

“No Imbecile at All”: How California Won the Autism Insurance Reform Battle, and Why Its Model Should be Replicated in Other States

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ABSTRACT

Autism is the fastest growing developmental disability in the United States today, with the Center for Disease Control and Prevention (CDC) reporting the incidence of autism at one in sixty-eight children. The cause and cure of autism remain unknown. Because autism affects each person at a different level of severity, a large number of symptom presentations are possible, making treatment difficult and costly. Despite the existence of effective, evidence-based early intervention treatments such as Applied Behavioral Analysis (ABA) therapy, which has lasting, long-term benefits and has been shown to improve functioning while reducing lifetime costs, the growing prevalence of autism has been declared a public health crisis by many states because those with autism who do not receive enough or any treatment are more dependent on society and have been recently estimated to cost \$236 billion in care from childhood through adulthood. Due to receding state budgets, many states are not able to adequately address the autism population's early intervention treatment needs through state-funded programs. Further, since health insurance did not cover treatment for autism until the Autism Insurance Reform Mandates that are the subject of this Note, families could not get treatment for their children with autism unless they were able to pay out-of-pocket. To provide a secure means of accessing treatment for people with autism, as of October 2015, forty-three states and Washington, D.C., have enacted autism insurance reform mandates requiring health insurance coverage of treatment for autism. While widespread existence of these mandates is surely progress and an acknowledgement of the problem, there is great legislative inconsistency among the mandates, which has created an imbalanced state of affairs for people with autism in the United States in that there are now some states that are better for autism families to live in than others. If the mandates are to accomplish their job of reducing the cost of the autism population to society in the long term, it matters equally as much that the appropriate evidence-based treatments are covered, and that the length of coverage is measured not by arbitrary criteria like age but by the continued efficacy of treatment, even if this means continued coverage through adulthood. Thus, there is still much work ahead to instill in society the notion that investing in the present to maximize the potential of the autism population will pay off in the long term for everyone in the country. This Note traces the issues that lead to the ongoing national autism insurance reform and offers insight as to how different modes of advocacy contributed to improving the lives of autism families in California, deemed one of the best states to live in for autism families. The goal of this Note is to compare how those strategies did or did not work in North Carolina, the most recent state to adopt a mandate, and to extend these lessons in social, political, and legal change to the remaining states that lack coverage or whose coverage could be improved in the states that currently provide coverage.

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“I feel like that show ‘24’—like there’s this clock ticking somewhere in the background of my life all the time of where I’m trying to get him the help that he needs before it’s too late. I think we just felt that we didn’t have the time to wait on our state to catch up.”¹

INTRODUCTION

In 1927, Supreme Court Justice Oliver Wendell Holmes Jr. delivered the decision of *Buck v. Bell*, which upheld a Virginia statute “that provided for the eugenic sterilization of people considered genetically unfit,” and led to the involuntary sterilization of Carrie Buck, described by the court as a “feeble minded white woman” whom other people classified as “mentally retarded.”² Justifying the decision, Holmes famously wrote “three generations of imbeciles are enough.”³ In 1980, years after being sterilized by the state, Carrie Buck was “discovered to be a woman of normal intelligence,” no imbecile at all.⁴ Although her case exemplifies views of the disabled and eugenics which are no longer held today and have since been harshly criticized, it is, unfortunately, very much representative of the historical lack of awareness and delayed understanding of the special needs population in the United States.⁵

The special needs population, referencing those with intellectual disabilities (IDs) and/or developmental disabilities (DDs) such as autism, Down syndrome, cerebral palsy, etc., has endured a long and multiphase struggle for acceptance and understanding in the United States, even though this population has been steadily on the rise since the 1970s.⁶ Autism, specifically, is the fastest growing developmental disability today, with the Centers for Disease Control and Prevention (“CDC”) reporting that one in sixty-eight children are now diagnosed with autism.⁷ Properly characterized as Autism Spectrum Disorder (“ASD”), autism describes a range of complex neurobiological disorders characterized by deficits in functioning including “impaired language development, impaired social development, and the

Note is dedicated to my younger brother, Andrew Cernius, who has autism and is my greatest inspiration.

¹ Paul Frysh, *Moving Out of State to Get Autism Treatment*, CNN (Sept. 17, 2010, 8:13 AM), <http://www.cnn.com/2010/HEALTH/09/17/autism.aba.legislation/index.html?section=cnn-latest> [<https://perma.cc/25QE-R7EV>]. Wendy Radcliff, the speaker of this quote, is the mother of a boy with autism, formerly of West Virginia, who moved to Florida following his diagnosis to be able to afford her son’s Applied Behavioral Analysis (ABA) therapy treatment, which was not covered by insurance in the family’s home state. *Id.*

² *Buck v. Bell*, 274 U.S. 200, 207 (1927).

³ *Id.*

⁴ ERWIN CHERMERINSKY, *CONSTITUTIONAL LAW: PRINCIPLES AND POLICIES* 834 (Aspen Law, 4th ed. 2011).

⁵ *See id.*

⁶ *See* Laura Hoffman, Comment, *Ensuring Access to Health Care for the Autistic Child: More is Needed than Federal Health Care Reform*, 41 SW. L. REV. 435, 436 (2012).

⁷ Press Release, CDC Estimates 1 in 68 Children Has Been Identified with Autism Spectrum Disorder (Mar. 27, 2014), <http://www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html> [<https://perma.cc/LP4F-AH2R>].

presence of excessive and stereotyped repetitive behaviors or interests.”⁸ Autism affects each person differently, at different levels of severity, making a large number of symptom presentations possible.⁹ This extreme variability in manifestation of autism makes treatment difficult and costly.¹⁰

Autism has never existed before in this country to the extent it does today. Consequently, only recently has society become aware that this underserved and underrepresented community is on the rise and in need of a broad range of services and improved access to those services to allow its members to participate in society. Autism Speaks estimates that autism costs the United States \$236 billion per year.¹¹ Because the severity of autism is a main driver of costs across the autistic person’s lifespan, the key to reducing costs is better access to quality early intervention services that have been shown to “improve functioning and have lasting, long-term benefits with the potential to improve lives while reducing lifetime costs.”¹² However, due to dwindling state budgets and the rising incidence of autism, many states are not able to adequately address the autism population’s needs under current state-sponsored programs like early intervention programs through regional centers and special education programs.¹³

As more children have been diagnosed with autism, obtaining adequate health insurance has become a growing challenge for parents of children with autism. Interventions offered through private providers place a huge financial burden on families just to meet their children’s needs.¹⁴ To close this gap and provide a secure means of accessing treatment for people with autism, as of October 2015, forty-three states and Washington, D.C., have enacted autism insurance mandates, and all but one state have introduced or are proposing legislatively mandated health insurance coverage.¹⁵ While significant progress has been made since Indiana became the first state to pass such a mandate in 2001,¹⁶ much work remains to be done. Just as autism is complex and multifaceted, so too is the challenge of creating a society that

⁸ Doreen Granpeesheh et al., *Applied Behavior Analytic Interventions for Children with Autism: A Description and Review of Treatment Research*, 21 ANNALS OF CLINICAL PSYCHIATRY 162, 163 (2009).

⁹ Melissa Stuart, Comment, *Autism Insurance Reform: A Comparison of State Initiatives*, 8 IND. HEALTH L. REV. 497, 501 (2011).

¹⁰ *Id.* at 504.

¹¹ *Lifetime Costs of Autism Average \$1.4 Million to \$2.4 Million*, AUTISM SPEAKS (June 9, 2014), <https://www.autismspeaks.org/science/science-news/lifetime-costs-autism-average-millions> [<https://perma.cc/X2AM-534W>].

¹² *Id.*

¹³ Stuart, *supra* note 9, at 499.

¹⁴ *Id.* at 504; Hoffman, *supra* note 6, at 437.

¹⁵ *State Initiatives*, AUTISM SPEAKS, <https://www.autismspeaks.org/state-initiatives> [<https://perma.cc/C925-2KSS>]; Athena Mandros, *An Update on ABA & State Autism Coverage Mandates*, OPEN MINDS (Dec. 18, 2015), <https://www.openminds.com/market-intelligence/executive-briefings/applied-behavioral-analysis-what-is-it-who-can-get-it.html/> [<https://perma.cc/4AFB-RYNH>]; *Coverage for ABA Through the Health Insurance Marketplace*, AUTISM SPEAKS, <https://www.autismspeaks.org/node/300226> [<https://perma.cc/4PKL-BGBB>].

¹⁶ *Indiana*, AUTISM SPEAKS, <https://www.autismspeaks.org/advocacy/state/indiana> [<https://perma.cc/US5G-HFVV>].

reflects the recognition that investing in the present to maximize the potential of this population of individuals with autism will pay off in the long term for everyone in the country. It is clear that the most effective solution, given the medical community's continued bafflement at autism and receding available government funding for services, is to mandate insurance coverage of treatment for autism in every state. And while the existence of such mandates in the majority of states is a positive acknowledgment of the problem, if the mandates are to accomplish their job of reducing the cost of autism to society over an extended period, it matters equally as much that the appropriate evidence-based treatments such as Applied Behavior Analysis are covered. It is also important that the length of coverage is measured not by arbitrary criteria like age but by the continued efficacy of treatment, even if this means continued coverage through adulthood. All states should mandate that insurance companies cover treatments for autism based on the continued effectiveness of ABA therapy and other evidence-based treatments, and there are important lessons the reader can derive from reform efforts in California and North Carolina for how this goal can be accomplished.

In Section I, I characterize the autism population, treatments for autism and their effectiveness, and the current cost of an increasing autism population to the United States. Section II provides a brief history of how treatment for autism was dealt with prior to the pursuit of state autism insurance mandates and lays out what coverage looks like in the broader United States as of 2015. I then narrow the focus to California and investigate the story of how litigating, organizing, lobbying, communicating, and planning for long-term enforcement produced a particularly successful coverage scheme for people in this state. In Section III, I highlight important similarities and differences between ideal states like California, which mandate coverage of behavioral therapy not subject to age or dollar limits; forward-thinking but less-than-ideal states like North Carolina, which mandate coverage of behavioral therapy but with age and monetary limitations; and states that have yet to mandate coverage for autism treatment of any kind. I will conclude with a discussion of which modes of advocacy might be used to improve coverage all around.

I. DEFINING AUTISM, EFFECTIVE TREATMENT, AND THE COSTS OF AUTISM

A. *What is Autism, and Why Should We Care?*

Any doctor who did a pediatric residency twenty or more years ago has a story similar to this one: during a pediatrics ward rotation, when I was a resident at Children's Hospital of Los Angeles, our attending called the medical residents into one child's room. He told us that this was an unusual case, that we might never see another child with this severe disorder for the rest of our careers. We filed into the small hospital room, and there in bed was a four-

year-old boy with autism. He was staring out the window, not even noticing the five doctors cramming into his space. He was destined to live his life in an institution. In 1978 there was no hope for this autistic child. Autism was considered a static, unchanging, controversial, mysterious, and unchangeable condition then.¹⁷

Since the 1970s when Dr. Jay Gordon, pediatrician, did his residency, the incidence of autism in the United States has gone from one in every 10,000 children to one in every sixty-eight, according to the latest statistic released by the CDC.¹⁸ Excitement at the novel opportunity of engaging with a child with autism no longer occurs because everyone today knows someone with autism—it affects people of all races and socioeconomic levels; is four times more likely to occur in boys than in girls; and is now more common than Down syndrome, intellectual disabilities, and cystic fibrosis combined.¹⁹

The cause and cure of autism are unknown, and the etiology of the disorder remains a controversial topic within the medical community and among advocates of all kinds. What is known is that autism is a medical-neurobiological disorder and a spectrum disorder, which means it affects each person differently and at different levels of severity, with symptoms ranging from mild cognitive, social, and behavioral deficits to more severe cases where children are nonverbal.²⁰ While the increase in the prevalence of autism is partly attributable to greater awareness and improved diagnosis, there is no denying that there has been an actual increase in the occurrence of the disorder. The latest research indicates that the cause very likely involves a blend of genetic predisposition and environmental factors.²¹ People with autism at all levels of severity have difficulty comprehending the world around them and often display characteristics such as repetitive movements and difficulties communicating and socializing with others.²² Although the cause and cure for autism remain unresolved mysteries, productive ways of treating people with autism that make significant improvements in decreasing symptoms and enabling independent living have developed over the years, of which ABA therapy is the most prominent, evidence-based form of treatment.

