

IS APPLIED BEHAVIORAL ANALYSIS EDUCATION, MEDICINE, OR BOTH?: A STUDY OF THE FUNDING CHALLENGES THAT ACCOMPANY AN AUTISM DIAGNOSIS

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I. INTRODUCTION

In the last fifty years or so, there has been an explosion in the rates of Autism Spectrum Disorder (“ASD”) diagnoses.¹ Fortunately, the same time period has seen the development of a method to take on this debilitating disorder—Applied Behavioral Analysis (“ABA”).² This method entails thorough analysis of behaviors, weeding out negative aspects and encouraging good ones.³ As one would expect, this is a costly endeavor unaffordable to anyone but the most well-off.⁴

ABA is perceived as lying on the intersection between medicine and education.⁵ While this provides for two potential sources of funding,⁶ the perception can hurt the cause by scattering responsibility and reducing accountability. These sectors provide a pretext for each other, leaving parents to fend for themselves with the deck stacked against them. The educational system provides, in an unfocused manner, the minimum required of it by the Individuals with Disabilities Education Act (“IDEA”),⁷ and medical insurance can only be relied upon when specific mandates are in place.⁸ What is needed

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¹ See *infra* notes 13–14 and accompanying text.

² See *infra* note 45 and accompanying text.

³ See *infra* notes 47–48 and accompanying text.

⁴ See *infra* notes 80–87 and accompanying text.

⁵ See, e.g., *Illinois Insurance Law Update*, AUTISM NEWS NETWORK, <http://www.autismnews.net/insurance.html> (last visited Jan. 25, 2016).

⁶ *Id.*

⁷ See *M.H. ex rel. P.H. v. N.Y.C. Dep’t of Educ.*, 685 F.3d 217, 252 (2d Cir. 2012); *Deal ex rel. Deal v. Hamilton Cty. Bd. of Educ.*, 392 F.3d 840, 861 (6th Cir. 2004); *Adams ex rel. Adams v. Oregon*, 195 F.3d 1141, 1149–1150 (9th Cir. 1999).

⁸ See *Illinois Insurance Law Update*, *supra* note 5.

is a clear division of responsibility with one sector—perhaps the educational—taking charge and seeing to it that the obligations are, in fact, discharged.

Part II provides some background information on ASD and its symptoms. The symptoms are broken down into three categories to give the reader a sense of the importance of treatment and what the treatment does, and does not, address. Part III introduces ABA, its role in treating children with ASD, and its costs. Part IV examines the extent to which funding for ABA is currently provided through the educational system. In addition, the case is made for the educational system to undertake the coordinating aspects of the treatment. Part V then analyzes the funding options that are available through the various medical channels. Part VI addresses, and debunks, some of the claims insurance companies make when denying coverage for ABA and argues that ABA has defined characteristics of both medicine and education. ABA is conventional medicine in terms of its ability to control the core symptoms of ASD and to prevent behavioral side-effects. That does not, however, take away from the fact that its methodology and immediate effect are otherwise educational. Finally, Part VII concludes that despite ABA's dual-character as both a medical and educational treatment, more must be done to define the responsibilities of each, and to relieve the parents of the grueling task of coming up with the funding for the only viable treatment available for their child.

II. ASD AND ITS SYMPTOMS

A. *What is ASD?*

Autism Spectrum Disorder (“ASD”) is an umbrella term used by the American Psychiatric Association for the diagnosis of a family of developmental disorders.⁹ Those disorders are: autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (“PDD-NOS”).¹⁰ According to Centers for Disease Control and Prevention (“CDC”) estimates, one in sixty-eight American children—for a total of

⁹ See *Autism Spectrum Disorder*, AM. PSYCHIATRIC PUB. (2013), <http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf> (outlining the American Psychiatry Association's revised recommendation, included in its DSM-5, for a single diagnosis for the four listed disorders).

¹⁰ *Id.*

4,750,000¹¹—are diagnosed with the disorder.¹² In the last fifty years or so, identification of the disorder has multiplied twenty to thirtyfold,¹³ with an increase of 123% in the last thirteen years alone.¹⁴

“Autism literally means ‘aloneness,’ or living in one’s own world.”¹⁵ The symptoms can range from difficulty in understanding and relating to other peoples’ perspectives or emotions, to non-interaction with others and treating them as objects.¹⁶ As a result, many autistic children do not develop appropriate social skills and they do not learn to talk and behave as they should.¹⁷

The challenges presented by the disorder vary by the case¹⁸ and can include any number of issues from the following categories: its core symptoms;¹⁹ physical or mental comorbidities;²⁰ and behavioral problems associated with the disorder.²¹

¹¹ This figure is based on current estimates of 323 million, as of February 19, 2016. U.S. *and World Population Clock*, U.S. CENSUS BUREAU, <http://www.census.gov/popclock/> (last visited Feb. 19, 2016).

¹² *Autism and Developmental Disabilities Monitoring (ADDM) Network*, CDC, <http://www.cdc.gov/ncbddd/autism/addm.html> (last visited Aug. 12, 2015).

¹³ *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010*, CDC (Mar. 28, 2014),

http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w.

¹⁴ *Autism and Developmental Disabilities Monitoring (ADDM) Network*, CDC (Aug. 12, 2015), <http://www.cdc.gov/ncbddd/autism/addm.html>.

¹⁵ James B. Adams et al., *Advice for Parents of Young Autistic Children (2012, Revised)-Part 1*, AUTISM RESEARCH INS. (2012), http://www.autism.com/understanding_advice. This paper was co-authored by Dr. Temple Grandin, a professor of animal science at Colorado State University and a well-known Autism success story. See Grandin, Temple, COLORADO STATE UNIVERSITY, <http://ansci.agsci.colostate.edu/people/ansci-faculty/grandin-temple/> (last visited September 4, 2016).

¹⁶ See Adams et al., *supra* note 15.

¹⁷ *Id.*

¹⁸ See *Autism Spectrum Disorder: Signs and Symptoms*, CDC (Feb. 21, 2016), <http://www.cdc.gov/ncbddd/autism/signs.html>.

¹⁹ David J. Posey et al., *Developing Drugs for Core Social and Communication Impairment in Autism*, U.S. NAT’L LIBR. OF MED. NAT’L INSTS. OF HEALTH (Oct. 17, 2008), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2566849/> (“Autistic disorder (autism) is defined by specific impairments affecting socialization, communication, and stereotyped behavior which together are called the ‘core symptoms’ of autism.”).

²⁰ See Isaac S. Kohane et al., *The Co-Morbidity Burden of Children and Young Adults with Autism Spectrum Disorders*, U.S. NAT’L LIBR. OF MED. NAT’L INSTS. OF HEALTH (Apr. 12, 2012), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3325235/>.

²¹ See Johnny L. Matson & Marie S. Nebel-Schwalm, *Assessing Challenging Behaviors in Children With Autism Spectrum Disorders: A Review*, 32 RES. IN DEVELOPMENTAL DISABILITIES 567, 574 (2007), available at <http://www.sciencedirect.com/science/article/pii/S0891422206000734> (noting that, although most diagnosticians are of the opinion that challenging behaviors are not core features of ASD, the general consensus is that these maladaptive responses covary with ASD at a high rate).

The core symptoms of ASD, from which the diagnosis is derived, are: (A) “[p]ersistent deficits in social communication and social interaction across multiple contexts;”²² and (B) “[r]estricted, repetitive patterns of behavior, interests, or activities.”²³ These symptoms are manifested through mild to severe challenges with thinking, and learning; impediments to socializing and communicating; and a lack of agility with regard to interests.²⁴ Moreover, individuals with ASD are significantly more prone to a host of physical and mental disorders.²⁵ Some examples are: anxiety and mental disorders;²⁶ attention-deficit

²² AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 315.39 (5th ed. 2013), available at <https://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria>. The manual goes on to explain that this deficit is manifested by the following:

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

Id. at 299.00.

²³ The manual indicates that this impairment is manifested by at least two of the following:

Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases). 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day). 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest). 4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Id.

²⁴ See CDC, *supra* note 18.

²⁵ See Kohane et al., *supra* note 20 (citing the prevalence of these conditions).

²⁶ See Susan W. White et al., *Anxiety in Children and Adolescents with Autism Spectrum Disorders*, 29 CLINICAL PSYCHOL. REV. 216, 216 (2009), <http://www.sciencedirect.com/science/article/pii/S027273580900004X>; Ailsa J. Russel et al., *Cognitive Behavior Therapy for Comorbid Obsessive-Compulsive Disorder in High-Functioning Autism Spectrum Disorders: A Randomized Controlled Trial*, 30 DEPRESSION AND ANXIETY 697, 697 (2013),

hyperactivity disorder (“ADHD”);²⁷ gastrointestinal problems;²⁸ epilepsy;²⁹ intellectual³⁰ and learning disabilities;³¹ motor abnormalities;³² sensory problems;³³ sleep disorders;³⁴ and speech deficits.³⁵ Perhaps the most visible signs of ASD are those in the third category—the behavioral. Problematic behavior may include any of the following:³⁶ aggression, bruxism,³⁷ coprophagy,³⁸ dawdling, destruction, disruption, drooling, elective mutism, elopement, feces smearing, food refusal, food theft, genital stimulation, hyperactive behavior, hyperventilation, inappropriate vocalizations, noncompliance, pica,³⁹ public disrobing, rapid eating, rectal digging,

<http://onlinelibrary.wiley.com/doi/10.1002/da.22053/abstract;jsessionid=16858E3BFAB9027FAD55FDCB3515F751.f01t03>; Susan L. McElroy, *Diagnosing and Treating Comorbid (Complicated) Bipolar Disorder*, 15 J. CLINICAL PSYCHIATRY 35, 35 (2004), <http://www.psychiatrist.com/JCP/article/Pages/2004/v65s15/v65s1509.aspx>; Johnny L. Matson & Marie S. Nebel-Schwalm, *Comorbid Psychopathology with Autism Spectrum Disorder in Children: An Overview*, 28 RES. IN DEVELOPMENTAL DISABILITIES 341–52 (2007), <http://www.sciencedirect.com/science/article/pii/S0891422206000497>.

