.* § 2(12).

818. *Id.* § 2(13).

819. *Id.* § 2(15).

access to health care.⁸²⁰

The Autism Services and Workforce Acceleration Act seeks to amend the Part R of title III of the Public Health Service Act 6 (42 U.S.C. 280i) to create the Autism Care Program Demonstration Project.⁸²¹ That project is designed to essentially unify the services for individuals with autism from health care to education to promote a coordinated and uniform system for the delivery of services to the individual with autism.⁸²² Under that model, an autistic individual may have care coordinated through a public or private organization that will “enable targeted beneficiaries to designate a personal care coordinator to be their source of first contact and to recommend comprehensive and coordinated care for the whole of the individual.”⁸²³ Through those public or private state entities, the entities are to develop a plan which specifics are outlined by the law of providing services, monitoring services, and coordinating services for individuals with autism that would be reviewed by the federal government.⁸²⁴ On the basis of the review of such an application, the federal government will then make determinations for three-year grant awards to enable the state entity to carry out the autism coordinated care program.⁸²⁵ An entity that is awarded a grant must then establish an autism care program advisory council.⁸²⁶ Another section of the Autism Services and Workforce Acceleration Act seeks to amend the Part R of title III of the Public Health Service Act 6 (42 U.S.C. 280i) to provide grant funding to entities that qualify to provide services for individuals with autism who are transitioning from youth to adulthood.⁸²⁷ Other sections of the bill include making media outlets part of a campaign to promote awareness and education regarding ASDs and improving the opportunities for training for professionals working with autistic individuals and their families to be able to provide them with information.⁸²⁸

The provisions discussed above are similar to portions of the original autism bill proposed in 2009 through ATAA. However, the Autism Services and Workforce Acceleration Act is substantially different from ATAA as it contains no provisions regarding amending ERISA to provide for coverage for autism in group health care plans or making any major change to insurance coverage that would create any kind of federal mandate. The

820. *Id.* § 2(16)

821. *Id.* § 399GG-1(a).

822. *Id.* § 399GG-1(b).

823. *Id.* § 399GG-1(c)(4)(A).

824. *Id.* § 399GG-1(c)(5)(A)-(J).

825. *Id.* § 399GG-1(d)(1)-(2).

826. *Id.* § 399GG-1(e).

827. *Id.* § 6.

828. *Id.* § 7, 8.

ATAA provided extensive coverage for treatments including ABA therapy. It is curious that the federal government would initially take a major stand for increasing insurance coverage for autistic individuals in the 2009 bill, but would completely eliminate those provisions in the 2011 bill. Even if it was believed that the passage of federal health care reform would mean improving the availability of health care services for autistic individuals, nothing in PPACA goes as far as to require the coverage of any particular treatments for autism including ABA therapy. The recent action of the federal government on the issue of “essential health benefits” in deferring to the states in making decisions regarding treatment further suggests the federal government is again removing itself from making the tough policy decisions regarding autism and access to health care.

VI. THE FEDERAL GOVERNMENT AND AUTISM TREATMENTS

This overview provides some insight of the current complexity of access to health care for individuals with autism at the federal and state levels, and the critical challenges that parents of autistic children face in seeking to secure treatments, in particular, for ABA therapy. As the prevalence of autism continues to rise, the time to address the uncertainties of how and who will finance such services through health care for autistic children will only become more significant. It is also further complicated over what will become of the definition of autism with its diagnostic criteria being revised for the DSM-V, which may or may not drastically reshape our understanding of which children are considered autistic and what that will mean for access to services. Debate exists in not only who should bear the costs, but whether a certain part of the law (i.e., health versus education) as well as what level (federal versus state) should take on such a challenge.