¹⁷ JAY GORDON, PREVENTING AUTISM: WHAT YOU CAN DO TO PROTECT YOUR CHILDREN BEFORE AND AFTER BIRTH 17 (2013).

¹⁸ *About Autism*, TALK ABOUT CURING AUTISM, <http://www.tacanow.org/about-autism/> [<https://perma.cc/WM7X-DLBW>].

¹⁹ *Id.*

²⁰ See generally Joseph B. Ryan et al., *Research-Based Educational Practices for Students with Autism Spectrum Disorders*, 47 TEACHING EXCEPTIONAL CHILDREN 94 (2014).

²¹ Granpeesheh, *supra* note 8, at 163; Ryan, *supra* note 20, at 95; see also *What is Autism?*, AUTISM SPEAKS, <https://www.autismspeaks.org/what-autism> [<https://perma.cc/QY8M-D83X>].

²² Ryan, *supra* note 20, at 94. People with autism also frequently have poor eye contact, are resistant to changes in daily routines, and have sensory processing problems which cause them to see, hear, smell, taste, and feel things around them differently and often more intensely than their neurotypical peers. *Id.*

B. What is ABA and Why is it Effective?

Although many treatments for autism exist, very few have been the subject of scientific research.²³ ABA therapy is a refined and effective form of behavior modification therapy that focuses on the adjustment of the person with autism's behavior through systematic use of rewards and punishments.²⁴ Because autism is a spectrum disorder, there is no one treatment that is perfect for every child, but ABA is unique because it is one of the only treatments backed by substantial empirical research and because of its demonstrated wide and long-term effectiveness among those with autism.²⁵

The ABA method was pioneered in part by University of California Los Angeles psychologist Dr. Ivar Lovaas, who reversed the previously dominant dogma, which held that "autistic children were biologically normal youngsters who had withdrawn from human contact because of supposed psychological mishandling by their 'refrigerator mothers'."²⁶ Rather than persisting in the ideology that the only two treatment options available for people with autism were psychotherapy and drugs (the first of which has since been found to be ineffective; the second, harmful), Dr. Lovaas's method employs techniques "based on scientific principles of behavior to

²³ CATHERINE MAURICE & GINA GREEN, *BEHAVIORAL INTERVENTION FOR YOUNG CHILDREN WITH AUTISM* 15 (1996). Other frequently pursued treatments for autism include speech therapy, physical therapy, occupational therapy, dietary adjustments, music therapy, deep pressure therapy, and vitamins and other "natural" substances. See Ohio Center for Autism and Low Incidence, *Chapter 4: Interventions*, in *OHIO PARENT'S GUIDE TO AUTISM SPECTRUM DISORDER* 71, 71–104 (2d ed. 2014), http://www.ocali.org/up_doc/Ohio_Parent_Guide_to_ASD_2015.pdf [<https://perma.cc/W4YN-K3KW>].

²⁴ See *Applied Behavior Analysis (ABA)*, AUTISM SPEAKS, <https://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba> [<https://perma.cc/B2FW-A78V>]; see also CATHERINE MAURICE, *LET ME HEAR YOUR VOICE: A FAMILY'S TRUMP OVER AUTISM* XV (1993).

²⁵ Granpeesheh, *supra* note 8, at 162. "In the past 20 years, 7 long-term, large-scale controlled studies have demonstrated that children who receive more than 25 hours per week of ABA for more than 1 year make tremendous gains, with some participants achieving functioning within the average range for their age." *Id.* at 165.

Continued benefit from behavior therapy in adulthood also is consistent with changing conceptualizations of brain development with age. It was previously assumed that the brain was no longer changing after adolescence. However, brain circuits continue to be modified throughout the lifespan. In particular, the frontal lobe of the brain, which is responsible for the most complex cognitive functions (planning, organizing, directing attention, etc.) and is impaired in autism, is still growing and changing dramatically well into the late 20s and early 30s. These data suggest that behavioral approaches may be useful for not just temporarily changing autism symptoms but also for providing lasting changes to brain circuitry that persist throughout life.

Thomas Frazier & Leslie Sinclair, *Behavior Therapy Beyond Childhood*, INTERACTIVE AUTISM NETWORK (Jan. 24, 2008), https://iancommunity.org/cs/therapies_treatments/beyond_childhood [<https://perma.cc/BH72-ZPD9>].

²⁶ MAURICE, *supra* note 24, at xiv. Prior to behavior modification replacing psychotherapy as the treatment of choice for autistic children, in most states, autism "fell within the purview of the mental health professions ('Tell me, Mother, just how did you make your child autistic?'). California, for one, had specifically excluded autistic children from the public schools on the grounds that their problem was considered 'psychiatric . . .'" *Id.* at xv.

build socially useful repertoires and reduce problematic ones,” and is predicated on the view that “autism is a syndrome of behavioral deficits and excesses that have a neurological basis, but are nonetheless amenable to change in response to specific, carefully programmed, constructive interactions with the environment.”²⁷

Essentially, ABA relies on the breakdown of tasks such as communicative language into a series of hierarchical steps, each step preparing the way for the next. Says Dr. Bernard Rimland, a psychologist who pioneered modern autism research and advocacy and who founded the Autism Society of America,

As an ardent early proponent of behavior modification, I was frequently asked, ‘Since you believe autism is a *biological* disorder, how can you advocate a behavioral approach as an effective treatment?’ My response was simple: ‘Behavior modification did not restore sight and hearing to Helen Keller—her biological handicaps remained with her—but it did permit her to learn the skills she needed to adapt to her environment.’²⁸

Teaching through the use of “discrete trials,” therapists and family members work as a team to create a highly structured and consistent learning environment in which the child with autism is rewarded for the mastery of each small step. Gradually, children learn “not only the discrete bits of subject matter they are being taught, but, far more important, to focus their attention, to concentrate more effectively, and thus to learn more easily.”²⁹

Extensive research shows that children with autism do not learn readily from typical environments but can learn if provided with appropriate instruction.³⁰ The goal of ABA is to teach the child how to learn from the normal environment and act on that environment in ways that will consistently produce positive outcomes for the child, the child’s family, and others in society.³¹ ABA is a medical treatment because it causes the developmental

²⁷ MAURICE & GREEN, *supra* note 23, at 29–30.

²⁸ MAURICE, *supra* note 24, at xvi (quoting Dr. Bernard Rimland). “Dr. Rimland overturned conventional theories about the origin of autism in the 1960s and later forced scientists and policymakers to consider alternative causes and treatments.” Benedict Carey, *Bernard Rimland, 78, Scientist Who Revised View of Autism, Dies*, N.Y. TIMES (Nov. 28, 2006), http://www.nytimes.com/2006/11/28/obituaries/28rimland.html?_r=0 [<https://perma.cc/9L5R-TZQ6>]. According to Dr. Fred Volkmar, director of the Child Study Center at Yale, Dr. Rimland was “tremendously important to the field, in that he reoriented research from a focus on the parents to a focus on the brain,” and “developed the first checklist for diagnosing autism,” as a “pathfinder and tireless advocate for families dealing with autism.” *Id.* In his book, *INFANTILE AUTISM*, “Dr. Rimland demolished the cold-mother theory by presenting lucid evidence that the disorder was rooted in biology,” and “quickly saw through spurious claims of facilitated communication, a therapy in which therapists claimed to help channel the thoughts of autistic children and heal them.” *Id.*

²⁹ MAURICE, *supra* note 24, at xv.

³⁰ MAURICE & GREEN, *supra* note 23, at 30; Meldestefano, *Dr. John Mantovani, Child Neurologist - Testimony in Support of SB 618*, YOUTUBE (Jan. 22, 2010), <https://www.youtube.com/watch?v=0a7WxgiRdsA> [<https://perma.cc/NVA9-5BV7>].

³¹ *Id.*

process to occur in those in whom it is not naturally occurring: it “changes the functioning of the brain in ways that are visible on fMRI and PET Scans.”³² An intervention model with demonstrated success involves intensive treatment requiring thirty to forty hours of therapy a week for several years.³³ While Dr. Lovaas first provided evidence of the effectiveness of ABA programs for children with autism in a study which reported that “nearly half (47%) of the children in the ABA program achieved higher functioning in comparison to only 2% of the control group not receiving treatment,” these results have been replicated “by several hundred single case experiments and an increasing number of between-groups studies” in the thirty years since.³⁴ Research, therefore, suggests that intensive ABA interventions implemented early in a child’s development can result in long-term positive outcomes, with treated individuals achieving goals including part or full-time employment in jobs in the community and semi-independent living that would not have been attempted prior to treatment.³⁵

C. *The Cost of Autism to Society*

Children with autism are more likely to lack general access to health care services as compared to children with other chronic conditions, and early treatment is still beyond the reach of many families.³⁶ According to Laura Hoffman,

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

³² MAURICE & GREEN, *supra* note 23, at 30; *see also* Meldestefano, *supra* note 30. An American Academy of Pediatrics clinical report on the medical management of children with autism noted ABA’s decades-long record of efficacy:

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 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.

Scott M. Myers & Chris Plauché Johnson, *Management of Children with Autism Spectrum Disorders*, 120 *PEDIATRICS* 1162, 1164 (2007) (footnotes omitted).

The substantial body of research supporting ABA for children with autism has led several independent entities to acknowledge ABA and endorse its use for children with autism, including the US Surgeon General, the New York State Department of Health, the National Academy of Sciences, and the American Academy of Pediatrics.

Granpeesheh, *supra* note 8, at 163.

³³ Stuart, *supra* note 9, at 503.

³⁴ Ryan, *supra* note 20, at 98; *see also* Granpeesheh, *supra* note 8, at 166–67.

³⁵ Frazier, *supra* note 25.

³⁶ Hoffman, *supra* note 6, at 441.

with autism and their parents have important implications for those aging members of the baby boom generation approaching retirement, including large financial burdens affecting not only those families but also potentially society in general.³⁷

Historically, the financial cost of providing treatment for people with autism has been borne by their families.³⁸

Those unfamiliar with the challenges of parents in acquiring access to health care services for their children with autism are often unaware of the distinct and urgent need for ensuring access to treatment. The issue has to do with the time-sensitivity of autism. From the time a child is diagnosed, the goal becomes obtaining immediate access to ABA and all recommended treatments at rates proportional to the severity of the child’s specific needs.³⁹ In theory, health insurance should pay for the therapeutic interventions medically necessary to improve the condition of children diagnosed with autism, because autism does not differ from other noncurable chronic medical conditions that health insurance routinely covers, including asthma, diabetes, and hypertension.