²⁷ See Angela M. Reiersen & Richard D. Todd, *Co-Occurrence of ADHD and Autism Spectrum Disorders: Phenomenology and Treatment*, 8 EXPERT REV. OF NEUROTHERAPEUTICS 657, 657 (2008), <http://www.tandfonline.com/doi/full/10.1586/14737175.8.4.657>.

²⁸ See Craig A. Erickson et al., *Gastrointestinal Factors in Autistic Disorder: A Critical Review*, 35 J. AUTISM AND DEVELOPMENTAL DISORDERS 713, 713 (2005), <http://link.springer.com/article/10.1007%2Fs10803-005-0019-4>.

²⁹ See Roberto Tuchman & Isabelle Rapin, *Epilepsy in Autism*, 1 THE LANCET NEUROLOGY 352, 352 (2002).

³⁰ See Johnny L. Matson & Mary Shoemaker, *Intellectual Disability and its Relationship to Autism Spectrum Disorders*, 30 RES. IN DEVELOPMENTAL DISABILITIES 1107, 1107 (2009), <http://www.sciencedirect.com/science/article/pii/S0891422209000948>.

³¹ M. DAWSON ET AL., *LEARNING AND MEMORY: A COMPREHENSIVE REFERENCE* 759–72 (2008).

³² See Meng-Chuan Lai et al., *Autism*, 383 THE LANCET 896, 897 (2014).

³³ See Grace T. Baranek, *Efficacy of Sensory and Motor Interventions for Children with Autism*, 32 J. AUTISM & DEVELOPMENTAL DISORDERS 397, 398 (2002), <http://link.springer.com/article/10.1023%2FA%3A1020541906063>.

³⁴ See Beth A. Malow et al., *A Practice Pathway for the Identification, Evaluation, and Management of Insomnia in Children and Adolescents With Autism Spectrum Disorders*, 2 PEDIATRICS 106, 107 (2012).

³⁵ See Ericka L. Wodka et al., *Predictors of Phrase and Fluent Speech in Children With Autism and Severe Language Delay*, 131 PEDIATRICS 1128, 1128–34 (2013) (“Autism is a disorder that significantly affects language/communication skills, with many children not developing fluent language.”).

³⁶ See *McHenry v. PacificSource Health Plans*, 679 F. Supp. 2d 1226, 1240 (D. Or. 2010) (quoting Robert H. Horner et al., *Problem Behavior Interventions for Young Children with Autism: A Research Synthesis*, 32 J. AUTISM & DEVELOPMENTAL DISORDERS 423, 431 (2002)).

³⁷ Defined as teeth grinding. *Id.*

³⁸ Defined as feces eating. *Id.*

³⁹ “The persistent eating of inedible substances, such as dirt or paint that have no nutritional value.” *Mental Health and Pica*, WEBMD, <http://www.webmd.com/mental-health/mental-health-pica> (last visited Oct. 21, 2015).

rumination, self-injurious behavior, tantrum, and tongue protrusion.⁴⁰

III. TREATMENT AND ABA

A. *How is ASD Treated?*

There is no known cure for the core symptoms of ASD.⁴¹ Treatment is primarily focused on the resultant developmental impairments.⁴² “The primary goals of treatment are to minimize the core features and associated deficits, maximize functional independence and quality of life, and alleviate family distress.”⁴³ Those goals are realized through therapy and, to a lesser extent, medication.⁴⁴ While medication targets adverse behaviors on a temporary basis, only therapy is effective in the development of positive life skills.⁴⁵

The therapies necessary for the treatment of ASD range from the conventional—e.g. occupational and speech—to the ASD specific: applied behavioral analysis (“ABA”).⁴⁶ ABA involves painstaking analysis of behaviors, and weeding out the negative aspects while encouraging the positive ones.⁴⁷ The common usage of the term “ABA” includes a number of different methods and variations, all based on similar principles.⁴⁸

⁴⁰ See *McHenry*, 679 F. Supp. 2d at 1240.

⁴¹ See *Treatment*, CDC, <http://www.cdc.gov/ncbddd/autism/treatment.html> (last visited Oct. 22, 2015); Scott M. Myers & Chris Plauché Johnson, *Management of Children With Autism Spectrum Disorders*, 120 PEDIATRICS 1162, 1162 (2007).

⁴² *McHenry*, 679 F. Supp. 2d at 1231 (quoting Patricia Howlin, *The Effectiveness of Interventions for Children with Autism*, J. NEURAL TRANSMISSION, Supplement 69, at 101 (2005)).

⁴³ Myers & Johnson, *supra* note 41; see also Susan E. Levy et al., *Autism*, 374 THE LANCET 1627, 1634 (2009) (“Comorbid conditions” in this context refers to both physical/mental disorders and behavioral problems).

⁴⁴ See Meng-Chuan Lai et al., *supra* note 32, at 904.

⁴⁵ See Michael G. Aman, *Medication and Parent Training in Children With Pervasive Developmental Disorders and Serious Behavior Problems: Results From a Randomized Clinical Trial*, 48 J. AM. ACAD. OF CHILD & ADOLESCENT PSYCHIATRY, 1143–54 (2009).

⁴⁶ *Treatment*, CDC, <http://www.cdc.gov/ncbddd/autism/treatment.html> (last visited Oct. 22, 2015). The effectiveness of ABA for ASD has created an association between the two despite the fact that it was not conceived as a treatment for ASD and is sometimes applied to other disorders. See Karola Dillenburger & Mickey Keenan, *None of the As in ABA stand for Autism: Dispelling the Myths*, 34(2) J. INTELL. & DEVELOPMENTAL DISABILITY 193, 193 (2009).

⁴⁷ *Id.*; see COOPER et al., APPLIED BEHAVIOR ANALYSIS 16 (2d ed. 1987); Donald M. Baer et al., *Some Current Dimensions of Applied Behavior Analysis*, 1 J. APPLIED BEHAV. ANALYSIS 1, 1 (1968), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1310980/pdf/jaba00083-0089.pdf> (for what is from the founding documents of the field).

⁴⁸ Some variations of ABA are: Discrete Trial Training (DTT), Early Intensive Behavioral Intervention (EIBI), Pivotal Response Training (PRT), Verbal Behavior

B. *Effectiveness of ABA for ASD*

The studies confirming the efficacy of ABA are conclusive.⁴⁹ Professional associations,⁵⁰ courts,⁵¹ and administrative agencies⁵² have all recognized ABA treatment as the closest to a cure currently available. As far back as 1999, the Surgeon General declared: “Thirty years of research demonstrated the efficacy of applied behavioral methods [for children with autism] in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”⁵³

In a 2007 peer-reviewed report, the American Academy of Pediatrics, had the following to say about 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 Children who receive early intensive behavioral treatment have

Intervention (VBI). CDC, *supra* note 46.

⁴⁹ “The reliable evidence” as defined by Florida law, conclusively shows that ABA is not “experimental.” . . . [T]here exists in the medical and scientific literature a plethora of peer-reviewed meta-analyses, studies, and article that clearly establish ABA is an effective and significant treatment to prevent disability and restore developmental skills to children with autism and ASD.” K.G. *ex rel.* Garrido v. Dudek, 864 F. Supp. 2d 1314, 1326 (S.D. Fla. 2012), *aff’d in part & vacated in part*, 731 F.3d 1152 (11th Cir. 2013).

⁵⁰ See, e.g., Scott M. Myers & Chris Plauché Johnson, *Management of Children With Autism Spectrum Disorders*, 120 PEDIATRICS 1162, 1164 (2007) (American Academy of Pediatrics); Eve Glicksman, *Catching Autism Early*, 43 MONITOR ON PSYCHOL. 56, 56 (2012) (the American Psychological Association, referring to the Early Start Denver Model (“ESDM”) that incorporates ABA methodology); *The Early Start Denver Model (ESDM)*, AUTISM SPEAKS, <https://www.autismspeaks.org/what-autism/treatment/early-start-denver-model-esdm> (last visited Oct. 25, 2015); see also James B. Adams et al., *Advice for Parents of Young Autistic Children (2012, Revised)-Part 1*, AUTISM RES. INS., (2012), http://www.autism.com/understanding_advice (stating that the American Medical Association recommends the treatment).

⁵¹ See, e.g., *Dudek*, 864 F. Supp. 2d at 1326; *McHenry v. PacificSource Health Plans*, 679 F. Supp. 2d 1226, 1231 (D. Or. 2010) (internal citation omitted) (listing a host of supportive studies and stating: “While the degree of ABA’s efficacy is the subject of current research and debate, ‘[d]ecades worth of scientific research provide clear and convincing support’ for its use as an ‘effective intervention.’”); *Potter v. Blue Cross Blue Shield*, No. 10-cv-14981, 2013 U.S. Dist. LEXIS 119391, at *30 (E.D. Mich. Mar. 30, 2013) (“[W]hat the studies and commentary in the record have in common is the conclusion that ABA therapy produces clinically proven and statistically significant positive results for children with autism spectrum disorder.”).

⁵² See, e.g., CDC, *supra* note 46; *See Autism Spectrum Disorder: Fact Sheet*, NAT’L INS. OF NEUROLOGICAL DISORDERS AND STROKE, http://www.ninds.nih.gov/disorders/autism/detail_autism.htm#3082_8 (last visited Oct. 25, 2015).

⁵³ NAT’L INST. OF MENTAL HEALTH, *MENTAL HEALTH: A REPORT OF THE SURGEON GENERAL* 164 (1999), <https://profiles.nlm.nih.gov/ps/access/NNBBJC.pdf>.