As one recommendation posits, the method of state mandates of insurance coverage force an increase in insurance cost to all when the government should instead bear the responsibility by tailoring programs uniquely to the needs of those with autism:

Private health insurance, with companies and individuals frequently changing plans or health care networks, doesn't provide the consistent care autistic children need. If legislators want to help these families, they should create programs specifically targeted to meet their needs and properly fund them from general revenues—better than Congress did under the IDEA program—rather than try to force the costs onto health insurance, which will just increase everyone's premiums.⁸²⁹

Even with the emergence of sweeping federal health care reform, individuals with autism, especially children, will not

829. Bunce & Wieske, *supra* note 231, at 2.

necessarily benefit. While the federal government's position on autism has been one of support, the only recent testament to this was the Autism Services and Workforce Acceleration Act of 2011, which primarily funds research initiatives. While research is important, it lacks what is needed to fully alleviate the financial burden on parents of children with autism for costly treatments. The federal government had the opportunity most recently to make a statement for its commitment on behalf of individuals with autism in making a determination on "essential health benefits" under PPACA but passed on this opportunity. One description of the recent turn of events regarding PPACA has been described as follows:

The health reform law in all its 2,000-plus page glory sets up a bevy of initiatives, specifications and several historic mandates all with the primary goal of making affordable and comprehensive health care available to most Americans. But what's become increasingly clear is that this transformation is a work in progress, evolving and adapting as politics, a faltering economy and policy insights trigger tweaks, compromises and new approaches.⁸³⁰

There is no doubt that for the federal government to define "essential health benefits" with greater specificity would have been a daunting task and one that would not have been free of difficulty. But the idea of "federal health reform" was to provide some uniformity. The challenge the federal government is avoiding and the parties involved is well articulated as follows:

The problem is that coming up with a national EHB standard is far harder than it sounds. For starters, what one segment of the population considers "essential" is not the same for another. And of course there is the looming issue of cost; if benefits are too generous, states and the federal government—who both will subsidize some portion of the premiums for many Americans who utilize the exchanges—will simply not be able to afford to help all those who need it. Meanwhile, lobbyists for medical device makers, drug companies, the home health industry and other "stakeholders" have descended on Washington to make the case for including their products and services in the package of essential benefits. Advocates for autistic children, the mentally ill and cancer patients (just to name a few) have also put pressure on HHS and lawmakers to specify coverage for often-costly—yet beneficial—behavioral therapies, drugs and other services. Defining "essential health benefits," according to the authors of a recent Institute of Medicine report that attempted to do just that "is a politically and socially charged endeavor."⁸³¹

830. *We Still Need a National Standard for Essential Health Benefits*, REFORMING HEALTH, <http://reforminghealth.org/2012/01/04/we-still-need-a-national-standard-for-essential-health-benefits/> (last visited Nov. 4, 2012).

831. *Id.*

In deferring to state governments, the federal government is failing vulnerable populations—including the families of children with autism. Part of the debate over mandating ABA therapy is that it puts the entire cost on the insurance industry, it makes clear that those using the exchanges will rely on both the federal and state governments to pick up the premiums. There is no doubt that there should be universality across the nation for access to certain services for particular conditions when the research has been developed to understand both the conditions and the treatment options. Is there true federal health care reform if the parents of an autistic child will still get coverage for ABA therapy in one state but not another? What does this “reform” do to alleviate this problem for them?

While there has been criticism of ABA, there is sufficient evidence to back its use as well as behavioral treatments and early intervention as the best approaches for autism, which is a lifelong disability. The federal government has even recently joined those supporting this contention by expressing a willingness to provide access to ABA therapy as part of health care for federal workers. Isn't it worth investing in treatment to try to help give these children the best chance possible of flourishing as members of society?

On October 12, 2012, a group of senators sent a letter to Kathleen Sebelius expressing their frustration about President Obama's healthcare reform potentially leaving those with autism and their families without coverage for ABA therapy.⁸³² In that letter, they stated:

All people affected by autism should have access to needed treatment. That will not occur under the guidance issued by the Department of Health and Human Services. Rather than setting a uniformly high national standard, the guidance allows states to select benchmark plans that neglect or skimp on autism care. The guidance requires states without ABA mandates and states with ABA mandates enacted in 2012 either to defray the cost of ABA coverage or provide no ABA coverage. If the guidance is not changed, children and adults with autism will not be better off when Affordable Insurance Exchanges launch in 2014 than they are today.