Because ABA therapy involves a great deal of time, it is quite expensive, with costs ranging from approximately \$30,000 to \$100,000 per year, depending on the needs of the particular child.⁴⁰ Most medical insurance policies did not cover it, or cover it properly, prior to the enactment of individual state insurance mandates.⁴¹ Reports Laura McKenna of *The Atlantic*,

Parents who have the educational and financial resources can provide these therapies for their children. They pay for it themselves. They move to wealthier school districts. They hire lawyers. They spend hours on the phone with insurance companies. They network with other parents to learn about new doctors and compare services in other school districts. Parents who don’t have those resources are unable to get the right help for their children.⁴²

According to *The New York Times*, “no disability claims more parental time and energy than autism.”⁴³

The problem is that without this early, intensive ABA therapy, or with ABA that is provided inconsistently or at the minimum level, children with autism are far more likely to place a large financial strain on the state through both direct and indirect costs.⁴⁴ The current societal cost of autism is

³⁷ *Id.* at 438; see also MICHAEL GANZ, UNDERSTANDING AUTISM: FROM BASIC NEUROSCIENCE TO TREATMENT 476 (Steven O. Moldin & John L.R. Rubenstein eds., 2006).

³⁸ Hoffman, *supra* note 6, at 441.

³⁹ *Id.* at 440.

⁴⁰ *Id.* at 437.

⁴¹ *Id.*

⁴² Laura McKenna, *The Economic Impact of Autism on Families*, ATLANTIC (May 31, 2012), <http://www.theatlantic.com/business/archive/2012/05/the-economic-impact-of-autism-on-families/257892/> [<https://perma.cc/5TAF-H4ZS>].

⁴³ Hoffman, *supra* note 6, at 442.

⁴⁴ Stuart, *supra* note 9, at 504.

estimated at \$35 billion to care for all individuals with autism during childhood and throughout their lifetime.⁴⁵ Direct costs are incurred through medical expenses similar to the costs of caring for neurotypical children, but because children with autism use health care services more frequently than typically developing children, their health care costs are higher. Indirect costs include “lost productivity by parents who may reduce the hours they work outside the home or forego outside employment entirely to care for their child” and the loss of production to society that results from adults with autism being unable to contribute to society due to the limitations created by their disability.⁴⁶ If a child with autism is not properly treated, the societal cost for that one child over his or her lifetime could be as high as \$3.2 million.⁴⁷

The good news is that early diagnosis and intervention can reduce the cost of life-long care for each person with autism by two-thirds.⁴⁸ To better understand the cost implications of autism treatments, Autism Speaks engaged leading independent actuarial firm Oliver Wyman Group to develop a cost model and cost estimates for various state autism insurance reform bills.⁴⁹ Based on the results of several studies, Oliver Wyman determined that the costs of the ABA treatments covered under mandates could be recovered through reductions in educational and medical expenditures alone, confirming that preventive services can mitigate other long-term health costs and save insurance companies money over time by reducing the need for expensive inpatient hospitalizations.⁵⁰

Lack of early intensive intervention can often lead to children with autism being placed in foster care, residential homes, and institutions. Lack of a current benefit is likely to increase the number of individuals who are dependent on others (including state sponsored programs) for housing, supervision, and vocational support as adults. Costs of institutionalization ranges from \$76,000 per year to over \$192,000.

Information Summary of Recommendations: Treatment of Autism Spectrum Disorders Mandated Benefit Sunrise Review, WASH. STATE DEP'T OF HEALTH 12 (2009), <http://www.doh.wa.gov/portals/1/Documents/Pubs/631002Autism.pdf> [https://perma.cc/TK7R-U4XX].

⁴⁵ Stuart, *supra* note 9, at 504.

⁴⁶ *Id.*

⁴⁷ *Id.*

⁴⁸ Press Release, ASA Publishes Model Legislation for Autism Insurance Coverage (Feb. 12, 2009), http://www.autism-society.org/site/DocServer/02-16-2009_ASAPublishesModel-Legislation_forAutismIn.pdf~docID=12061 [https://perma.cc/CD5W-J8HV].

⁴⁹ *Cost Studies: State Autism Insurance Reform*, AUTISM SPEAKS, <https://www.autism-speaks.org/node/214706> [https://perma.cc/ACV4-YXBH]. While the analysis focuses primarily on estimating the insured costs of mandated medical benefits, Oliver Wyman also summarizes information “related to the lifetime costs of Autism, which include the costs associated with medical services, education, custodial care, and the lost productivity and wages of individuals affected by Autism, as well as their family caregivers.” Marc Lambright, *Actuarial Cost Estimate: Alaska House Bill 79 and Senate Bill 74*, OLIVER WYMAN 2 (2011), https://www.autismspeaks.org/sites/default/files/docs/gr/ak.wyman_3.4.2011.pdf [https://perma.cc/XMP6-VCGR].

⁵⁰ *Legislation Requiring Health Plans to Cover Autism Treatment Would Have Minimal Effect on Health Insurance Premiums*, AUTISM SPEAKS (Oct. 8, 2010), <http://advocacy.autismspeaks.org/site/apps/nlnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=8781579> [https://perma.cc/SU2X-ZPRC]. For an example of the results of Oliver Wyman’s calculations, see Marc Lambright, *Actuarial Cost Estimate: Nebraska Legislative Bill 1129*, OLIVER

Oliver Wyman’s results confirm the findings of other studies and have been validated by the experiences of states that have had mandates for many years.⁵¹ For instance, University of Pennsylvania health policy researcher Dr. David Mandell calculated the cost-savings produced by a high-quality and intensive early behavioral intervention program and found that while early intensive ABA intervention costs more to deliver in the early years, “it more than pays for itself in terms of reduced needs for therapy and educational support by the time a child reaches high school.”⁵² Following the enactment of mandates in twenty-nine states, Autism Speaks began collecting data from states where such laws apply to members of the state employee health plan and have been in effect for at least one year, showing that the average first year cost of coverage per member per month was \$0.15, and the average second year cost was \$0.31 per member per month.⁵³ More recently, annual reports done by the Department of Insurance in individual states reveal that implementing the insurance reform mandates had a low impact on overall health claim costs, even though thousands of individuals accessed autism-related treatment.⁵⁴ These reports are important because, unlike the actuarial studies and the data collection done by Autism Speaks, they report the real life impact of the mandates on the entire market.⁵⁵

WYMAN (2012), https://www.autismspeaks.org/sites/default/files/docs/gr/ne.wyman_2.6.2012.pdf [https://perma.cc/BB32-VS8W].

⁵¹ See, e.g., *High-Quality Early Intervention for Autism More Than Pays for Itself*, AUTISM SPEAKS (May 1, 2013), <https://www.autismspeaks.org/science/science-news/high-quality-early-intervention-autism-more-pays-itself> [https://perma.cc/2WLQ-YNLD].

⁵² See *id.* Working under an Autism Speaks research grant, Dr. Mandell and his research team tracked the autism-related services used by thirty-nine children who had participated in a two-year ABA early intervention study led by Jeff Munson, Ph.D., and Annette Estes, Ph.D., at the University of Washington. *Id.* At the time, the children were eighteen to thirty months old. *Id.* Twenty-one received two years of ABA, and for comparison, eighteen children received a comparable amount of services through early intervention programs in their Seattle community. *Id.* After the trial ended, parents were referred to their community’s early intervention and special education programs for further services. *Id.* The researchers tracked their use of these services over the following four years. *Id.* While the cost of autism-related services during the two years of the study for those receiving ABA totaled \$9,619 per child per month, whereas the cost of services received by the children in the outside community averaged \$2,458 each per month, the trend toward cost benefits emerged in the four years after the study concluded. *Id.* During this period, the children in the ABA group received an average of 158 hours of autism-related services per child per month, whereas the children in the comparison group received an average of 257 hours of services each per month. *Id.* The cost breakdown for the four follow-up years averaged \$3,569 per child per month for the ABA group and, by contrast, it averaged \$5,033 per month for those in the comparison group. *Id.*

⁵³ See *The Fiscal Impact of Autism Insurance Reform*, AUTISM SPEAKS (2011), https://www.autismspeaks.org/sites/default/files/docs/gr/summary_of_claims_data_w_tables_and_appendices.pdf [https://perma.cc/5FRZ-PA7C]. For a report summarizing the results of states that implemented mandates, see *id.*

⁵⁴ See, e.g., *MO Regulator: Autism Insurance Reform Works*, AUTISM SPEAKS (Mar. 21, 2014), <https://www.autismspeaks.org/advocacy/advocacy-news/mo-regulator-autism-insurance-reform-works> [https://perma.cc/SV72-WF67]; DEP’T OF INS., FIN. INST. & PROF’L REGISTRATION, ANNUAL REPORT TO THE MISSOURI LEGISLATURE: INSURANCE COVERAGE FOR AUTISM TREATMENT, STATISTICS SECTION (2014), <http://insurance.mo.gov/consumers/autismFAQ/documents/2014AutismReport.pdf> [https://perma.cc/N9UT-SY8F].

⁵⁵ See *MO Regulator: Autism Insurance Reform Works*, *supra* note 54. Several states have also created forecasts predicting the cost of behavioral therapy mandates and found that early

II. CURRENT INSURANCE COVERAGE SCHEMES FOR TREATING AUTISM

One reason for the financial difficulties that autism families face is the failure of the health insurance industry to cover treatments for, and sometimes even diagnosis of, autism.⁵⁶ According to Professor Samuel R. Bagenstos, “Insurers frequently offer policies that are subject to ‘exclusion waivers,’ which bar reimbursement for any treatment for particular named conditions.”⁵⁷ Many insurance companies designate autism as a diagnostic exclusion, “meaning that any services rendered explicitly for the treatment of autism are not covered by the plan, even if those services would be covered if used to treat a different condition.”⁵⁸ And, when they do not exclude coverage altogether, insurance companies typically impose strict limitations on the specific treatments and other interventions for which they will pay.⁵⁹ Essentially, private insurance, which most nondisabled people rely on for their health needs, fails to cover the services people with autism need most.⁶⁰

Insurance companies assert two main defensive arguments. The first is that although autism is a medical condition, ABA is “educational” or “habilitative,” and therefore should be covered by government-funded rehabilitative agencies or, alternatively, special education classrooms.⁶¹ “A mandate is not justified, insurance companies argue, when coverage for services is already available.”⁶² The second argument is that the autism population is forecasted to keep growing in coming years, and insurers fear the consequences of offering coverage for ABA, citing studies that estimate a 1–3% increase in the cost to other policyholders not affected by autism.⁶³ While these arguments appear reasonable, they are unfortunately based upon unrealistic expectations and a policy of inefficient burden shifting. Both autism and ABA are medical, as illustrated in Section I.B., so denying autism families coverage for the reason that ABA is educational or habilitative is no longer a valid argument.⁶⁴ Furthermore, as demonstrated in Section I.C.,

intervention programs could lower health care costs overall. For instance, the Pennsylvania Commonwealth Insurance Department estimated that Medicaid could save \$16.5 to \$22.2 million in the first year following the adoption of ASD insurance reform. Stuart, *supra* note 9, at 529. Researchers estimated that the state of Texas would save \$208,500 per child across eighteen years of education with early intensive behavioral intervention. Gregory S. Chasson, Gerald E. Harris & Wendy J. Neely, *Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism*, 16 J. CHILD & FAM. STUD. 401, 408 (2007).

⁵⁶ LORRI SHEALY UNUMB & DANIEL R. UNUMB, AUTISM AND THE LAW: CASES, STATUTES, AND MATERIALS 9 (2011).

⁵⁷ Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 28 (2004).

⁵⁸ *Id.*

⁵⁹ *Id.* at 28.

⁶⁰ *Id.* at 27.