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.⁵⁴

Likewise, in a report published in the *Journal of Clinical Child and Adolescent Psychology*, the authors summarize available peer-reviewed research and conclude that ABA has been generally proven to provide significant benefits to individuals with ASD.⁵⁵ The report analyzes both Randomized Controlled Trials (“RCTs”)—the *gold standard* of medical research⁵⁶—and replicative studies, finding the general efficacy of the approach to be well corroborated while suggesting that further research should be conducted into the tailoring of specific approaches to individual subjects.⁵⁷

The overwhelming evidence in ABA’s favor led the experts testifying in *K.G. v. Dudek* to declare “that they have never seen a study in the peer-reviewed literature where the authors concluded that ABA was ineffective as treatment for children with autism or a study that characterized ABA as experimental.”⁵⁸

In a recent study, the authors concluded that “[a]utism spectrum disorders (ASDs) were once considered lifelong disorders, but recent findings indicate that some children with ASDs no longer meet diagnostic criteria for any ASD and reach normal cognitive function.”⁵⁹

⁵⁴ See Myers & Johnson, *supra* note 50, at 1164.

⁵⁵ See Sally J. Rogers & Laurie A. Vismara, *Evidence-Based Comprehensive Treatments for Early Autism*, 37 J. CLINICAL CHILD & ADOLESCENT PSYCHOL. 1, 18–19 (2008); see also Zachary Warren et al., *Therapies for Children With Autism Spectrum Disorders*, EFFECTIVE HEALTH CARE PROGRAM 30–37 (2011) (providing an extensive review of existing research prepared by Vanderbilt Evidence-based Practice Center for the U.S. Department of Health and Human Services’ Agency for Healthcare Research and Quality); Glenn O. Sallows & Tamlynn D. Graupner, *Intensive Behavioral Treatment for Children With Autism: Four-Year Outcome and Predictors*, 110 AMER. J. ON MENTAL RETARDATION 417, 417 (2005).

⁵⁶ See Gail M. Sullivan, *Getting Off the “Gold Standard”*: *Randomized Controlled Trials and Education Research*, 3 J. OF GRADUATE MED. EDUC. 285 (2011).

⁵⁷ *Id.*

⁵⁸ *K.G. ex rel. Garrido v. Dudek*, 981 F. Supp. 2d 1275, 1288 (S.D. Fla. 2013).

⁵⁹ Alyssa J. Orinstein et al., *Intervention History of Children and Adolescents with High-Functioning Autism and Optimal Outcomes*, 35 J. OF DEVELOPMENTAL AND BEHAV. PEDIATRICS 247, 247 (2014). The passage was quoted on account of its use of recovery-like terms, which are more in line with what this author heard from a parent. Although unclear from the quote to what extent the authors attribute those outcomes to ABA, a look at the actual study will clear up any uncertainty. The authors assume the effectiveness of ABA and examine the data in that context. The study is not about ABA, per se, but about optimal outcomes for ASD in general. See also Ruth Padawer, *The Kids who Beat Autism*, N.Y. TIMES MAGAZINE (July 31, 2014),

These children are considered to have achieved ‘optimal outcomes.’”⁶⁰ The authors then write that the “[optimal outcome] individuals generally receive earlier, more intense interventions and more ABA.”⁶¹ In another study entitled “Early Behavioral Intervention Is Associated With Normalized Brain Activity in Young Children With Autism,” the authors, after confirming the efficacy of ABA,⁶² present data and conclude that their study “underscores the dynamic and plastic nature of early brain development in ASD and the potential of early intervention to alter the course of brain and behavioral development in young children with ASD and thereby promote the most positive long-term outcomes.”⁶³

Of course, ABA is not without its detractors. Dr. Ole Ivor Lovaas, the acknowledged father of ABA’s application to ASD, has taken on the cherry picking of studies with less impressive results.⁶⁴ In a 2006 article, he calls for viewing such studies in the context of the whole—individual studies within a mass of five-hundred.⁶⁵ Regarding criticism that ABA encourages robot-like behavior in children, Dr. Lovaas points out that ABA is progressing to the point where that is no longer the case.⁶⁶ Dr. Lovaas also addresses concerns that he has overstated the results in his original study⁶⁷ by labeling the results as “recovery.”⁶⁸ He points out that he has self-criticized his study and has always called for rigorous peer-review on his findings.⁶⁹ The precise degree of effectiveness should be of limited concern when evaluating a treatment in isolation. What is important is that it provides a real chance to better the lives of so many children and their families, which is why it is currently recommended by so many.⁷⁰

http://www.nytimes.com/2014/08/03/magazine/the-kids-who-beat-autism.html?_r=0.

⁶⁰ See Orinstein et al., *supra* note 59.

⁶¹ *See id.*

⁶² Geraldine Dawson et al., *Early Behavioral Intervention is Associated with Normalized Brain Activity in Young Children with Autism*, 51 J. AMER. ACADEMY OF CHILD & ADOLESCENT PSYCHIATRY 1150, 1150–52 (2012).

⁶³ *Id.* at 1159.

⁶⁴ See O.I. Lovaas & Scott Wright, “A Reply to Recent Public Critiques. . .”, 3 J. EARLY AND INTENSIVE BEHAV. INTERVENTION 234, 234 (2006).

⁶⁵ *Id.* Those numbers reflect the reality in 2006, when the article was written. *See Id.*

⁶⁶ *Id.* at 235.

⁶⁷ See O. I. Lovaas, *Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children*, 55 J. CONSULTING & CLINICAL PSYCHOL. 3 (1987).

⁶⁸ *Id.*; Lovaas & Wright, *supra* note 64, at 235.

⁶⁹ Lovaas & Wright, *supra* note 64, at 235.

⁷⁰ *See infra* note 199 and accompanying text.

C. *The Imperative of Early Intervention*

In the realm of ABA, time is of essence.⁷¹ The earlier the treatment begins, the greater the odds of recognizing its full benefit.⁷² While the facts speak for themselves, a review of the literature suggests the following assumptions: (1) as the child lives with the condition, bad behaviors are learned and ingrained;⁷³ (2) “core symptoms of autism [are] malleable in early childhood;”⁷⁴ (3) “the neurologic plasticity of the toddler years affords the best opportunity to attempt fundamental, broad based behavioral change;”⁷⁵ (4) once the impediment, ASD, is contained, age-appropriate development can resume;⁷⁶ (5) only early intervention can “alter the course of brain and behavioral development,”⁷⁷ or, most importantly; (6) many of the problem behaviors associated with ASD stem from the frustrating inability of the child to express himself.⁷⁸ Teaching the child, at a young age, how to express himself, renders the cause of those behaviors moot. Regardless of the psychological or neurobiological reasons behind the phenomenon, the consensus is clear that the longer a child lives with ASD, the more the condition progresses and takes root.⁷⁹

D. *The High Cost of Treatment*

The cost of effective ABA therapy can be beyond the reach of many.⁸⁰ The treatment must be administered by qualified professionals

⁷¹ See Eric B. Larsson, *Applied Behavior Analysis (ABA) for Autism: What is the Effective Age Range for Treatment?*, THE LOVAAS INS. FOR EARLY INTERVENTION: MIDWEST HEADQUARTERS (2012), <http://www.abia.net.au/images/Larsson-What-is-the-effective-age-range-of-ABA-for-autism.pdf>; see also Glicksman, *supra* note 50, at 56.

⁷² See Larsson, *supra* note 71. Glicksman, *supra* note 50, at 56.

⁷³ *Start Treatment Early—By Age Three!*, SYNAPSE: RECONNECTING LIVES, <http://www.autism-help.org/story-early-intervention.htm> (last visited Oct. 31, 2015).

⁷⁴ See Rogers & Vismara, *supra* note 55, at 20.

⁷⁵ Gail G. McGee et al., *An Incidental Teaching Approach to Early Intervention for Toddlers with Autism*, 24 RES. AND PRAC. FOR PERSONS WITH SEVERE DISABILITIES 133, 135 (1999) (internal citation omitted).

⁷⁶ See K.G. *ex rel.* Garrido v. Dudek, 864 F. Supp. 2d 1314, 1319–20 (S.D. Fla. 2012), *aff'd in part & vacated in part*, 731 F.3d 1152 (11th Cir. 2013).

⁷⁷ Dawson et al., *supra* note 62, at 1159.

⁷⁸ See Holly Bortfeld, *Dealing with Aggression in ASD*, TALK ABOUT CURING AUTISM (Nov. 12, 2012), <http://www.tacanow.org/family-resources/dealing-with-aggression-in-asd/>. The gender-specific use of “himself” is intentional; according to the CDC, boys are more likely to be identified with ASD by a ratio of 4.5:1. See *Autism and Developmental Disabilities Monitoring (ADDM) Network*, CDC, <http://www.cdc.gov/ncbddd/autism/addm.html> (last visited on Nov. 4, 2015).

⁷⁹ See *supra* notes 71–77.

⁸⁰ See Deanna L. Sharpe & Dana Lee Baker, *Financial Issues Associated with Having a Child with Autism*, 28 J. FAM. AND ECON. ISSUES 247, 248 (2007), http://pfp.missouri.edu/documents/research/sharpe_financialissues.pdf.

and with the requisite intensity.⁸¹ On average, the treatment costs more than \$29,000 a year.⁸² Taken together with the other direct and indirect costs associated with the disorder, the annual cost of ASD can range anywhere between \$77,000 and \$173,000.⁸³ Assuming a median household income of \$53,657,⁸⁴ an ASD diagnosis can amount to financial devastation. Additionally, parents of autistic children often have to spend more time with the child, further reducing their income potential.⁸⁵ It is most unfortunate when a family must suffer the long-term consequences of missing the ABA window of opportunity⁸⁶ due to relatively short-term financial considerations. The high cost of treatment, without education or medical coverage, translates into vastly different outcomes based on economic factors, with the brunt of the effects, predictably, falling upon the indigent.⁸⁷

IV. SERVICES AVAILABLE THROUGH THE EDUCATIONAL SYSTEM AND IDEA

One avenue of reprieve is through the educational system and the

⁸¹ *See id.*

⁸² The full quote reads as follows:

Direct costs include direct medical costs, such as physician and outpatient services, prescription medication, and behavioral therapies (estimated to cost, on average, more than \$29,000 per person per year) and direct non-medical costs, such as special education, camps, and child care (estimated to annually cost more than \$38,000 for those with lower levels of disability and more than \$43,000 for those with higher levels). Indirect costs equal the value of lost productivity resulting from a person having autism, for example, the difference in potential income between someone with autism and someone without. It also captures the value of lost productivity for an autistic person's parents. Examples include loss of income due to reduced work hours or not working altogether. Ganz estimates that annual indirect costs for autistic individuals and their parents range from more than \$39,000 to nearly \$130,000.