According to the December 2011 Essential Health Benefits Bulletin, the benefit category “mental health and substance use disorder services, including behavioral treatment” should cover the behavioral health services associated with autism treatments and therapies. In our deliberations over the Affordable Care Act,

832. Michelle Diament, *Senators Want ABA Therapy Deemed 'Essential'*, DISABILITYSCOOP.COM (Oct. 23, 2012), <http://www.disabilitycoop.com/2012/10/23/senators-aba-essential/16705/>.

Congress recognized autism as a top national health priority. We intended not to preserve the status quo but to reduce the burdens faced by families across the nation. In finalizing the guidance for essential health benefits, we urge you to clarify behavioral health treatment as including ABA for individuals on the autism spectrum.⁸³³

If the future definitional changes regarding the autism spectrum by the APA are accurate, then those autistic children who are in the greatest need of the most intensive treatments such as ABA therapy will be the ones who have access to the treatment by the revised diagnosis. That being the case, it is likely less children will need such treatments or will need them in a much more limited duration than previously thought, as the APA indicated more accurate diagnosis will improve providing children with different degrees of autism with the correct treatment. This makes an even stronger case for making behavioral treatments available across the country.

The federal government's position on ABA therapy has never been said to change since the 1999 U.S. Surgeon General's Report on it supporting its use. Additionally, the Autism Acceleration Act of 2009 failed to move forward required specific insurance coverage of particular treatments for autism including ABA therapy to be implemented as changes under several of the federal programs for insurance coverage such as ERISA, Federal Health Benefit Plans (FEHBP), and TRICARE. The next federal bill to be introduced for autism completely eliminated these major changes as states continue to pass laws requiring insurance companies to provide coverage for ABA therapy and other behavioral treatments. For the federal government to say it has really moved forward for access to health care for autistic children, it must deal candidly with the issue of treatments for autistic children, especially ABA therapy. If the federal government has doubts about ABA therapy and treatments, the research should be done in conjunction with federal legislators and policymakers to move forward on federal legislative changes to insurance coverage to provide ABA therapy and other appropriate treatments for autism as well as federal health care reform. As the DSM plans to change the definitions regarding autism, the federal government must utilize this opportunity to try to also determine how certain treatments impact particular populations of autistic children, and explore ways to design federal legislation to allow treatments to be tailored to the specific needs of different forms of autism. This

833. Letter from Kirsten E. Gillibrand, Sherrod Brown, Barbara Boxer, and Al Franken, U.S. Senators, to Kathleen Sebelius, Secretary of Health and Human Services (Oct. 12, 2012), *available at* http://www.autismspeaks.org/sites/default/files/docs/gr/4.senators_10.15.pdf.

means that the classic case of autism may have significantly different needs than a child on the highest end of the spectrum with Asperger's syndrome, and legislation to create federal programming can and should take these differences into consideration if possible and workable. The federal government must step in to federally mandate or provide alternative programming for treatments for autism based on a coordinated effort between federal researchers and federal policymakers that has obviously been lacking in this area. For whatever reason, it seems that research and policy at the federal level on autism has not had the necessary coordination that is required for effective policy results.

The alternative is letting autistic children and their families continue to battle at the state level or going from state to state to secure treatments. The greater medical costs associated with autistic children could be lessened if they are provided with the treatments that assist their continued growth and development at the earliest stage. This also increases the chances of their functionality into adulthood that impacts the overall cost, as autism is a lifelong disorder. For the federal government to do any less, it not only harms a vulnerable population—autistic children and their families—but our entire nation as more and more U.S. families are impacted by autism every day.