⁶¹ Stuart, *supra* note 9, at 512.

⁶² *Id.* at 528.

⁶³ *An Autism Treatment Worth Funding*, L.A. TIMES (Sept. 30, 2011), <http://articles.latimes.com/2011/sep/30/opinion/la-ed-autism-20110930> [https://perma.cc/HY34-HBPU].

⁶⁴ See *supra* Section I.B.; see also Michelle Diamant, *Feds Approve ABA Therapy as Medical Benefit*, DISABILITY SCOOP (June 4, 2012), <https://www.disabilityscoop.com/2012/06/04/feds-aba-medical-benefit/15771/> [https://perma.cc/7RCF-24ZC].

multiple studies of multiple states conducted by agencies like Autism Speaks and independent actuarial firms like Oliver Wyman, as well as annual reports produced by the Departments of Insurance in different states, all show the same things. Despite the thousands of people who receive coverage for ABA every year, the cost implications on other policyholders not affected by autism have been uniformly low-impact. Furthermore, the cost to insurance companies for paying for ABA treatment will be recovered by the amounts saved in the future due to the increased functioning of those with autism who received early intervention treatment.⁶⁵

The United States has made progress in both its perception and its treatment of the disabled in the years since forced sterilization of people like Carrie Buck was considered the norm. While the failure to cover treatment for autism is not an equivalent harm, it is a major neglect by the nation of one of its fastest growing and most helpless populations. Advocating for the adoption of autism insurance mandates in all fifty states is not to argue that “we should all hold hands and cheerfully insist that we’re all disabled in some way or another.”⁶⁶ Rather, it is an argument for the policy of pro-active cost reduction of a population that has been demonstrated to be costly and of giving those in society who require more help the best chance to live at the highest level of independence attainable. In order to avoid the enormous, costly consequences to both the autism population and wider society, the United States must change from the path it has been pursuing and commit to providing people with autism the coverage they need.

A. *Previous Approaches to Service Provision, and Why Insurance Coverage is the Solution*

Prior to the movement towards mandating insurance coverage for people with autism, few common standards existed for the diagnosis and management of many aspects of care, meaning that families lacking access to comprehensive and coordinated health care had to “fend for themselves to find the best health care, treatments, and services in a complex clinical world.”⁶⁷ Traditionally, ABA therapy programs have existed through private practitioners, agencies, and some public and private schools.⁶⁸

Some states have also made coverage for ABA therapy programs available through state-funded agencies. For example, California’s “regional centers” are nonprofit private corporations that contract with the Department of Developmental Services (“DDS”) to provide and coordinate services and

⁶⁵ See, e.g., Lambright, *supra* note 50; AUTISM SPEAKS, *supra* note 53; DEP’T OF INS., FIN. INST. & PROF’L REGISTRATION, *supra* note 54.

⁶⁶ KIM E. NIELSEN, A DISABILITY HISTORY OF THE UNITED STATES xv (2012).

⁶⁷ Hoffman, *supra* note 6, at 474.

⁶⁸ See Stuart, *supra* note 9, at 528. See generally *Applied Behavior Analysis (ABA)*, *supra* note 24.

supports for individuals with developmental disabilities.⁶⁹ Regional Centers are allowed to exist under the authority of the Lanterman Developmental Disabilities Services Act (“The Lanterman Act”), the piece of legislation that says people with developmental disabilities and their families have a right to get the services and supports they need to live like people without disabilities.⁷⁰ While these programs are effective, they are expensive to operate.⁷¹ In 2012, the California DDS spent \$4.7 billion on services for over 259,000 people with developmental disabilities.⁷² Thus, one downfall of this system, in addition to the fact that ABA is medical and medical treatments are not *mandated* under the Lanterman Act, is its dependence on the financial fitness of the state. When the state economy suffers, the budget for ABA therapy programs suffers. With the state and federal governments increasingly in debt, these volatile circumstances in which treatment is available in some years and uncertain in others cause regression in children with autism who experience inconsistency in their treatment, which is premised upon persistence and reinforcement.⁷³

Insurance companies claim that the uncertainty surrounding provision of treatment should be mitigated by the performance of school districts under the Individuals with Disabilities Education Act (IDEA) special education law, which requires the provision of services and treatments to children with autism.⁷⁴ However, this thinking overlooks the current struggle for re-

⁶⁹ *Information About Regional Centers*, CAL. DEP’T OF DEV. SERVS., <http://www.dds.ca.gov/rc/> [<https://perma.cc/DP5N-U2ML>].

⁷⁰ *See generally* The Lanterman Act, CAL. WELF. & INST. CODE § 4500 (West, Westlaw through Ch. 2 of 2016 Reg. Sess. and Ch. 1 of 2015–2016 2nd Ex. Sess.).

When the Lanterman Act was passed in 1969, it envisioned a joint venture between government and the community in search of a more humane way to help the neediest members of our society. Rather than lock people up in large institutions, government would provide funds and guidance to regional centers that, in turn, would work with communities to provide solutions at a local level.

Department of Developmental Services, ALLGOV CAL., http://www.allgov.com/usa/ca/departments/health-and-human-services-agency/departments_of_developmental_services?agencyid=128 [<https://perma.cc/82VH-XUVP>].

⁷¹ *Id.*

⁷² DEP’T OF DEV. SERVS., 2012 MAY REVISION’S HIGHLIGHTS (2012), http://www.dds.ca.gov/Budget/Docs/2012_MayRevisionHighlights.pdf [<https://perma.cc/CSW5-P95Q>]. This spending is paralleled in other states. In 2009, Indiana’s Bureau of Developmental Disabilities Services spent approximately \$536 million on services for people with autism and other developmental disabilities. Stuart, *supra* note 9, at 505.

⁷³ *On the Brink of Collapse: The Consequences of Underfunding California’s Developmental Services System*, ASS’N OF REG’L CTR. AGENCIES 17 (2015), <http://arcanet.org/wp-content/uploads/2015/02/on-the-brink-of-collapse.pdf> [<https://perma.cc/S43H-7S9K>].

⁷⁴ *See* Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2012).

Concerning ABA therapy, opponents of insurance reform argue that ABA is more accurately described as educational and should, therefore, be provided by the schools. Supporters for ASD insurance reform point to the inadequacies of the public education system in dealing with children with ASDs. IDEA, the law guaranteeing a free and appropriate public education for children with disabilities, has historically failed to produce the statute’s maximum funding provided to states, forcing public schools across the nation to absorb \$381.8 billion in special education costs that are left unfunded. Therefore, supporters of insurance reform argue that

sources and trained staff that special education classrooms face on a daily basis as well as the intensity of the therapy and importance of a narrow focus on the child in question that ABA demands in order to be successful. Educational programs are designed to accommodate medical disabilities but not to treat underlying medical conditions—the treatment of underlying medical conditions is the responsibility of qualified medical providers and not educators. In other words, schools simply do not have the structure to create productive programs.⁷⁵ Additionally, while “mental health parity” laws, which require that people receive equal treatment, provide for “medically necessary” services for people with autism, very few individuals receive behavioral services under those provisions.⁷⁶

While paying out-of-pocket to obtain ABA for a child with autism and enduring the tangled pursuit of services through state programs or special education is avoided by families in which the parents’ place of employment provides insurance that covers autism, and behavioral therapy within that coverage, many families are currently not served or underserved, and a great many stand to join them in the coming years. Autism insurance reform and coverage mandates are essentially responses to the realization that the incidence of autism continues to soar and society’s previous strategies to provide treatment for the autism population have been exhausted or are no longer viable for the reasons previously articulated. Mandates are laws that require state-licensed health-insuring organizations to include coverage for certain benefits or services.⁷⁷ Mandates “remedy the failure of the market to provide effective coverage for a significant public health challenge,”⁷⁸ provide treatment and services for people with autism and their families, and reflect the growing movement toward the recognition of the disability in its own category of health insurance coverage (*e.g.*, “one of the latest state legislative trends is to pass an autism mandate separately from mental health benefit mandates”⁷⁹). The existence of autism insurance reform mandates, therefore, is the baseline mark of success in the review of the efforts of different states to care for people with autism.

reliance on the education system to treat individuals with an ASD places an unmanageable burden on a school’s finances. . . . Still, opponents of autism insurance reform argue that the fix should be with the education system, not by shifting the cost to private insurers.

Stuart, *supra* note 9, at 528 (footnotes omitted).

⁷⁵ Stuart, *supra* note 9, at 528.

⁷⁶ Katie Hornberger, *History of SB 946*, DISABILITY RIGHTS CAL. 2 (2013).

⁷⁷ Stuart, *supra* note 9, at 514.

⁷⁸ Hoffman, *supra* note 6, at 475 (quoting Stuart Spielman, *State Authority and Health Insurance Laws Should be Part of a National Benefit Package*, AUTISM SPEAKS OFFICIAL BLOG (Jan. 12, 2011) (link no longer available)).

⁷⁹ Hoffman, *supra* note 6, at 477.

B. *State Statistics and Details of Varying Insurance Plans
(or Lack Thereof)*

However, even as states have moved towards some legislative consistency in passing insurance mandates, the mandates themselves differ drastically from state to state on a number of issues.⁸⁰ The extent to which states with mandates cover ABA is an additional criterion that makes certain states better and more beneficial for families with autism to live. Indiana was the first state to enact an individual autism insurance mandate in 2001, followed by forty-two other states and Washington, D.C., as of October 2015.⁸¹ Seven states remain with no autism insurance mandate at all and fall into two categories: (1) states that are currently pursuing autism insurance reform (Alabama, North Dakota, Ohio, Oklahoma, Tennessee, and Wyoming), and (2) states that are not pursuing autism insurance reform legislation whatsoever (Idaho).⁸²

While the existence of mandates in the vast majority of states sends a strong message about the urgency of the problem as well as about the uniformity of attitudes that mandating coverage is the best solution, the extent of insurance coverage differs by state. Insurance mandates can essentially be grouped into two broad categories: (1) states that have mandates, include ABA therapy or behavioral therapy explicitly as treatment that is covered, and which measure the extent of coverage according to no age or monetary limits, but rather the continued efficacy of the treatment; and (2) states that have mandates and cover appropriate therapy like ABA, but measure the extent of coverage according to age (*e.g.*, ABA only offered until the age of six, fifteen, eighteen, or twenty-one, depending on the state) or monetary limits (*e.g.*, only \$36,000 of ABA covered annually, even if the child's treatment is more expensive).⁸³ Today, six states fall within the first category, while thirty-seven states fall within the second.⁸⁴ California, the subject of the remainder of this Note, falls within the first.⁸⁵

⁸⁰ *Id.* at 478.

⁸¹ *Id.* at 449; *State Initiatives: Autism Insurance Reform*, AUTISM SPEAKS, <https://www.autismspeaks.org/state-initiatives> [<https://perma.cc/4WJS-TYZ6>].

⁸² *State Initiatives: Autism Insurance Reform*, *supra* note 81.

⁸³ *Id.*

⁸⁴ *Id.* The states in the first group are California, Indiana, Massachusetts, New York, Oregon, and Washington D.C. The states in the second group are Alaska, Arizona, Arkansas, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, North Carolina, Pennsylvania, Rhode Island, South Carolina, South Dakota, Texas, Utah, Vermont, Virginia, West Virginia, and Wisconsin.

⁸⁵ *State Initiatives: Autism Insurance Reform*, *supra* note 81.