Autism Has High Costs to U.S. Society, HARVARD: SCH. OF PUB. HEALTH (Apr. 25, 2006), <http://archive.sph.harvard.edu/press-releases/2006-releases/press04252006.html> (summarizing the findings of recent study).

⁸³ *Id.*

⁸⁴ CARMEN DENAVAS-WALT & BERNADETTE D. PROCTOR, U.S. CENSUS BUREAU, *INCOME AND POVERTY IN THE UNITED STATES: 2014* (2015).

⁸⁵ *See Sharpe & Baker, supra* note 80. It should be noted that the numbers cited previously factored in parental wage loss as well as indirect costs. *See HARVARD, supra* note 82.

⁸⁶ *See supra* notes 71–79 and accompanying text.

⁸⁷ *See Gregory J. Wallance, Autistic Children on Medicaid Missing Out on Crucial Therapy*, ORLANDO SENTINEL (Nov. 14, 2013), http://articles.orlandosentinel.com/2013-11-14/news/os-ed-medicaid-and-autism-111413-20131113_1_therapy-autistic-children-state-medicaid-program.

Individuals with Disabilities Education Act (“IDEA”).⁸⁸ IDEA is a federal law that was enacted to ensure educational opportunity for children with disabilities by setting out detailed steps to be taken by educational authorities for the identification and remediation of impediments to learning.⁸⁹ While Part B of the Act addresses children with disabilities between the ages of three and twenty-one, Part C pertains to infants and toddlers, together ensuring some degree of education for the disabled.⁹⁰

The mandates of the Act are not limited to the provision of services that are *educational* per se, but include what the Act calls *related*

⁸⁸ See generally 20 U.S.C. § 1400 (2015).

⁸⁹ See *Individuals with Disabilities Education Act (IDEA)*, AMERICAN PSYCHOL. ASS’N, <http://www.apa.org/about/gr/issues/disability/idea.aspx> (last visited Oct. 31, 2015).

⁹⁰ The six principles in Part B are as follows:

- (1) Every child is entitled to a free and appropriate public education (FAPE).
- (2) When a school professional believes that a student between the ages of 3 and 21 may have a disability that has substantial impact on the student’s learning or behavior, the student is entitled to an evaluation in all areas related to the suspected disability.
- (3) Creation of an Individualized Education Plan (IEP). The purpose of the IEP is to lay out a series of specific actions and steps through which educational providers, parents and the student themselves may reach the child’s stated goals.
- (4) That the education and services for children with disabilities must be provided in the least restrictive environment, and if possible, those children be placed in a “typical” education setting with non-disabled students.
- (5) Input of the child and their parents must be taken into account in the education process.
- (6) When a parent feels that an IEP is inappropriate for their child, or that their child is not receiving needed services, they have the right under IDEA to challenge their child’s treatment (due process).

Id.

Part C, pertaining to infants and toddlers, contains the following four provisions:

- (1) Every family is entitled to appropriate, timely, and multidisciplinary identification and intervention services for their very young child. These services must be made available to all families with infants and toddlers.
- (2) Families are required to receive an Individualized family Service Plan (IFSP). This plan lays out the priorities, resources and concerns of the family. In addition it describes the goals of the child, the services to be provided to the child, and steps for eventual transitioning of the child into formal education.
- (3) Families have a right to participate in the creation of the IFSP, and must give consent prior to the initiation of intervention services.
- (4) Lastly, parents are entitled to timely resolution of all conflicts or complaints regarding the evaluation or services provided to their child.

Id.

services, as well.⁹¹ The Act defines “related services” to include a host of therapies and services that are “designed to enable a child with a disability to receive a free appropriate public education.”⁹² The definition goes on to list such services as medical, psychological, and physical or occupational therapies, among many others.⁹³ The Act explicitly includes autism in its definitions,⁹⁴ which, it appears, would implicate the Act for the provision of ABA therapy either as education or as *related services*.

The case law on the subject both endorses and limits the conclusion that ABA therapy is mandated by the provisions of IDEA.⁹⁵ While the cases confirm the Act’s inclusion of ABA, they also highlight the shortcomings of ancillary coverage under what is, at its core, an educational tool.

In *Board of Education v. Rowley*, regarding IDEA’s predecessor,⁹⁶ the Supreme Court of the United States severely limited the scope of the Act.⁹⁷ The Court made clear that the congressional objective was not to bring out the full potential of the child, but to allow the child to receive *some* benefit from the education to which he is already

⁹¹ 20 U.S.C. § 1401(26) (2015); *see also Related Services*, CENTER FOR PARENT INFORMATION AND RESOURCES, <http://www.parentcenterhub.org/repository/iep-relatedservices/> (last visited on Oct. 31, 2015).

⁹² In context, the passage reads as follows:

[Related services shall include] . . . transportation, and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children.

20 U.S.C. § 1401(26)(A) (2015).

⁹³ *Id.*

⁹⁴ 20 U.S.C. § 1401(3)(A)(i) (2015).

⁹⁵ *See M.H. ex rel. P.H. v. N.Y.C. Dep’t of Educ.*, 685 F.3d 217, 252 (2d Cir. 2012); *Deal ex rel. Deal v. Hamilton Cty. Bd. of Educ.*, 392 F.3d 840, 861 (6th Cir. 2004). *See also Adams ex rel. Adams v. Oregon*, 195 F.3d 1141, 1149 (9th Cir. 1999).

⁹⁶ The ruling regards the Education for All Handicapped Children Act of 1975 (“EHA”), 20 U.S.C. § 1401, which is how IDEA was referred to before the 1990 amendments. *See M.H.*, 685 F.3d at 241 (noting that the court’s decision applies to IDEA as well).

⁹⁷ *See Bd. of Educ. v. Rowley*, 458 U.S. 176, 176 (1982).

entitled.⁹⁸ Whereas, before the Act, a disabled child was effectively denied all *access* to education, Congress was remedying that situation and mandating *some access*.⁹⁹ In the Court's opinion, the Act does not provide for more than "some educational benefit" and the "basic floor of opportunity" for the child.¹⁰⁰

Based on *Rowley*, many courts have, in fact, denied children the costly ABA therapy.¹⁰¹ Even courts that do grant consideration of ABA, allow some consideration of the costs as well.¹⁰² In *Deal v. Hamilton County Board of Education*, the Court tempered the effects of *Rowley* and required that services be designed towards the goal of "meaningful" benefit and "self-sufficiency" where deemed realistic.¹⁰³ But *Deal* explicitly allowed the school board to factor in costs as well.¹⁰⁴

The *Rowley* ruling, taken together with the cost consideration of *Deal*, illustrates the futility of reliance on non-focused media for an ABA funding solution. A parent would, understandably, want his/her child's disabilities to be addressed in its own context, not in the context of the school's responsibility to provide a minimal education. For that, the IDEA comes up short.

There is another potential matter regarding IDEA and ABA that is worthy of attention. In the statute's definition of *related services*, "medical services" contain the following qualification: "except that such medical services shall be for diagnostic and evaluation purposes only."¹⁰⁵ The controlling authority on this definition is the Supreme Court's ruling in *Cedar Rapids Community School District v. Garret F.*¹⁰⁶ In *Garret*, the Court adopted the United States Secretary of Education's definition of "medical services" as "services provided by a licensed physician."¹⁰⁷ The Court reasoned that this definition "was designed to spare schools from an obligation to provide a service that might well prove unduly expensive and beyond the range of their competence."¹⁰⁸ Furthermore, the Court stated that although "Congress plainly

⁹⁸ *Id.* at 198, 200–01.

⁹⁹ *Id.* at 191–92, 200.

¹⁰⁰ *Id.* at 200–01.

¹⁰¹ *See Deal ex rel. Deal v. Hamilton Cty. Bd. of Educ.*, 392 F.3d 840, 861–62 (6th Cir. 2004).

¹⁰² *See id.* at 864 ("School districts are permitted to consider cost in devising an appropriate educational program.").

¹⁰³ *Id.* at 864.

¹⁰⁴ *See id.*

¹⁰⁵ 20 U.S.C. § 1401(26)(A) (2015).

¹⁰⁶ *Cedar Rapids Cmty. Sch. Dist. v. Garret F.*, 526 U.S. 66 (1999).

¹⁰⁷ *Id.* at 74 n.6 (quoting *Irving Indep. Sch. Dist. v. Tatro*, 468 U.S. 883, 892 (1984)).

¹⁰⁸ *Id.*

required schools to hire various specially trained personnel to help handicapped children such as trained occupational therapists, speech therapists, psychologists, social workers,” and although “[s]chool nurses have long been part of the educational system . . . school nursing services are not the sort of burden that Congress intended to exclude as a ‘medical service.’”¹⁰⁹ In other words, the Court sees the IDEA as a vertical expansion of educational services and not a horizontal one. The schools are required to do more of, or perhaps better, what they customarily do, but they are not required to expand the scope of their operations. Even for the provision of “related services,” schools are not required to change their character and become multi-faceted providers.

This point is further illustrated in *Mary Courtney T. v. School District*.¹¹⁰ In that case, the petitioner sought reimbursement for services received from a long-term psychiatric residential treatment center.¹¹¹ The United States Court of Appeals for the Third Circuit denied the reimbursement and rejected *Garret* as a bright-line standard of whether the service is provided by a physician or not.¹¹² Instead, the court stated that the focus is on whether the service is within the traditional competence of a school, regardless of the actual provider.¹¹³

As of now, school districts do not decline coverage for ABA on the grounds that it is a “medical service,” or that it is out of a school’s traditional competence.¹¹⁴ That may change. As coverage for the treatment expands under medical plans,¹¹⁵ this argument may become more credible. Given the costs of ABA, and the legitimacy of such a consideration both under *Rowley*¹¹⁶ and *Garret*,¹¹⁷ there is a real possibility that, in the future, school boards will start raising such challenges.

¹⁰⁹ *Id.* at 893 (internal citation and quotation marks omitted).

¹¹⁰ *Mary T. v. Sch. Dist.*, 575 F.3d 235 (3d Cir. 2009).

¹¹¹ *Id.* at 240.

¹¹² *Id.* at 247.

¹¹³ *Id.* at 247–48. The exact standard introduced by the court is debatable. At one point, it seems, the court contrasts school services and hospital services. *Id.* at 247. Such a standard would create uncertainty where it is arguably neither. Further on, the court drops the contrast to hospital services and judges whether the service is traditionally within the educational realm or the “care is far beyond the range of competence of any public school district . . .” *Id.* at 248.

¹¹⁴ *See, e.g.,* *BD v. DeBuono*, 130 F. Supp. 2d 401, (S.D.N.Y. 2001) (Defendants did not argue, in defense of their rejection of ABA under IDEA, that the treatment is not, strictly speaking, educational or *related services*).

¹¹⁵ As is the current trend. *See infra* notes 148–149 and accompanying text.

¹¹⁶ *See* *Bd. of Educ. v. Rowley*, 458 U.S. 176, 176 (1982).

¹¹⁷ *See* *Cedar Rapids Cmty. Sch. Dist. v. Garret F.*, 526 U.S. 66 (1999).

This state of affairs underscores the need for an analysis of ABA itself, whether it is an educational tool or a medical one. To the extent ABA is inherently educational, it cannot be subjected to standards used to measure non-educational related services.¹¹⁸ Conversely, if ABA is inherently medical, it can then be subjected to the *Garret* standard, and, given its costs, it may be constrained.

There is, however, a potential role, beyond the direct provision of ABA, for the educational system to fill. The process of establishing the correct treatment and procuring the funding—even when the sources exist—can be tough and drawn out in the best of circumstances. For a typical parent facing an ASD diagnosis, it is one more source of confusion among many.¹¹⁹ Making matters worse, the placement of ABA in the grey area between medicine and education pits the uninitiated parent against experienced and well-funded insurance companies and school boards in a fight that should be between themselves. This is where the school boards should come in.

School boards are well-positioned to take organizational responsibility for these children within existing frameworks. It should be incumbent upon them to coordinate the treatment and do what it takes to secure the funding. Whatever the division of financial responsibility between them and the insurance companies may be, it should be the schools that oversee the process. This would be appropriate for a number of reasons. First, with schools there is always a distinct entity that cannot defer to others—the school district within which the child resides. Second, the schools have a personal relationship with children and their families, and they already evaluate the children in compliance with IDEA.¹²⁰ Third, since many of them do provide ABA to some extent¹²¹ they are already involved and familiar with the field. Even if, under *Rowley* and *Deal*,¹²² the school boards can escape the full financial burden, they should still see to it that the children receive the necessary care.

Finally, the IDEA framework already contemplates for schools just such a role. As mentioned above, under “related services,” the schools are to provide “medical services, except that such medical services shall

¹¹⁸ See *supra* notes 105–106 and accompanying text.

¹¹⁹ See Mari-Jane Williams, *Advice for Parents of Children Just Diagnosed with Autism, From Those Who've Been There*, WASH. POST (July 30, 2014), <https://www.washingtonpost.com/news/parenting/wp/2014/07/30/advice-for-parents-of-children-just-diagnosed-with-autism-from-those-whove-been-there/>.

¹²⁰ See *supra* note 90.

¹²¹ See *supra* note 95.

¹²² See *supra* notes 96–104 and accompanying text.

be for diagnostic and evaluation purposes only.”¹²³ As the Supreme Court said in *Garret*, the qualification attached to medical services is meant to limit the scope of IDEA within each school board’s range of competence.¹²⁴ Nevertheless, schools are to provide medical services for “diagnostic and evaluation purposes.”¹²⁵ This limited imposition implies that some degree of general responsibility and charge has been contemplated for the school districts and has been deemed to be within their purview. This role should be extended to where it is so sorely lacking—the coordination of treatment of ASDs.

V. COVERAGE UNDER MEDICAL-PLANS

A. *The Coverage Types*

Health insurance is another potential source for ABA coverage. Under our fragmented insurance regime of different payors and mandates, however, the details can be murky. Additionally, there is the question of what effects, if any, the Patient Protection and Affordable Care Act (“ACA”) has on the types of coverage.

By far the biggest coverage cohort is that of private insurance.¹²⁶ Forty-nine percent of Americans have insurance through their employer, and an additional six-percent have it through other means.¹²⁷ Benefits under private plans are determined, primarily, by three factors: (1) the specific contractual terms of each plan; (2) state mandates; and (3) federal mandates, including the ACA.

B. *Specific Contractual Terms of Each Plan*

An insurance certificate-of-coverage typically includes a list of the benefit categories covered.¹²⁸ Following the list of categories is a list of the types of services excluded despite their potential inclusion within a benefit category.¹²⁹ Two of those exclusions are relevant to our discussion—the exclusion of “not medically necessary” treatments and of “experimental procedures.”¹³⁰ ABA therapy would, then, be covered

¹²³ See *supra* note 92.

¹²⁴ See *supra* notes 107–113 and accompanying text.

¹²⁵ See *supra* note 92.

¹²⁶ See *Health Insurance Coverage of the Total Population*, HENRY J. KAISER FAM. FOUND., <http://kff.org/other/state-indicator/total-population/> (last visited Nov. 2, 2015).

¹²⁷ *Id.*

¹²⁸ See, e.g., *NJ FamilyCare B*, HORIZON BLUE CROSS BLUE SHIELD, http://www.horizonnjhealth.com/sites/default/files/pdf/Member_Benefits_NJ_FamilyCare_B_REV_1-21.pdf (last visited Apr. 20, 2016).

¹²⁹ See *id.*

¹³⁰ *Id.*

under a “Mental-Health Outpatient Services”¹³¹ category, as long as it is not deemed “not medically necessary” or “experimental.” As it turns out, it is those clauses, and the argument that ABA is not medicine but education,¹³² that the insurance companies invoke to avoid the costly burden of ABA.¹³³ Most importantly, absent a mandate, the insurer can skip mental-health altogether,¹³⁴ exclude ABA specifically,¹³⁵ or place caps on those services.¹³⁶

It should be noted that most denials of coverage are, for the majority of ASD cases, that the disorder impeded initial development in the child.¹³⁷ In about thirty-two percent of cases, however, the children exhibit development and then regress.¹³⁸ In those cases, treatment is restorative and should be covered. Insurance companies, however, require the parents to provide evidence of the development that was subsequently lost.¹³⁹ Ascertaining whether development has occurred and proving it beyond reasonable deniability is, of course, a challenge, placing those parents in the same position as the others.

C. Mandates: State and Federal

Historically, health-insurance regulation was a matter left to the states.¹⁴⁰ One significant break from that tradition was the insurance

¹³¹ ASD’s characterization as a *mental*—as opposed to a *developmental* or *neurological*—condition, for the purposes of coverage, is not in doubt. That may be due to its inclusion in the American Psychological Association’s DSM. See *supra* note 22; see also K.G. *ex rel.* Garrido v. Dudek, 981 F. Supp. 2d 1275, 1292 (S.D. Fla. 2012) (relying on the DSM for that determination).

¹³² See *infra* notes 179–181 and accompanying text.

¹³³ See, e.g. K.G. *ex rel.* Garrido v. Dudek, 864 F. Supp. 2d 1314, 1315 (S.D. Fla. 2012), *aff’d in part & vacated in part*, 731 F.3d 1152 (11th Cir. 2013); McHenry v. PacificSource Health Plans, 679 F. Supp. 2d 1226, 1228 (D. Or. 2010).

¹³⁴ See *Mental Health Benefits: State Laws Mandating or Regulating*, NAT’L CONF. OF ST. LEGISLATURES, <http://www.ncsl.org/research/health/mental-health-benefits-state-mandates.aspx> (last visited Nov. 3, 2015).

¹³⁵ See *AUTISM SPECTRUM DISORDERS (ASD): STATE OF THE STATES OF SERVICES AND SUPPORTS FOR PEOPLE WITH ASD*, L & M POL’Y RES. (2014), <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf> (providing a comprehensive state-by-state survey commissioned by CMS).

¹³⁶ See *id.*

¹³⁷ See Katrina Williams et al., *Regression in Autism Spectrum Disorder*, 51 J. PEDIATRICS AND CHILD HEALTH 61, 62 (2015), <http://onlinelibrary.wiley.com/doi/10.1111/jpc.12805/pdf>.

¹³⁸ *Id.*

¹³⁹ As communicated to the author by a provider of ABA.

¹⁴⁰ See Mila Kofman & Karen Pollitz, *Health Insurance Regulation by States and the Federal Government: A Review of Current Approaches and Proposals for Change*, HEALTH POLICY INSTITUTE, GEORGETOWN UNIV. 1 (2006),

regulatory regime contained in the 1974 Employee Retirement Income Security Act (“ERISA”).¹⁴¹ The Act goes so far as to preempt state regulation and to immunize plans against their mandates.¹⁴² Although preemption is limited to employer self-funded plans, or ERISA plans,¹⁴³ those alone amount to sixty-percent of employer provided plans.¹⁴⁴ That leaves only Medicaid¹⁴⁵ and approximately forty-three percent of private insurance¹⁴⁶ subject to state ABA policy.¹⁴⁷

Recently, the push for state legislation mandating autism coverage has picked up.¹⁴⁸ Already, thirty-seven states have enacted some form of mandate covering children with the disorder.¹⁴⁹ Additionally, once a group plan includes coverage for the treatment, it is subject to the federal Mental Health Parity and Addiction Equity Act (“MHPAEA”) of 2008.¹⁵⁰ That Act prohibits the capping of mental-health services, in large group or individual plans,¹⁵¹ beyond the caps placed on medical or surgical procedures.¹⁵² However, that prohibition does not affect small-group employer plans.¹⁵³ Those plans, on the other hand, are subject to the ACA mandates.¹⁵⁴

D. *The Affordable Care Act and its Consequences for ABA*

In 2010, Congress enacted the Patient Protection and Affordable

<http://www.allhealth.org/briefingmaterials/HealthInsuranceReportKofmanandPollitz-95.pdf>.