C. *Why Other States Should Endeavor to Be in the Same Category as California*

The diversity of legislation mandating insurance coverage for people with autism is an indication of the present instability and inconsistency in the availability of health care for these individuals that is largely a matter of where the person with autism resides—there are really some states that are better for families with autism to live in than others.⁸⁶ California, for instance, is an advantageous state for families with autism to live because the autism insurance mandate covers ABA with no age or dollar caps. This means that the person with autism, if so prescribed by a physician, may continue to receive covered ABA treatment even through adulthood, until treatment is no longer effective.⁸⁷ The thirty years’ worth of studies discussed in Sections I.B. and I.C. show that an ABA program that is consistent and long-term, beginning with early intervention, leads to increased independence, decreased need for ABA in adulthood, and decreased costs to society overall. California’s policy is simultaneously beneficial to the state because ABA has the best outcomes in both human costs and long-term economic benefits.⁸⁸ While states with mandates that limit coverage according to age or amount are better places for autism families to live than states that lack mandates altogether, such states are damaging in other ways. The existence of mandates might give the illusion to those who are less familiar with the issue of being the end of the autism insurance reform battle. However, the reality is that providing children with autism treatment until they reach a certain age, regardless of whether or not the child continues to benefit from treatment, or providing treatment for many years but only providing a certain amount of funding, limits the progress of the child and undermines the effectiveness and purpose of having mandates at all.⁸⁹

III. HOW CALIFORNIA GOT COVERAGE—THE STORY OF CALIFORNIA’S SUCCESSFUL BILL, AND HOW MODES OF ADVOCACY AND COLLABORATION PLAYED A ROLE

The key, then, to effectively serving the autism population, which exists in every state, while also proactively reducing the financial strain this population will place on society in the near future for their care as adults if they have not received proper treatment in their earlier lives, can be summarized into two tasks. First, since coverage of treatment for people with autism is the preliminary goal, the states that currently lack autism insurance reform mandates should create such legislation as quickly as possible. Second, the quality of coverage is extremely important, and states that currently have

⁸⁶ Hoffman, *supra* note 6, at 475.

⁸⁷ *Id.* at 484.

⁸⁸ *Id.*

⁸⁹ *Id.* at 480–81.

mandates but whose mandates tailor ABA coverage according to age or monetary limits should shape their legislation to resemble California's legislation as much as possible. An inquiry as to how California was so successful in achieving its legislation can be helpful in both of these pursuits.

California became the twenty-eighth state to pass autism insurance reform legislation when Governor Jerry Brown signed Senate Bill 946 (SB 946) into law in 2011.⁹⁰ The SB 946 insurance mandate requires that "every health care service plan and health insurance policy issued, amended, or renewed . . . which provides hospital, medical, or surgical coverage shall provide coverage for behavioral health treatment for autism."⁹¹ The passage of SB 946 was the result of many years of effort involving different cross-sections of society: professionals, parents, nonprofit agencies, politicians, advocates, and various media, which all worked, sometimes together and sometimes merely simultaneously, to produce a positive result for the people of California.⁹²

Where the story of autism insurance reform began in California is a matter of opinion, experience, and perspective. However, many would agree insufficient insurance coverage for autism became an issue with an incentive for change in the early 2000's, when the California Health Benefits Review Program estimated "there could be a decrease in expenditures such as the Department of Developmental Services, the state public school system, enrollees, their families, and charities, among other payers of up to approximately \$146.2 million."⁹³ Prior to these budget cuts, coverage of treatment for autism in California was characterized as a three-legged stool comprised of state-funded programs, special education, and mental health parity laws.⁹⁴

⁹⁰ *California*, AUTISM SPEAKS, <https://www.autismspeaks.org/advocacy/state/california> [<https://perma.cc/S3SJ-6CER>].

⁹¹ Hornberger, *supra* note 76, at 1.

⁹² The bill was strongly supported by nearly every major statewide and national autism advocacy organizations [sic], families and a wide range of disability advocacy groups . . . who argued that behavioral intervention treatments are medical or health services that should be covered by health plans and health insurance as other treatments and services are and that denying such coverage harms their children at a crucial stage of lives – and is outright discrimination due to their disability.

CDCAN Report: Governor Signs SB 946 Autism Private Health Insurance Mandate Reform Bill – Major Landmark Victory in Disability Rights Supporters Say, TRI-COUNTIES REG'L CTR. (Oct. 9, 2011), <http://www.tri-counties.org/index.php/budget-watch-cat/404-governor-brown-signs-sb-946> [<https://perma.cc/876C-K5CC>].

⁹³ Hornberger, *supra* note 76, at 5. "In California, the Lanterman Developmental Disabilities Services Act and related laws define the obligations of the state and the California Department of Developmental Services ('DDS') to provide services and supports to persons with developmental disabilities. Individuals with autism are eligible to receive services over a person's lifetime." *An In-Depth Look: State of California's Role in Serving Adults with Autism*, AUTISM SPEAKS, <https://www.autismspeaks.org/sites/default/files/documents/family-services/california2.pdf> [<https://perma.cc/648R-WZ8U>].

⁹⁴ *See Informational Hearing: Health Insurance Coverage for Autism Spectrum Disorders (ASD): Current Regulatory Oversight of Behavioral Intervention Therapy Before the S. Select Comm. on Autism & Related Disorders* 9–10, 18 (Cal. 2011), <http://autism.senate.ca.gov/sites/autism.senate.ca.gov/files/Transcript7-13-11.pdf> [<https://perma.cc/7M2M-TRX4>].

When families were denied coverage of ABA treatment by insurance under mental health parity laws on the basis that ABA was not “medically necessary,” the loss, while still devastating, was less impactful when funding for Regional Centers was robust.⁹⁵ The problem arose when two of the stool’s three legs were cut due to funding reductions⁹⁶ and families were left with the one wobbling mental health parity leg that had historically denied coverage.⁹⁷ Autism insurance coverage thus became “a system that [wa]s designed to require parents to take on the role of sophisticated advocates at best, and at worst, experienced insurance lawyers.”⁹⁸

A. *Litigation and Framing*

At the realization of the effect these factors would have on obtaining treatment for their children, autism parents did not immediately turn towards the solution of new legislation. Instead, they sought help for coverage through litigation, by appealing their children’s denials of coverage to the two governing regulatory agencies: the California Department of Insurance and the Department of Managed Health Care (DMHC).⁹⁹ While some of these individual appeals were successful, the success was owed not to the just or proper functioning of the system but to the persistence of families who had the resources to afford appealing countless cases.¹⁰⁰ The rest of the autism community faced insurance companies that refused to issue denials that could be appealed, that repeatedly changed the reasons for a denial once issued and once the companies lost an appeal, or that authorized extremely short ABA treatment plans and then revoked treatment altogether, claiming lack of progress.¹⁰¹

At the first hint of new legislation mandating insurance companies to offer coverage for ABA, discussed in a 2005 meeting of a special committee on autism established to begin working on a solution to these issues through legislative action called the California Legislative Blue Ribbon Commission on Autism,¹⁰² the Department of Insurance and DMHC fell into line and gave recognition to the struggle of autism parents.¹⁰³ In an effort to make the system that was in place effective so the autism community would not pursue mandate legislation, the Department of Insurance and DMHC overturned

⁹⁵ Autism Deserves Equal Coverage, *Areva Martin, CA Senate Select Committee on Autism*, YOUTUBE (July 13, 2011), <https://www.youtube.com/watch?v=jQzPwA13m5E> [<https://perma.cc/2PYS-VKAL>].

⁹⁶ *Id.*

⁹⁷ *Id.*

⁹⁸ *Id.*

⁹⁹ *Id.*

¹⁰⁰ *Id.*

¹⁰¹ *Id.*

¹⁰² *Id.*

¹⁰³ Autism Deserves Equal Coverage, *CA Insurance Commissioner Dave Jones on Autism Treatment and Insurance*, YOUTUBE (July 16, 2011), <https://www.youtube.com/watch?v=E8RyDOMXzfc> [<https://perma.cc/LG6L-CSA9>].

many previous denials of behavioral treatment.¹⁰⁴ By doing so, they established a precedent that ABA was the medically necessary standard of care for people with autism, forcing big providers like Blue Shield of California into settlement agreements which “include[d] no denial of coverage for behavioral treatments, though medical necessity of treatments still would be considered, broader access to health providers, forbidding interruptions in care and reimbursing a handful of people for previous treatments they received that Blue Shield would not pay for.”¹⁰⁵

Such rulings made parents hopeful and were a victory in acknowledgement. Nevertheless, they turned out to be substantively less effective when insurance companies began using the settlement requirement that ABA providers have a license or be supervised by a licensed individual as a loophole to continue to deny coverage to autism families, even though there was no such requirement in California.¹⁰⁶ Because no state license exists for ABA therapy in California, and other licensed medical professionals like clinical social workers were not willing to take on the duty of supervising and paying for liability insurance covering services done by others and outside of the scope of their practice and expertise, only a few of the tens of thousands of children who needed the treatment found a provider to offer it.¹⁰⁷ Parents grew more frustrated, disillusioned, and confused trying to get their children treatment by drafting multiple extensive letters, hiring attorneys, engaging in protracted appeals, and navigating a convoluted system involving two different regulatory agencies.¹⁰⁸

At the same time, several already-existing autism awareness and advocacy agencies such as Alliance of California Autism Organizations, Autism Speaks, and Special Needs Network followed the results of the cases.¹⁰⁹ These agencies began writing letters reporting the problems with enforcement of the settlement agreements to California politicians like State Senate President Pro Tempore Darrell Steinberg, a Democrat who had recently been appointed the chair of the Blue Ribbon Commission and who had made a name for himself in the California General Assembly for being a fierce advocate for mental health.¹¹⁰ The involvement and support of the advocacy agencies, especially Autism Speaks, which has developed a national campaign directed specifically at pursuing autism insurance reform in the United

¹⁰⁴ *Id.*

¹⁰⁵ Wyatt Buchanan, *Blue Shield to Pay for Autism Behavioral Therapy*, SF GATE (July 14, 2011), <http://www.sfgate.com/bayarea/article/Blue-Shield-to-pay-for-autism-behavioral-therapy-2354634.php> [<https://perma.cc/8GGL-LYR7>].

¹⁰⁶ Autism Deserves Equal Coverage, *supra* note 95.

¹⁰⁷ See Buchanan, *supra* note 105.

¹⁰⁸ See Autism Deserves Equal Coverage, *supra* note 95.

¹⁰⁹ See generally Autism Deserves Equal Coverage, Kristin Jacobsen, *On Senate Select Committee on Autism*, YOUTUBE (July 16, 2011), https://www.youtube.com/watch?v=p8RN_vizkhU&feature=youtu.be [<https://perma.cc/Q5VY-2PPK>].

¹¹⁰ See Karen Fessel, *June 2013: Autism Hero: The Man Responsible for California's Autism Insurance Mandate*, MENTAL HEALTH & AUTISM HEALTH INS. PROJECT (2013), <http://www.autismhealthinsurance.org/blog/newsletters/21-june-2013-autism-hero-the-man-responsible-for-california-s-autism-insurance-mandate> [<https://perma.cc/WT5G-UJ6U>].