¹⁴¹ 29 U.S.C. § 1144 (2013).

¹⁴² *Id.* § 1144(a)–(b).

¹⁴³ *Id.*

¹⁴⁴ See *2013 Employer Health Benefits Survey*, HENRY J. KAISER FAM. FOUND. (2013), <http://kff.org/report-section/ehbs-2013-section-10/>.

¹⁴⁵ See *infra* notes 174–179 and accompanying text.

¹⁴⁶ The approximate total of all private insurance, taking into account the forty-percent employer provided and the six-percent other private. See *supra* notes 126–127 and accompanying text.

¹⁴⁷ The only significant cohort besides those two is Medicare, which pertains to seniors and is irrelevant to our discussion. See *supra* note 126.

¹⁴⁸ For a fifty-state survey of state ASD mandates, see *Insurance Coverage for Autism*, NAT’L CONF. OF ST. LEGISLATURES (2012), <http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx>.

¹⁴⁹ *Id.*; see also *supra* note 135.

¹⁵⁰ 26 U.S.C. § 9812 (2015); 29 U.S.C. § 1185a (2015); 42 U.S.C. § 300gg-5 (2015).

¹⁵¹ The expansion of the MHPAEA to include the individual market was part of the Affordable Care Act of 2010. See *The Mental Health Parity Addiction Equity Act*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/mhpaea_factsheet.html (last visited Nov. 3, 2015).

¹⁵² See *id.*

¹⁵³ *Id.*

¹⁵⁴ See *infra* note 155 and accompanying text.

Care Act (ACA).¹⁵⁵ One of its provisions requires small-group and individual non-grandfathered plans to cover essential health benefits (“EHB”).¹⁵⁶ EHB are determined by the Secretary of Health and Human Services (HHS) and must include the following ten-categories:

- (A) ambulatory patient services; (B) emergency services;
- (C) hospitalization; (D) maternity and newborn care;
- (E) mental health and substance use disorder services, including behavioral health treatment; (F) prescription drugs;
- (G) rehabilitative and habilitative services and devices;
- (H) laboratory services; (I) preventive and wellness services and chronic disease management; (J) pediatric services, including oral and vision care.¹⁵⁷

Within these categories, the plans must include all the same benefits as “a typical employer plan, as determined by the Secretary.”¹⁵⁸ In addition, no plans, big or small group, may place lifetime or annual limits on coverage for the EHB.¹⁵⁹

In accordance with the Secretary’s role in determining “typical employer plan[s],”¹⁶⁰ the Centers for Medicare and Medicaid Services (“CMS”) announced that it will allow states to choose an existing plan, within limits, to serve as a “benchmark” against which the scope of the EHB of other plans will be modeled.¹⁶¹ As such, if a benchmark plan includes coverage for ABA, small-group and individual plans must include it as well, and neither they, nor large-groups, may place lifetime or annual limits on it.¹⁶² However, limitations as to the quantity

¹⁵⁵ 42 U.S.C. § 18001 (2015).

¹⁵⁶ 42 U.S.C. § 300gg-6(a) (2015).

¹⁵⁷ 42 U.S.C. § 18022(b) (2015).

¹⁵⁸ *Id.*

¹⁵⁹ See *Lifetime & Annual Limits*, DEP’T HEALTH & HUM. SERVS., <http://www.hhs.gov/healthcare/about-the-law/benefit-limits/index.html> (last visited Nov. 3, 2015).

¹⁶⁰ See *supra* note 158 and accompanying text.

¹⁶¹ See *Information on Essential Health Benefits (EHB) Benchmark Plans*, CTR. FOR CONSUMER INFO. & INS. OVERSIGHT, <https://www.cms.gov/ccio/resources/data-resources/ehb.html>.

¹⁶² The author has been told that insurers have put forth an argument that inclusion of ABA in a benchmark plan, if only in compliance with a state-mandate, cannot be used as a determinant for EHB. Insurers argue that since the coverage is only due to a mandate, it does not reflect the scope of *mental-health* or *habilitative services* in their plans. However, the CMS bulletin itself seems to negate that argument. In its attempt to define what a “typical” plan means, CMS presents the prevailing trends regarding coverage of EHB and states that “[s]tate laws regarding required coverage of benefits vary widely in number, scope, and topic, so that generalizing about mandates and *their impact on typical employer plans* is difficult.” *Id.* at 7 (emphasis added). This quote demonstrates that CMS was of the opinion that mandates should impact EHB. That

of the treatment can be imposed equal to the limitations in the benchmark.¹⁶³ If ABA is not covered by the benchmark, it can still be included if the benchmark is missing an entire category that includes ABA.¹⁶⁴ For example, if the benchmark does not include mental-health or, more likely, habilitative services,¹⁶⁵ and ABA falls under that category, then it may be included.¹⁶⁶ The likelihood of ABA's inclusion in *habilitative services*, however, is weak at best. CMS's proposals for the definition of the novel category include: parity with rehabilitative services' scope of traditional therapies, or a try-your-luck approach.¹⁶⁷ Neither of these proposals contemplate an expansion to include the costly ABA.¹⁶⁸

This is not to say that ABA will not, conceivably, in the future, be mandated as a habilitative service. The Secretary can reverse course and, pursuant to its authority, include it in the category, as it has already contemplated.¹⁶⁹ In addition, due to the deference awarded the states by the Secretary, governors can, by declaration, include the

impact was not negative, but positive, and the only impact which would present a challenge to generalization.

A slightly different version of the same argument may be plausible. If a benchmark plan does not cover *habilitative services* at all, as contemplated by CMS, *see id.* at 10–11, but does include ABA due to a mandate, insurers may claim that ABA cannot reflect the scope of *habilitative services* since the category does not exist. The relevance of this matter is mostly dependent upon the ultimate question of whether ABA is educational or medical. Only if ABA is educational would its coverage depend upon inclusion in *habilitative services*, otherwise it should be included in *mental and behavioral health*. *See supra* note 157 and accompanying text.

¹⁶³ *See ObamaCare Essential Health Benefits*, OBAMACARE FACTS, <http://obamacarefacts.com/essential-health-benefits/> (last visited Nov. 4, 2015).

¹⁶⁴ *See* CTR. FOR CONSUMER INFO. & INS. OVERSIGHT, *supra* note 161.

¹⁶⁵ The phrase “habilitative services” refers to the acquisition of new life-skills. *See id.* at 11.

¹⁶⁶ *Id.*

¹⁶⁷ *Id.*

¹⁶⁸ *See Definitions of and Coverage Requirements for “Habilitative Services,”* AMER. OCCUPATIONAL THERAPY ASSOC., INC. (2013), <http://www.aahd.us/wp-content/uploads/2013/02/HabilitSrvcsStDefintionsAOTAFeb2013.pdf> (containing a survey of the definition of habilitative services in thirteen states, only three of which include ABA; conceivably, even those three only included ABA as a backdoor mandate).

¹⁶⁹ This contemplation is inferred from the discussion of ABA in its EHB bulletin. *See Essential Health Benefits Bulletin*, CTR. FOR CONSUMER INFO. & INS. OVERSIGHT (Dec. 16, 2011),

https://www.cms.gov/CCIIO/Resources/Files/Downloads/essential_health_benefits_bulletin.pdf. There is, however, no indication that such a contemplated mandate would be under the rubric of *habilitative care*.

treatment in the EHB package.¹⁷⁰

According to The Kaiser Family Foundation, more than one in three children are enrolled in either Medicaid or CHIP,¹⁷¹ with Medicaid being by far the more dominant of the two.¹⁷² This low-income cohort—those without the means of self-financing—are most vital to our discussion.

In a September 2014, statement, CMS, in response to a question about whether it mandates coverage for ABA, stated that it does not endorse or require ABA any more than it does for any “medically necessary”¹⁷³ treatment.¹⁷⁴ Nonetheless, the statement continued, to the extent ABA is “medically necessary,” states may no longer refuse it.¹⁷⁵ While some consider this an effective mandate,¹⁷⁶ it is only so if states do not challenge ABA’s status as “medically necessary.”¹⁷⁷ CMS has, however, stated that in the event that states do include the treatment, the federal government will pay its share as it does with

¹⁷⁰ See *id.*; Joe Guillen, *Gov. John Kasich Adds Autism Treatment Services to Ohio’s Health Insurance Plans*, CLEVELAND.COM (Dec. 21, 2012), http://www.cleveland.com/open/index.ssf/2012/12/gov_kasich_adds_autism_treatment.html.

¹⁷¹ The Children’s Health Insurance Program (CHIP) that was created to insure children in families with too high an income to be covered by Medicaid. See *Children’s Health Insurance Program (CHIP)*, MEDICAID.GOV, <https://www.medicare.gov/chip/chip-program-information.html> (last visited Apr. 20, 2016).

¹⁷² Robin Rudowitz et al., *Children’s Health Coverage: Medicaid, CHIP, and the ACA*, HENRY J. KAISER FAM. FOUND. (Mar. 26, 2014), <http://kff.org/health-reform/issue-brief/childrens-health-coverage-medicare-chip-and-the-aca/>. Specifically, twenty-eight million children are enrolled in Medicaid and 5.7 million in CHIP. *Id.*

¹⁷³ See *Glossary-M*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.medicare.gov/glossary/m.html> (last visited Nov. 2, 2015) (defining “medically necessary” as “[h]ealth care services or supplies needed to diagnose or treat an illness, injury, condition, disease, or its symptoms and that meet accepted standards of medicine”).

¹⁷⁴ *Medicaid and CHIP FAQs: Services to Address Autism*, CMS (Sept. 2014), https://www.autismspeaks.org/sites/default/files/docs/ASLRC/medicaid.cms_faq_9.24.2014.pdf.

¹⁷⁵ *Id.*

¹⁷⁶ *Medicaid: States Cannot ‘Delay or Deny’ Autism Treatment*, AUTISM SPEAKS (Sept. 29, 2014), <https://www.autismspeaks.org/advocacy/advocacy-news/medicaid-states-cannot-delay-or-deny-autism-treatment>.

¹⁷⁷ See *K.G. ex rel. Garrido v. Dudek*, 864 F. Supp. 2d 1314, 1327 (S.D. Fla. 2012) (mandating Medicaid coverage for ABA prior to the CMS clarification on grounds that the treatment is not experimental and thus, presumably, medically necessary), *aff’d in part & vacated in part*, 731 F.3d 1152 (11th Cir. 2013).

other Medicaid covered services.¹⁷⁸

E. *Summary of Potential Coverage Under Medical Plans*

The following summarizes the current landscape of medical coverage and mandates as they apply to ABA: large-group self-funded plans—ERISA plans—are only affected by the MHPAEA, mandating parity if it is contractually included; large-group non-ERISA plans are subject to state-mandates and the MHPAEA; small-group plans are subject to state-mandates and the ACA, but not the MHPAEA; individual plans are subject to all three—state-mandates, the ACA, and MHPAEA. Medicaid, on the other hand, is solely dependent on state policy. As is apparent, we are far from universal coverage for the vital ABA by way of mandates alone. This leaves many at the mercy of the insurance companies and their interpretation of the covered-benefit terms.

VI. REASONS FOR DENIAL OF COVERAGE ANALYZED

A. *Most Common Reasons for Non-Coverage*

Insurance companies assert three primary justifications for declining coverage of ABA: the treatment is not medical, but rather educational,¹⁷⁹ experimental;¹⁸⁰ or not medically necessary.¹⁸¹

B. *Counter-Arguments in Favor of Coverage*

1. Medical or Educational

Insurance companies categorically deny coverage for ABA with the argument that the treatment is not medical, but rather educational.¹⁸² This argument is not advanced solely by insurance

¹⁷⁸ See *CMCS Informational Bulletin*, CMS (July 7, 2014), <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>.

¹⁷⁹ See *Illinois Insurance Law Update*, AUTISM NEWS NETWORK, <http://www.autismnews.net/insurance.html> (last visited Jan. 25, 2016).

¹⁸⁰ *Id.*

¹⁸¹ *Id.*

¹⁸² See *McHenry v. PacificSource Health Plans*, 679 F. Supp. 2d 1226, 1229 (D. Or. 2010); see also *State Initiatives*, AUTISM SPEAKS, <https://www.autismspeaks.org/state-initiatives> (last visited Nov. 4, 2015); Lea Winerman, *Autism Diagnoses Bring Slew of Costs for Families*, PBS (Apr. 13, 2011), http://www.pbs.org/newshour/updates/health-jan-june11-autismcosts_04-13/; Colleen D. Holland, Note, *Autism, Insurance, and the IDEA: Providing a Legal Comprehensive Legal Framework*, 95 CORNELL L. REV. 1253, 1253 (2010). It is noteworthy that the court in *McHenry* did not feel that an “educational” characterization should in itself be grounds for an exclusion. See *McHenry*, 679 F. Supp. 2d at 1239–40. Instead, it focused on an explicit exception in the plan documents,

companies refusing coverage, but also by lawmakers.¹⁸³ After decades of schools providing the treatment under the IDEA, it is no surprise that this conception has taken hold.¹⁸⁴ The merits of this argument will be evaluated in the next section.

The question of whether ABA should be regarded as medical or educational is not merely a matter of semantics—it is about assigning responsibility for the funding of the sole lifeline available to autistic children. When there is ambiguity in the very nature of the treatment, neither sector can be held to account. Any sense of moral obligation or sympathy an entity would feel is blunted by the presence of another player. If an insurance company—or a school board for that matter—can lay the responsibility at somebody else’s doorstep, they are going to jump at the opportunity. Also, if insurance companies are treated as reservoirs of funds, imposed upon not when they *should* be, but when they *can* be, they will respond in kind. This leaves the parent in the precarious situation of having to take on two powerful institutions without the wherewithal to do so. A definitive characterization of ABA—as medical or educational—is sorely lacking. Such clarity can come in the form of an argument that it is one and not the other, implying that one player should leave the scene, or in the form of a clear and convincing case that ABA is inherently both medical and educational. This Comment advocates the latter.

A description for what is considered “medical” can be derived from the Medicare definition of “medically necessary,” namely: “[h]ealth care services or supplies needed to diagnose or treat an illness, injury, condition, disease, or its symptoms and that meet accepted standards of medicine.”¹⁸⁵ “Education,” on the other hand, as defined in the *Merriam-Webster Dictionary*, in relevant part, is: “the knowledge, skill, and understanding that you get from attending a school, college, or university.”¹⁸⁶ In juxtaposition, “medicine” is retrospective and “education” is prospective. Medicine addresses

and even that was rejected by construing an ambiguity in favor of the insured, as, it says, should be done for ERISA plans. *Id.* (citing *McClure v. Life Ins. Co.*, 84 F.3d 1129, 1134 (9th Cir. 1996)).

¹⁸³ See *Insurance Coverage for Autism*, NAT’L CONF. OF ST. LEGISLATURES (Aug. 2012), <http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx> (“However, opponents to this approach argue that care for individuals with autism is the responsibility of parents and the school systems.”).

¹⁸⁴ The fact that ABA is required under IDEA, however, is not an indication that it is educational, since the Act requires related services as well. See *supra* notes 105–118 and accompanying text.

¹⁸⁵ See *CTRS. FOR MEDICARE & MEDICAID SERVICES*, *supra* note 173.

¹⁸⁶ *Education*, MERRIAM-WEBSTER, <http://www.merriam-webster.com/dictionary/education> (last visited Nov. 4, 2015).

complications that arose in the past in order to continue into the future; education provides for fresh tools and development.

For the sake of analysis, medicine can itself be subdivided into two subcategories: there are treatments (1) that target core illnesses; and (2) treatments that target their consequences or side-effects. Cancer treatments, for example, focus on the removal or containment of the cancerous cells. Restorative or palliative services, on the other hand, are focused on the effects of the illnesses and restoration to the extent possible. ABA has both—containment and restoration.

However, in application, ABA is very much educational. It “focuses on *teaching* [c]ore [l]earning [s]kills, [v]erbal [b]ehavior, and social/play skills.”¹⁸⁷ As the court in *McHenry* points out, ABA is frequently referred to in educational terms,¹⁸⁸ but the means do not identify the ends.

The goals of ABA are classical medicine. The imperative of early-intervention, and its rationale, as discussed above,¹⁸⁹ are as follows: (1) bad behaviors are learned and ingrained; (2) the core symptoms are relatively more malleable early on; (3) the toddler’s brain affords more potential for change; (4) impediments must be removed early for age-appropriate development to resume; (5) only early intervention can “alter the course of brain and behavioral development;” or (6) many of the problem behaviors associated with ASD stem from the lack of ability to express oneself. These reasons for early intervention indicate ABA’s twin-objectives: (1) to contain the progression of the disorder and its symptoms; and (2) to restore natural developmental capacity.¹⁹⁰ These two objectives are aligned with the two medical subcategories discussed above.

ABA can be characterized as containment in the sense that it halts the progression of the disorder before it establishes itself and becomes unmanageable—both in terms of the core symptoms and the resulting behaviors.¹⁹¹ It is restoration as well, in the sense that the teaching of skills tempers the disorder to allow the restoration of the natural capacity for development.¹⁹² If ASD were a static disorder and therapy were only necessary for the skills to live with the disorder, ABA can,

¹⁸⁷ *McHenry v. PacificSource Health Plans*, 679 F. Supp. 2d 1226, 1239 (D. Or. 2010) (internal citation omitted).

¹⁸⁸ *Id.* at 1239–40.

¹⁸⁹ See *supra* notes 71–78 and accompanying text.

¹⁹⁰ See *supra* note 47 and accompanying text.

¹⁹¹ *Id.*

¹⁹² See *id.*

conceivably be characterized as merely educational.¹⁹³ However, that is not the case.

The fact that early intervention is crucial indicates that there is, in a sense, effective progression of the disorder. It is that progression that makes the treatment so important and why it is *medically necessary* to treat what is, in effect, a degenerative disease.

Perhaps another way to look at it is in comparison with regressive ASD. It is well documented that, at times, children begin developing normally before the ASD takes effect, at which time they begin to regress.¹⁹⁴ In such cases, the treatment is undeniably restorative.¹⁹⁵ Ordinary ASDs are fundamentally the same and should be no different. The fact that regressive ASDs allow for development before having an effect does not constitute an entirely different disorder. Instead, regressive ASDs typically allow for some development of the child's potential and *capacity* that is then restored with ABA, while ordinary ASDs require restoration of the *capacity* alone, since no development was allowed to result.

This should not, by any means, undermine ABA's educational value; the teaching of skills is classical education as well. The two are not mutually exclusive. ABA is educational in application and in the short-term, and medical in result and in the long-term.

2. Experimental

The definition of "experimental" is not that the *degree* of effectiveness is in question, but that its entire effectiveness is in

¹⁹³ Although such analysis is not applied when it comes to traditional therapies.

¹⁹⁴ See Sally Ozonoff et al., *The Onset of Autism: Patterns of Symptom Emergence in the First Years of Life*, NAT'L INSTS. OF HEALTH 1 (2008), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2857525/pdf/nihms-118847.pdf>.