States,¹¹¹ is what changed the perception and framing of this problem in California from an individual issue of scattered battles between autism parents and insurance companies to the already-existing national framework of the issue of “autism insurance reform.”¹¹²

B. Legislation and Lobbying

Senator Steinberg took on the project of drafting SB 946 after hearing stories about “parents who had to mortgage their homes in order to pay for treatments.”¹¹³ Areva Martin, an attorney, mother of a son with autism, and founder of Special Needs Network, was one of a class of uniquely qualified autism “parent professionals” who worked with the California Legislative Commission on Autism to bring awareness to the fact that health care coverage for behavioral services for people with autism was limited, inconsistent, or altogether excluded by private health plans.¹¹⁴ In 2009, the Senate Select Committee on Autism, comprised of eleven regional task forces around the state, unanimously reported that families continued to experience tremendous challenges in their efforts to obtain coverage for basic behavioral therapies and interventions.¹¹⁵ These sentiments were again echoed in the 2010 hearing held by the Committee that featured evidence and commentary on denial of insurance coverage for people with autism from autism experts, insurance companies, advocates, and parents.¹¹⁶ Senator Steinberg believed the advocates were correct in their assessment and viewed the situation as unacceptable.¹¹⁷ After hearing from dedicated parents, community members, and medical experts that early intervention treatments were similar to other forms of medical therapy, he was resolved that “SB 946, the Autism Insurance Mandate, was the only remedy.”¹¹⁸

The autism mandate faced fierce opposition from the representatives of insurance companies and the DMHC who were present at the 2010 hearing. “[T]estimony from representatives of Kaiser Permanente, Blue Shield of California, and the Association of Health Plans created frustration for both

¹¹¹ See generally *Autism Speaks Announces Multi-State Insurance Legislation Campaign*, AUTISM SPEAKS (Dec. 27, 2007), <https://www.autismspeaks.org/about-us/press-releases/autism-speaks-announces-multi-state-insurance-legislation-campaign> [https://perma.cc/9AZA-DZ WV].

¹¹² Telephone Interview with Lorri Unumb, Vice President of State Gov’t Affairs, Autism Speaks (Feb. 22, 2016). To see more specifically how the story of autism insurance reform unfolded in California, see *California Autism News*, AUTISM SPEAKS, <http://advocacy.autismspeaks.org/site/c.frKNI3PCImE/b.3937859/k.13F7/California.htm> [https://perma.cc/KF8F-Y9Y9].

¹¹³ Fessel, *supra* note 110.

¹¹⁴ Autism Deserves Equal Coverage, *supra* note 95.

¹¹⁵ *Id.*

¹¹⁶ *Insurance Coverage for Autism in California: A Medical or Educational Expense?*, ABILITYPATH.ORG, <http://www.abilitypath.org/areas-of-development/delays—special-needs/autism/articles/insurance-coverage-for-autism.html> [https://perma.cc/L952-X5ME].

¹¹⁷ Fessel, *supra* note 110.

¹¹⁸ *Id.*

legislators and parents in attendance”¹¹⁹ since “some insurers pegged behavioral therapies as experimental or ineffectual and then, after independent medical reviews sided with families, some insurers denied coverage by claiming that the therapy isn’t medical.”¹²⁰ Insurance companies also lobbied against those in favor of autism insurance mandates, making statistical arguments about the projected increase in cost to other policyholders unaffected by autism given the huge and ever-growing population of people with autism.¹²¹ However, pro-mandate parties, armed with research conducted by Autism Speaks on the cost impact seen in the previous twenty-seven states that enacted mandates, proved the projections of insurance companies to be inflated.¹²² Autism Speaks produced persuasive evidence that, based on the experience in states which have enacted autism insurance reform laws, the impact on premiums has ranged from 0.27% to 0.63%,¹²³ translating into the cost of \$.31 per person per month to provide ABA, or around \$4 a year in most states.¹²⁴ At the same time, pro-mandate parties emphasized that the early intervention provided through autism therapy “is expected to reduce long-term costs to state and local governments for education and services.”¹²⁵ In addition to establishing the financial feasibility of mandates, pro-mandate parties adopted a strategy of achieving empathy for their cause

¹¹⁹ *Insurance Coverage for Autism in California*, *supra* note 116.

¹²⁰ Fessel, *supra* note 110.

¹²¹ See, e.g., *DMHC Settlement with Blue Shield is ‘Not the Answer’ for Families Paying Thousands of Dollars a year in Out-of-Pocket Expenses*, AUTISM SPEAKS (July 15, 2011), <http://advocacy.autismspeaks.org/site/apps/nlnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=10905645> [<https://perma.cc/TH23-PXXL>].

¹²² See *id.*; *Autism Insurance Coverage Reform – What’s New*, LITTLE STAR CTR., <http://littlestarcenter.org/autism-insurance-coverage-reform-whats-new/> [<https://perma.cc/E5F2-339L>] (“An actuarial study which provides ‘real’ cost impact data (compiled by Autism Speaks) proved to be a critical resource which countered insurance company inflated cost claims.”); *Autism Speaks Hails Michigan Gov. Snyder for Support of Autism Insurance Reform, Urges Speedy Senate Action*, AUTISM SPEAKS (Sept. 14, 2011), <https://www.autismspeaks.org/advocacy/advocacy-news/autism-speaks-hails-michigan-gov-snyder-support-autism-insurance-reform-urges> [<https://perma.cc/M9HK-Y4Z6>] (“In the fight for autism insurance reform in statehouses around the nation, the insurance industry has floated inflated claims as to the projected impact on premiums. Actual experience in those states which have enacted reform has shown repeatedly that the impact is less than 1 percent. The savings for taxpayers, in the form of reduced special education, Medicaid and social service costs, has been calculated in the billions of dollars in states around the nation.”).

¹²³ See *DMHC Settlement with Blue Shield is ‘Not the Answer,’ supra* note 121.

In opposing state legislative actions around the nation, insurance companies have routinely cited cost impacts on individual policies that, after years of real life experience, prove to have been inflated. Based on the experience in states which have enacted autism insurance reform laws, the impact on premiums has ranged from 0.27 percent to 0.63 percent. The early intervention provided through autism therapy, meanwhile, is expected to reduce long-term costs to state and local governments for education and services.

Id.

¹²⁴ *The Fiscal Impact of Autism Insurance Reform*, AUTISM SPEAKS (Dec. 6, 2011), https://www.autismspeaks.org/sites/default/files/images/advocacy/Resources.FiscalImpact_3.2012.pdf [<https://perma.cc/78PC-4UU9>].

¹²⁵ *DMHC Settlement with Blue Shield is ‘Not the Answer,’ supra* note 121.

in people of power by “creating a sense of identification.”¹²⁶ They further undermined the insurance companies’ argument about inconveniencing parties unaffected by autism by highlighting the pervasiveness of autism and the fact that “very few people are not related to or associated with a family raising a child on the autism spectrum,” a disorder which “cuts across all environments, cultures, races, and economic classes.”¹²⁷

C. *Media and Organizing*

The success of California autism insurance reform can be credited in a big way to grassroots mobilization and use of the media. Grassroots organizing for autism insurance reform was different in one major way from the grassroots campaigns that have occurred for other causes: many agencies dedicated to raising awareness about autism were already established, respected, and powerful. Agencies may have already existed in autism’s case and not others because autism is such a complex disorder, requiring attention to and rehabilitation in several areas including the medical, educational, social, behavioral, and legal spheres. As a result, the advocate leaders of autism insurance reform were able to spend far less time growing the grassroots and creating the structure through which the campaign would flow and instead spent more time adding like-minded partners, creating both interactive and informational platform web pages, and advertising and educating the rest of society on the urgency of this particular need of the autism community. Autism awareness and more general “special needs” advocacy agencies everywhere in California, from the national level, such as Autism Speaks and Autism Society of America, and the state and regional levels, such as Talk About Curing Autism, took on autism insurance reform as a project of their own, communicating to both the autism communities they directly served and the general population not directly affected by autism.

In the beginning stages of the campaign for legislative reform, media attention and support were crucial to making the bill un-opposable for autism mandate advocates.¹²⁸ Autism agencies drafted form letters for people in the autism community to send to politicians and legislators.¹²⁹ They also dedicated a section of their websites to the issue of insurance reform where

¹²⁶ Jennifer Gordon, *The Campaign for the Unpaid Wages Prohibition Act: Latino Immigrants Change New York Wage Law 20* (Carnegie Endowment for Int’l Peace Global Policy Program, Working Paper No. 4, 1999).

¹²⁷ *Coverage for Autism Services*, BUTTERFLYEFFECTS, <http://butterflyeffects.com/resources/insurance/> [https://perma.cc/U9KS-HT8A].

¹²⁸ Harben Porter & Kristan Sartor, *Autism Spectrum Disorder Health Care in California*, 15–16 (unpublished manuscript) <http://harbenporter.myefolio.com/Uploads/ASD%20Health%20Care%20in%20CA.pdf> [https://perma.cc/5QC2-YQVR]; Unumb, *supra* note 112.

¹²⁹ *See, e.g.*, John J. Pitney, *Last-Minute Action Alerts on California Mandate Bill*, AUTISM POL’Y AND POL. (May 26, 2011), <http://www.autismpolicyblog.com/2011/05/last-minute-action-alerts-on-california.html> [https://perma.cc/GR3T-WBTB]; Letter from Greg Fletcher, All. of Cal. Autism Org. Representative, to Darrell Steinberg, Chair, Senate Select Comm. on Autism & Related Disorders (Jan. 25, 2010), <http://www.feat.org/portals/0/publicdocuments/acainsurancemandatecoverlettersteinber.pdf> [https://perma.cc/6JWV-H5FB].

the form letters could be easily accessed. Those websites also included detailed, updated information on the progress of the legislation to inform those who had a vested interest in the issue, like autism parents, as well as suggestions as to which legislators to target, plans for when the committee hearings would occur, guidelines for conduct at the committee hearings, and much more.¹³⁰ They utilized Twitter, email lists, and Facebook pages to send a more simplified message about the campaign cause and to gather more support from outside the autism community.¹³¹ Autism Speaks even developed and broadcast commercials to raise general awareness of the issue.¹³²

The final version of SB 946 that was submitted for approval endorsed behavioral treatments as the medical standard and required insurance companies to cover autism treatments subject to no age or monetary limitations.¹³³ In doing so, California followed in the footsteps of Indiana and Massachusetts, creating a particularly effective law without imposing such limita-

¹³⁰ For instance, Autism Speaks' website has a link for the autism insurance reform initiatives in each state, and it includes information such as state and federal officials, history of reform bills, educational information, maps showing progress, frequently asked questions, and articles written about autism insurance reform. See *State Initiatives*, AUTISM SPEAKS, <https://www.autismspeaks.org/state-initiatives> [<https://perma.cc/N8VB-NVWF>]. For an example of an Assembly Agenda that was made available to families via the Autism Speaks website, see S. Select Comm. on Autism & Related Disorders, *Informational Hearing: Health Insurance Coverage for Autism Spectrum Disorders (ASD): Current Regulatory Oversight of Behavioral Intervention Therapy*, AUTISM SPEAKS (Jul. 13, 2011), http://advocacy.autismspeaks.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/Hearing%20Agenda_C_%20july%2013_2011.pdf [<https://perma.cc/BQ2K-9H4U>]. The Autism Deserves Equal Coverage Foundation provided information, articles, videos, links, and text of the bills on its *News and Legislative Advocacy* page. See *News and Legislative Advocacy*, AUTISM DESERVES EQUAL COVERAGE FOUND., <http://www.autismcoverage.org/Advocacy.html> [<https://perma.cc/AYS4-8AC6>]. National Autism Network dedicated a webpage to the issue of California's autism insurance reform movement, making information easily accessible to the community. See *California Autism Insurance Legislation*, NAT'L AUTISM NETWORK, <http://nationalautismnetwork.com/legislation/state-initiatives/california-insurance-legislation.html> [<https://perma.cc/KLP6-D5RJ>].