¹⁹⁵ See AUTISM NEWS NETWORK, *supra* note 179.

question.¹⁹⁶ As quoted extensively above,¹⁹⁷ ABA easily surpasses that minimal threshold. The court in *Dudek* gave this matter considerable attention and ruled, in no uncertain terms, that ABA is not experimental, and that a determination to the contrary is “arbitrary, capricious, and unreasonable.”¹⁹⁸ The court quoted the testimony of doctors that ABA “is the standard means of treatment for autism;” that “it would be medical malpractice not to prescribe ABA for a child with autism;” and that “the consensus in the medical community is that ABA has been the standard means of treatment for children with autism and ASD since the 1990’s, evidenced by consensus statements from [a plethora of prominent medical authorities].”¹⁹⁹ The proceedings in *Dudek* demonstrated the existence of an abundance of “peer-reviewed meta-analyses, studies, and articles that clearly establish” the efficacy of ABA as a treatment “to prevent disability and restore developmental skills to children with autism and ASD” including “findings of large to moderate changes in IQ . . . effects in terms of intellectual functioning, language development, acquisition of daily living skills, and social functioning in children with autism and ABA”²⁰⁰ “Notably,” the

¹⁹⁶ This can be inferred from the language itself. See, e.g., *Potter v. Blue Cross Blue Shield*, No. 10-cv-14981, 2013 U.S. Dist. Lexis 119391, at *9 (E.D. Mich. Mar. 30, 2013) (interpreting the following definition of experimental: “[m]edical literature or clinical experience is inconclusive as to whether the service is safe or effective for treatment of any condition, or [the service] has been shown to be safe and effective treatment for some conditions, but there is *inadequate medical literature or clinical experience* to support its use in treating the patient’s condition.”) (internal citations omitted); see also *NJ FamilyCare B*, *supra* note 128 (excluding “[e]xperimental procedures, or procedures not accepted as being effective, including experimental organ transplants[.]” equating experimental with “not accepted as being effective”). This conclusion comports, as well, with common sense: the vast-majority of medical procedures lack guaranteed effectiveness, and some have a fairly low likelihood of success, and yet no one denies payment for those treatments because they are experimental. See Eric V. Larsson, *Intensive Early Intervention using Behavior Therapy is the Single Most Widely Accepted Treatment for Autism*, LOVAAS INST. FOR EARLY INTERVENTION (2008), http://www.wncbest.org/fileadmin/user_upload/ieibt-Lovaas.pdf (“The total cure rates and effective treatment rates for early intervention for autism are comparable to those of most medically accepted treatments.”).

¹⁹⁷ *Supra* notes 49–63 and accompanying text.

¹⁹⁸ See *K.G. ex rel. Garrido v. Dudek*, 864 F. Supp. 2d 1314, 1321–27 (S.D. Fla. 2012), *aff’d in part & vacated in part*, 731 F.3d 1152 (11th Cir. 2013).

¹⁹⁹ *Id.* at 1326. The quoted testimony referred to statements issued by the Centers for Medicare and Medicaid Services, the United States Surgeon General, the Center for Disease Control and Prevention, the National Institute for Child Health and Human Development, the National Institute for Neurological Disorders and Stroke, the National Institute for Mental Health, the American Society of Child and Adolescent Psychiatry, the American Academy of Pediatrics, and the American Psychological Association. *Id.*

²⁰⁰ *Id.*

court continued, “all the experts that testified for Plaintiffs and Defendant stated that they have never seen a study in the peer-reviewed literature where the authors concluded that ABA was ineffective as a treatment for children with autism or a study that characterized ABA as experimental.”²⁰¹

3. Medical Necessity

The definition of “medically necessary” provided by Medicare is as follows: “[h]ealth care services or supplies needed to diagnose or treat an illness, injury, condition, disease, or its symptoms and that meet accepted standards of medicine.”²⁰² This defense, as opposed to the first one, takes for granted the treatment’s original characterization as a medical treatment. Instead, it probes its relative necessity to the patient in question. Regarding ABA, as long as ASD is either an “illness, injury, condition, or disease” and ABA meets “accepted standards of medicine,” it clears this threshold. ASD is certainly an “illness, injury, condition, or disease,” so that leaves us to figure out whether it meets the “accepted standards of medicine.” This question is, effectively, subsumed by the second defense—it is *experimental*.²⁰³ As stated above,²⁰⁴ ABA is by consensus the *standard* treatment for ASDs, hence, it falls well within the “accepted standards of medicine.” If autism is a “condition,” and the treatment, when prescribed by a physician, is consistent with *standard* medical-practice, it is, by definition, *medically necessary*.

VII. CONCLUSION

The scientific approach—with its evidence-based methods—does not convey a sense of the overwhelming success of ABA methodology.²⁰⁵ The more unrestrained testimony comes from those

²⁰¹ *Id.* at 1327; see also *Potter*, 2013 U.S. Dist. LEXIS 119391, at *17 (“[T]he Court finds that BCBS’s denial-of-benefits for ABA therapy on the grounds that such therapy is experimental or investigative was arbitrary and capricious.”); *McHenry v. PacificSource Health Plans*, 679 F. Supp. 2d 1226, 1237 (D. Or. 2010) (“Based upon a thorough examination of the record, this court concludes that the weight of the evidence demonstrates that ABA therapy is firmly supported by decades of research and application and is a well-established treatment modality of autism and other PDDs. It is not an experimental or investigational procedure.”).

²⁰² See CTRS. FOR MEDICARE & MEDICAID SERVICES, *supra* note 173.

²⁰³ See *K.G. ex rel. Garrido v. Dudek*, 864 F. Supp. 2d 1314, 1320 (S.D. Fla. 2012) (addressing “medically necessary” and “experimental” as one), *aff’d in part & vacated in part*, 731 F.3d 1152 (11th Cir. 2013).

²⁰⁴ See *supra* note 199 and accompanying text.

²⁰⁵ See *Lovaas & Wright*, *supra* note 64.

not bound by scientific conventions—the parents.²⁰⁶ It is not uncommon to hear parents exclaim that through ABA, “I’m getting my child back.”²⁰⁷ One woman, the host of a program on autism, refers to the treatment as “the autism miracle in my living room.”²⁰⁸ Other parents describe the therapy as “nothing short of a miracle,” as they saw “huge improvements even in areas that were not set as goals,” or saw their son “now attending high school and . . . fully integrated in General Ed.”²⁰⁹ Another child with a “classic” diagnosis of ASD, after two-years of extensive ABA therapy, was deemed cured, leaving the parents as “[shocked] as when he was diagnosed,” saying, “[w]e didn’t even know recovery was a possibility.”²¹⁰

The financial burden of ABA is indeed heavy,²¹¹ but casting off the burden is no solution. According to one study, the savings to society from treating ASD with ABA is estimated to be between \$2,439,710 and \$2,816,535 before the age of fifty-five alone.²¹² In reality, the costs in premium increases for ABA inclusion are only about three-tenths of one-percent.²¹³ The long-term benefit to society from the relatively short-term, and timely, treatment, is well worth the cost.

Unfortunately, the current state of coverage for ABA is porous at best. The educational system is only obligated to provide for minimal results, and even then is allowed to factor in cost. State-mandated medical coverage, even in those states that impose them, only covers non-ERISA plans and perhaps Medicaid. The federal MHPAEA is hardly a factor since it only regulates the limits of already existing

²⁰⁶ See HARVARD, *supra* note 82.

²⁰⁷ *The Autism Miracle in my Livingroom*, ABA (Jan. 27, 2011), <https://autismmiracles.wordpress.com/2011/01/27/aba/>.

²⁰⁸ *Id.* The program is accessible on iTunes, and the program on ABA in particular is at: <https://itunes.apple.com/us/podcast/aba-therapy-for-autism/id356451530?i=117605530&mt=2>.

²⁰⁹ *Client Testimonials: What are Satisfied Parents Saying About Their Experiences With Positive ABA*, POSITIVE ABA, <http://www.positiveaba.org/about-us/client-testimonials/> (last visited Oct. 27, 2015). The author is aware of the inherent unreliability of customer testimonials; nevertheless, a representative sample is in order to develop a sense of the real-life reception to this approach. Ideally, there would be no biased non-scientific sources in an academic paper. However, the purpose is not to convince the reader with these quotes, but to inspire further examination.

²¹⁰ Shirley S. Wang, *Who Can Outgrow or Recover From Autism*, WALL ST. J. (Jan. 21, 2013), <http://www.wsj.com/articles/SB1000142412788732330110457825572188737238>.

²¹¹ See HARVARD, *supra* note 82.

²¹² See AUTISM SPEAKS, AUTISM SPEAKS SUBMISSION TO THE PENNSYLVANIA HEALTH CARE COST CONTAINMENT COUNCIL 17 (2007), https://www.autismspeaks.org/docs/gr/HC4_testimony.pdf.

²¹³ See CTR. FOR CONSUMER INFO. AND INS. OVERSIGHT, *supra* note 169, at 7.

coverage. Likewise, the much heralded ACA is of little consequence, since, by all indications, it is not being construed as a meaningful expansion in this area. Insurance companies have resorted to dubious claims to avoid coverage—e.g., the treatment is “not medically necessary” or is “educational.” Worst of all, it is the parents, at their most vulnerable state and where time is of essence, that are left to take on these powerful interests.

ABA has within it elements of education and elements of medicine, and the two should be sharing the burden. However, as long as the burdens are not clearly defined, with a definitive and recognizable apportionment of the responsibility, neither will voluntarily undertake more than absolutely required. Whether the solution should be fractional apportionment or by milestone, the parents are ill-equipped and unlikely to be effective in the imposition of a solution. As mentioned earlier, it is the school boards that are equipped and in the position to take control and see to it that the children do in fact receive the care that they so vitally require. This can be accomplished within the IDEA framework and with minimal, if any, legislative input. It is imperative that these children receive the help that they need, and no less important, when they need it.