¹³¹ For example, Autism Speaks reached out to get more people involved and aware through Facebook, Twitter, and YouTube. See *Autism Votes*, FACEBOOK (last visited Mar. 30, 2016), <https://www.facebook.com/pages/Autism-Votes/183383669243?ref=mf> [<https://perma.cc/ANY6-AMUQ>]; *Autism Votes*, TWITTER (last visited Mar. 30, 2016), <https://twitter.com/autismvotes> [<https://perma.cc/2BPB-RBBC>]; *Autism Votes*, YOUTUBE (last visited Mar. 30, 2016), <https://www.youtube.com/user/AutismVotes> [<https://perma.cc/5F56-ZTG3>]; *Autism Speaks TV Ad—"Neighbors,"* YOUTUBE (Jul. 7, 2009), https://www.youtube.com/watch?v=7rVX_nSLFtg [<https://perma.cc/9Q5K-6WR3>].

¹³² See, e.g., Autism Speaks, *1 in 88 Can't Wait—Autism Votes*, YOUTUBE (Sept. 18, 2012), <https://www.youtube.com/watch?v=yjqQ555KL1A> [<https://perma.cc/F5QB-R4SK>].

¹³³ See CAL. HEALTH & SAFETY CODE §§ 1374.73–74 (West, Westlaw through Ch. 2 of 2016 Reg. Sess. and Ch. 1 of 2015–2016 2nd Ex. Sess.); see also Daisy Lin, *FAQ: California's New Autism Insurance Mandate*, NBC SOUTHERN CALIFORNIA, <http://www.nbclosangeles.com/news/health/Questions-Answers-California-New-Autism-Insurance-Mandate-161286345.html> [<https://perma.cc/Z8VU-HRUSJ>].

tions.¹³⁴ The bill was passed first by the Assembly, which voted 51-11 in favor, and then by the Senate, which passed it at 25-4.¹³⁵

When it came time for Governor Brown to decide whether to sign the bill and make it official law in California, the campaign used a more targeted media approach. Pro-mandate advocates utilized editorials in big-name newspapers like the *Los Angeles Times* to urge the governor to sign the bill, making clear statements about the interests at play.¹³⁶ Additionally, all the supporters of the bill—the politicians behind it, hundreds of families affected by it, and the agencies which championed it—held a rally in Sacramento to encourage Governor Brown to sign the bill.¹³⁷ In October 2011, Governor Brown signed SB 946 into law.¹³⁸

D. Plan for Long-Term Enforcement and Significance

Possibly even more important than the milestone of passing SB 946 was the creation of an accountable environment which would allow it to be enforced. SB 946 mandated the creation of the Autism Advisory Task Force, which was charged with overseeing the enforcement of SB 946’s provisions,¹³⁹ increasing the likelihood that the law would be effective beyond the career terms of the politicians who were responsible for its success.¹⁴⁰ Finally, with this mandate set to expire in 2014, Senator Steinberg introduced and successfully passed SB 126 to extend coverage until 2019, to “continue ensuring a bright future for all children and families.”¹⁴¹

California’s clear refusal to take the incremental approach of other states cannot be credited to one force, but to many, including the sustained

¹³⁴ See UNUMB & UNUMB, *supra* note 56, at 58 (“In 2001, the Indiana legislature passed the first truly effective autism insurance mandate.”); *Indiana: Frequently Asked Questions About the Autism Insurance Reform Law*, AUTISM SPEAKS, https://www.autismspeaks.org/images/advocacy/Indiana_FAQs.pdf [<https://perma.cc/48M3-ZXK9>]; see also *Massachusetts Becomes the 23rd State to Enact Autism Insurance Reform*, AUTISM SPEAKS (Aug. 4, 2010) <https://www.autismspeaks.org/advocacy/advocacy-news/massachusetts-becomes-23rd-state-enact-autism-insurance-reform> [<https://perma.cc/KK7N-HGH6>].

¹³⁵ *Assembly, Senate Votes on Final Day of Legislative Session Offer Families Hope for Reform*, AUTISM SPEAKS (Sept. 9, 2011), <http://advocacy.autismspeaks.org/site/apps/nlnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=11212415> [<https://perma.cc/DXF9-QGWZ>].

¹³⁶ “[The insurance companies’] position reflects how crucial parts of the healthcare system are wedded to the status quo, regardless of what’s best for patients. State lawmakers have passed a bill to overcome the insurers’ resistance, and Gov. Jerry Brown should sign it.” *An Autism Treatment Worth Funding*, L.A. TIMES (Sept. 30, 2011), <http://articles.latimes.com/2011/sep/30/opinion/la-ed-autism-20110930> [<https://perma.cc/WCR3-MGYU>].

¹³⁷ See Areva Martin, *Special Needs Network Joins Hundreds of Autism Advocates at Rally for SB 946*, YOUTUBE (Sept. 27, 2015), <https://www.youtube.com/watch?v=67w4avC7qwc> [<https://perma.cc/MSB6-5NJJ>].

¹³⁸ See *California*, *supra* note 90.

¹³⁹ CAL. DEPT OF MANAGED HEALTH CARE, AUTISM ADVISORY TASK FORCE: REPORT TO THE GOVERNOR OF CALIFORNIA AND THE CALIFORNIA STATE LEGISLATURE 1 (2013), <https://www.dmhc.ca.gov/Portals/0/AbouttheDMHC/PublicInformationAndReports/aatfr.pdf> [<https://perma.cc/M7QK-ZBFF>].

¹⁴⁰ See *id.*

¹⁴¹ Fessel, *supra* note 110.

passionate advocacy of autism parents, the strong and persuasive leadership of Senator Steinberg, the organizing and public education of autism awareness agencies, and the unfortunate conditions which existed before—that “the settlements initially appeared to provide the needed coverage, but contained a flaw that substantially negated their intended impact, requiring the legislative remedy provided through SB 946.”¹⁴²

E. California Versus North Carolina—What Made the Difference?

The case of North Carolina autism insurance reform is an interesting comparison to the case of California because the campaigns were very similar in many ways, yet had noticeably different outcomes. North Carolina, just like California, took around six years to enact mandate legislation and was motivated by the same lack of support for services as motivated the legislation in California.¹⁴³ Both the North Carolina and California campaigns were able to benefit from the resources generated as a result of a national campaign for insurance reform (for example, Autism Speaks’ insurance policy increase measurements). Both campaigns employed grassroots efforts and worked with nonprofit agencies,¹⁴⁴ and both campaigns faced big insurance companies making identical arguments against mandate legislation.¹⁴⁵ North Carolina held its first discussion on autism insurance reform in 2010, through the Joint Study Committee on Autism Spectrum Disorder and Public Safety, and was organized by the main leaders of the initial North Carolina autism insurance reform campaign, Autism Society of North Carolina (ASNC), with Autism Speaks in the background.¹⁴⁶ The committee received testimony from doctors, agency leaders, and parents who “spoke of insurance initiatives in other states as well as the cost benefits of removing the exclusion of coverage for autism related treatments.”¹⁴⁷ Testimony in

¹⁴² *Coverage for Behavioral Health Treatments to Start July 1, 2012, Lead to Job Creation, Save Taxpayers \$140 Million*, AUTISM SPEAKS (Oct. 9, 2011), <http://advocacy.autismspeaks.org/site/apps/lnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=11282473> [<https://perma.cc/63AJ-N98T>].

¹⁴³ See generally Robert Weiner Associates, *N.C. Lagging on Insurance for Autism Behind 29 States, Say Autism Society’s Bridget Mora and Ex-White House/Congress Staff Robert Weiner on Eve of NC State Autism Conference*; *Oped Column in Charlotte Observer*, PR NEWSWIRE (Mar. 28, 2012, 9:38 AM), <http://www.prnewswire.com/news-releases/nc-lagging-on-insurance-for-autism-behind-29-states-say-autism-societys-bridget-mora-and-ex-white-house-congress-staff-robert-weiner-on-eve-of-nc-state-autism-conference-oped-column-in-charlotte-observer-144616705.html> [<https://perma.cc/CT6Q-69PU>].

¹⁴⁴ See *id.*

¹⁴⁵ See *Autism Speaks Takes on ‘Big Insurance’ in NC with Ad Campaign*, AUTISM SPEAKS (July 15, 2014), <https://www.autismspeaks.org/advocacy/advocacy-news/autism-speaks-takes-big-insurance-nc-ad-campaign> [<https://perma.cc/DYV4-2C4K>].

¹⁴⁶ See David Laxton, *Autism Insurance in North Carolina—First Steps*, AUTISM SOC’Y OF N.C. (Feb. 3, 2010), <https://autismsocietyofnc.wordpress.com/2010/02/03/autism-insurance-in-north-carolina-first-steps/> [<https://perma.cc/8QT9-ABZC>].

¹⁴⁷ See *id.*

opposition was provided by the insurance industry.¹⁴⁸ Although North Carolina has a lower incidence of autism than California has, at one in fifty-eight as of 2014, the prevalence of people with autism in North Carolina is not insignificant.¹⁴⁹ However, despite all these apparent similarities, North Carolina’s bill, SB 676, unlike California’s, is subject to both age and monetary limitations: it requires health plans to cover treatment of autism for children up to age 18 and covers ABA up to \$40,000 per year.¹⁵⁰

The important question to ask is how California’s bill made such great strides while North Carolina’s has only taken incremental steps. As seen from California’s example, it takes many different approaches to get legislation passed. Generally, a campaign needs to have a good policy, *i.e.*, be practical, low (or lower) cost, high return, and for a good reason; have the people in power desire it to be successful because they see it is in their interest and the public interest; and have grassroots support so the environment in which the law is established is conducive to its long-term success. And, as California’s story shows, all of these things need to be working in favor of the legislation in order for it to be effective—having four times the grassroots support would not have overcome a lack of political support or a bad policy.

Over the time it took for North Carolina to pass an autism mandate, many versions of the legislation were introduced, and the law that resulted is acknowledged by most to be a starting point—a compromise “between what you know is best and what is politically possible.”¹⁵¹ In response to the North Carolina autism community’s inquiries as to why the bill failed to offer more coverage, ASNC commented that “[p]olicymaking is all about windows of opportunity: they are open for a short period of time and ASNC felt that it was important to work to pass some kind of benefit now, to make sure families and children would get a benefit while we had the support of the General Assembly.”¹⁵² Republican Representative Chuck McGrady, one of the bill’s political allies who “shepherded the autism bill in the House for several years,” “was visibly disappointed that his version of the bill,” which provided broader coverage for families with autism, “was not going to pre-

¹⁴⁸ *Battle of Words & Numbers: Autism Insurance*, AUTISM SOC’Y OF N.C. (Mar. 6, 2010), <https://autismsocietyofnc.wordpress.com/2010/03/06/battle-of-words-numbers-autism-insurance/> [https://perma.cc/KP3M-3VQH].

¹⁴⁹ See *North Carolina: Tracking Autism Spectrum Disorder and Other Developmental Disabilities in North Carolina: What You Need to Know*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/ncbddd/autism/states/addm-north-carolina-fact-sheet.pdf> [https://perma.cc/UCC8-2PHU]; *Study Finds Rise in NC Autism Rates*, CITIZEN-TIMES (Apr. 6, 2014), <http://www.citizen-times.com/story/news/local/2014/04/06/study-finds-rise-nc-autism-rates/7397301/> [https://perma.cc/2KQU-FPMT].

¹⁵⁰ N.C. GEN. STAT. ANN. § 58-3-192 (West, Westlaw through the end of the 2015 Reg. Sess. of the Gen. Assem.); see also *NC Passes Autism Insurance: What it Means for Families*, AUTISM SOC’Y OF N.C. (Oct. 1, 2015), <https://autismsocietyofnc.wordpress.com/2015/10/01/nc-passes-autism-insurance-what-it-means-for-families/> [https://perma.cc/6T8W-EXDR].

¹⁵¹ *NC Passes Autism Insurance: What it Means for Families*, *supra* note 150.

¹⁵² *FAQs Related to SB 676: Autism Health Insurance Coverage*, AUTISM SOC’Y OF N.C. (July 2, 2015), <https://autismsocietyofnc.wordpress.com/2015/07/02/faqs-related-to-sb-676-autism-health-insurance-coverage/> [https://perma.cc/6PTE-2ARY].

vail.”¹⁵³ The breakdown in North Carolina which led to the lukewarm reception of SB 676 by those who were its strongest advocates appears to have been due to, among many things, reluctant and negotiated (rather than enthusiastic) political support and a less-than-effective initial strategy to increase political support to the level necessary to create the strongest bill possible.

By no means did North Carolina advocates make a “weak” case. The autism awareness and advocacy agencies and autism parents in North Carolina are no less capable than those in California. The first major difference between the campaigns of the two states was North Carolina’s lack of a strong Senator Steinberg-like political figure who placed the passing of this legislation as number one on his list of priorities. While there was strong political support for an autism insurance mandate in North Carolina, evidenced by the 105-7 vote to pass the initial SB 498 draft bill by the House of Representatives,¹⁵⁴ there were also issues of higher priority, sympathy for insurance companies, and vehement opposition from people who mattered. Senate Committee Rules Chair Tom Apodaca, also a Republican, and Senate Majority Leader Phil Berger were two such important individuals. Both Senator Apodaca and Senator Berger did not like the idea of imposing mandates of any kind for fear of alienating people not directly affected by autism who would pay increased premiums in compliance with the mandates.¹⁵⁵

Another difference is found in the breadth of the initial approach used by North Carolina mandate advocates. California’s campaign was led primarily by autism advocacy agencies, but also included noticeable support from organizations surrounding the general special needs community and doctors in psychology and psychiatry, all of whom worked to give the impression to those deciding the fate of the bill that the broader special needs community in California was moving towards autism legislation, whether the state was ready for it or not. This momentum was simply not present in North Carolina. The beginning campaign, lead by ASNC and Autism Speaks, was not as expansive as it could have been, though the need was just as great, and the parents just as passionate.¹⁵⁶ Additionally, the level of controversy surrounding autism insurance reform was high,¹⁵⁷ which was favorable to the insurance companies in North Carolina in that it made them comfortable in their unwillingness to compromise. As Senator McGrady said, “something will be just wildly controversial this year, and then three years later, you can’t find anybody that opposed it.”¹⁵⁸ As a result, several proposed bills were

¹⁵³ Rose Hoban, *Finish Line in Sight for Autism Insurance Reform Bill*, N.C. HEALTH NEWS (July 1, 2015), <http://www.northcarolinahealthnews.org/2015/07/01/finish-line-in-sight-for-autism-insurance-bill/> [https://perma.cc/V3HN-V7H9].

¹⁵⁴ H.B. 112-498, 2013–2014 Sess. (N.C. 2013), <http://www.ncleg.net/gascrpts/BillLookUp/BillLookUp.pl?Session=2013&BillID=H498&votesToView=all> [https://perma.cc/4W4W-7QAW].

¹⁵⁵ See Hoban, *supra* note 153.

¹⁵⁶ See *FAQs Related to SB 676*, *supra* note 152.

¹⁵⁷ See Hoban, *supra* note 153.

¹⁵⁸ *Id.*

reviewed by the House and passed, only to be stalled multiple times in the Senate between 2010 and 2015.¹⁵⁹

To address the lack of momentum that allowed the first mandate bill to be used as a bargaining chip by people in power to get work done on other issues perceived to be a higher priority,¹⁶⁰ and then to be written out of a high-priority regulatory bill due to an overstretched budget,¹⁶¹ North Carolina adjusted its strategy. Since the initial North Carolina campaign partnership of Autism Speaks and ASNC was not enough to shake those in leadership out of apathy, ASNC and Autism Speaks decided to take a new approach to convey to the legislature the necessity and sense of societal movement towards an autism mandate. These two organizations came together with other North Carolina advocacy groups, professionals, and clinicians, with Autism Speaks taking on a more prominent role,¹⁶² to form a coalition to fight for a mandate, adopting the slogan “families and children cannot wait another year”¹⁶³ and re-emphasizing their goal of having an “achievable, measured approach that would provide for a broad range of treatment options while assuring an annual benefit amount.”¹⁶⁴ Additionally, to solve the apathetic politicians issue, the North Carolina campaign turned to newly elected Republican House Representative Tom Murry.¹⁶⁵ Representative Murry was a strong proponent of the bill who was well respected by both political parties, who increased the legitimacy of the bill, and who highlighted its necessity and practicality to his colleagues rather than simply relying on the popularity and perception of the bill.¹⁶⁶ He helped ease fiscal conservatives’ fears of the effect of mandates, educating those in charge about the spectrum nature of autism as a disorder and explaining that mandating coverage for ABA would in no way be mandating the same amount of coverage for all kids with autism, since higher functioning children need less costly therapy for fewer years.¹⁶⁷ In the face of national pressure from other states that had implemented mandates, Senator Apodaca pushed the insurance companies to commit to joining the negotiations.¹⁶⁸ Ultimately, the North Carolina autism insurance reform mandate was passed as a heavily negotiated compromise between families with autism and insurance compa-

¹⁵⁹ See *id.*; Robert Weiner Associates, *supra* note 143.

¹⁶⁰ See Carolina Center for ABA & Autism Treatment, *Autism Insurance Reform in North Carolina—Part I*, YouTube (Oct. 29, 2014), <https://www.youtube.com/watch?v=lajVFrBzRsY> [https://perma.cc/5AX8-VEAG] (23:15–33:07).

¹⁶¹ See *id.* at 25:18–26:55.

¹⁶² See *One Small Step for Awareness, One Giant Leap for Coverage*, AUTISM SOCIETY OF N.C. (Jun. 9, 2010), <https://autismsocietyofnc.wordpress.com/2010/06/09/one-small-step-for-awareness-one-giant-leap-for-coverage/> [https://perma.cc/S7GT-TRBB].

¹⁶³ *FAQs Related to SB 676*, *supra* note 152.

¹⁶⁴ *Id.*

¹⁶⁵ Carolina Center for ABA & Autism Treatment, *supra* note 160.

¹⁶⁶ *Id.* at 23:00–32:06.

¹⁶⁷ *Id.*

¹⁶⁸ See Hoban, *supra* note 153; *FAQs Related to SB 676*, *supra* note 152.

nies—the enactment of a mandate, but one with strict limitations on age and money.¹⁶⁹

While passing of the autism mandate was certainly a victory for autism families who were “happy to have some forward motion on the bill,” families also acknowledged that “there are some things in there that aren’t great.”¹⁷⁰ Legislators who worked with the bill noted that “policy changes have happened incrementally” and vowed to return to the legislature in several years, “once the state has had some time to see how the law plays out in terms of cost and the effects on insurance premiums.”¹⁷¹

F. *Lessons and the Role of the Lawyer*

Legal and societal change is never easy. In undertaking campaigns to reform an area in which an injustice exists, it is helpful to be aware of the aspects one has control over, such as building grassroots support and drafting legislation, and the aspects one has less control over, such as the existing state politics, players, and interests. There were just some things in the case of North Carolina that pro-mandate advocates could not anticipate or do anything about, even if they were or could have been anticipated. For example, the higher credibility and, therefore, bargaining power of insurance companies in North Carolina as compared to the perception of and faith in those in California following the failed regulatory insurance department settlement allowed North Carolina insurance companies to maintain the status quo longer without real pressure to change. The more positive, accessible lessons in advocacy drawn from this state comparison include the importance of pursuing strong political leadership, of supporting that leadership with a broad and persuasive grassroots campaign, of engaging with the media and data-based arguments, and of creating a plan for future long-term enforcement. The existence of mandates is rightfully considered progress for North Carolina and other states that have seen more incremental change. A mandate that needs to be revisited and revised is better than no mandate at all. Nevertheless, it is critical to keep in mind that laws for which the support is negotiated are the ones that have the highest risk of being undone in future political terms. Therefore, future lawyers for this cause will need to take on many advocate roles in order to achieve the ultimate success—matching California’s standard as closely as possible.

Families with autism are familiar with their community’s issues and needs but may be deficient in knowledge of the law. As a result, the working relationship between lawyers for this cause and their clients should be one in which the “creative energies” of the lawyer are “brought into line with the

¹⁶⁹ Hoban, *supra* note 153; *North Carolina Gov. McCrory Signs Autism Insurance Reform Legislation*, AUTISM SPEAKS (Oct. 15, 2015) <https://www.autismspeaks.org/news/news-item/north-carolina-gov-mccrory-signs-autism-insurance-reform-legislation> [https://perma.cc/K765-2GBA].

¹⁷⁰ Hoban, *supra* note 153.

¹⁷¹ *Id.*

needs and desires of their clients.”¹⁷² As Betty Hung suggests in her essay on social organization, “community members—not lawyers or organizers—should lead and be at the center of efforts seeking to improve their lives. Organizers and lawyers can and should find common ground as facilitators, supporters, and allies of affected community members.”¹⁷³ While the grass-roots manpower already exists in the autism community, lawyers can take on the role of political enablers and help autism families and advocates identify which politicians to target, offer advice on which arguments to emphasize when interacting with media, help families to frame the issue into concrete legal goals capable of being accomplished, and offer strategies to get new legislation passed. North Carolina and the other states with mandates, as well as states still lacking mandates, are currently in the best position to improve the unequal state of affairs for autism families seeking treatment in the United States because they have the experience of the states that came before them at their disposal. If they take advantage of and learn from the strategies that have worked before, and adapt them to their own campaigns, they have a good chance of gaining bipartisan support for autism insurance reform mandates and reducing controversy surrounding the issue in the next few years.

CONCLUSION

For families with autism, the time for change is now. Continuing to maintain a state of affairs in which families are compelled to move locations just so their disabled child can receive treatment is not the kind of nation the United States is or should be. Although society does not yet know the cause of autism, it is known that autism is the fastest growing developmental disability and that people with autism will impose enormous costs on the United States if they are not properly treated with early intervention therapy like ABA. Since it is also known that early intervention preventive treatments both improve the functioning and quality of life of people with autism at very low cost to other policyholders not affected by autism and reduce costs for insurance companies in the long term, it is to the betterment of the entire nation to make these treatments available to all autism families. Individual state mandates campaigned for by parents, agencies, professionals, and politicians have been very successful in ensuring access to these very important treatments. The states that have yet to enact such mandates should make doing so a top priority. States whose mandates impose monetary or age limits in the coverage of early intervention treatments should make an effort to refine those mandates to emulate the mandates of the states that offer treatment based on continued efficacy, because the quality of coverage matters as

¹⁷² Derrick Bell, *Serving Two Masters: Integration Ideals and Client Interests in School Desegregation Litigation*, 85 *YALE L.J.* 470, 488 (1976).

¹⁷³ Betty Hung, *Law and Organizing From the Perspective of Organizers: Finding a Shared Theory of Social Change*, 1 *L.A. PUB. INT. L.J.* 4, 6 (2008).

much in achieving the goal of reducing costs and improving quality of life as the act of supplying coverage through mandates. Where society has been shortsighted in its treatment of the disabled in the past, it now has the opportunity to solve a great injustice currently existing in the United States. Society can give the autism population more than just the opportunity for a mere existence, and, in doing so, can proactively do itself a service as well.