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AUTISM INSURANCE COVERAGE
Which state policies work and why?

By

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Introduction: Virginia's HB 2467 and SB 1062 Pass into Law

In the spring of 2011, Virginia's legislature passed its first autism insurance mandate via Senate Bill 1062 and House Bill 2467. As a legislative intern for Senator Janet Howell – the primary sponsor of SB 1062 – I was able to track the mandate from beginning to end. I observed conferences between Senator Howell and representatives from autism advocacy groups, I sat in on various Senate and House committee meetings, I carefully reviewed changes in the mandate's text when Senator Howell compressed her two original autism bills into one new bill in order to match Delegate Greason's HB 2467, and I watched as the votes were counted and the mandate was passed on both the Senate and House floors.

Over the course of this legislation's development, I began to understand both the political and economic considerations that go into crafting an autism insurance mandate. First, although it is clearly welfare legislation, the autism insurance mandate receives an overwhelming amount of bipartisan support because of the population that it affects; (1) almost every representative on either side of the aisle has some personal or familial connection to an autistic child, and (2) autistic children are an incredibly dependent and vulnerable class of individuals. Second, I learned that the most vocal opponents to these bills are small business owners, who feel that they would not be able to afford to cover the premiums that would result from the inclusion of autism treatments in their insurance plans. To assuage this constituent base, representatives try to soften the mandate by using caps, age limitations, and specific wording. Third, I discovered that this kind of mandate is beneficial to state governments because, according to many cost-benefit analyses, it saves the state money over the long term. The young children who receive the treatments and therapies these mandates provide for are usually much less dependent on state welfare and much more likely to be productive citizens as adults. Lastly, I recognized that

Virginia's autism insurance mandate is part of a national movement for autism policy reform across the United States. As such, its design and passage were greatly affected by the success of similar bills in other states.

Virginia joined a long list of other states and the District of Columbia when Governor McDonnell signed the legislation into law. Many of these states' laws are incredibly analogous, while others vary dramatically. Moreover, most states that have passed an autism insurance mandate recognize that the legislation is somewhat experimental. In fact, on February 7, 2012, Virginia corrected a flaw in its 2011 autism insurance reform law when Governor McDonnell signed HB 1106, which assured coverage for providers of Applied Behavioral Analysis – one of the most popular treatments for autism – by establishing a state licensing procedure for the field.

This thesis seeks to examine the autism insurance reform movement more closely, to address and explain the discrepancies between state mandates, and to evaluate their success according to various cost-benefit analyses. In doing this, I hope to provide an objective comparison of these mandates that could be used to improve the efficiency and effectiveness of current law, to incentivize more states to enact autism legislation, and to better acknowledge the legislative accomplishments that have resulted from the national movement for autism insurance reform.

Autism: Understanding the Disorder, its Effects, and Treatments

"Autism" is a commonly misused and misunderstood word. While it is often associated with an additional diagnosis of mental retardation, "which can range from mild to profound,"[1] it is not the same. In fact, autism is a complex disorder with a myriad of symptoms that relate to social relations, language, communication, and specific abnormal behaviors. Autism affects both children and adults, but symptoms are usually present by the age of three or four. While there is no known cure for autism, and only hypotheses regarding its cause, some treatments have proven to be effective.

Autistic Disorder is found in the fourth edition text revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) under the umbrella term of Pervasive Developmental Disorders. According to the DSM-IV-TR, these disorders "are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities."[2] Although it took until 1980 for the American Psychiatric Association to formally recognize autism as a biologically based developmental disorder in the third edition of the Diagnostic and Statistical Manual, the first person to define autism – an American psychiatrist named Leo Kanner – identified it as a "condition in its own right, characterized by a distinctive set of behavioral abnormalities. Moreover, Kanner suggested as early as 1943 that autism is a brain-based condition with a biological origin."[3]

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[1] American Psychiatric Association, Task Force on DSM-IV, *Diagnostic and statistical manual of mental disorders DSM-IV-TR*, American Psychiatric Association [database online], Washington, DC, 2000: 69.

[2] *Ibid.*, 71.

[3] Jill Boucher, *The Autistic Spectrum: Characteristics, Causes, and Practical Issues,* Thousand Oaks, CA: SAGE Publications Inc., 2009, 9.

However, Kanner's use of the word "autism," which was historically linked to descriptions of schizophrenia, and his focus on the inability of autistic children to relate resulted in two very misled theories regarding the disease:[4] (1) that autism is a neurotic condition resulting from an unloving mother, and (2) that autism is a form of psychosis synonymous to childhood schizophrenia. Both of these theories were disproven by the early 1970s with the aid of electroencephalography (EEG) and studies that compared children with a very early onset of symptoms and children who developed abnormal behaviors in their school years.[5]

The term "Autism Spectrum Disorders" developed a little later, with the observation that some children had impaired social and communicative skills, but normal language and learning abilities. Two researchers, Wing and Gould, "initially coined the phrase autistic continuum to refer to the varied forms this multi-dimensional, multi-profile condition might take. However, in later publications Wing preferred the term autistic spectrum disorders [...] because 'spectrum' captures the lack of clear boundaries between different forms of autism."[6] Autism spectrum disorders include "classic" autism, Asperger syndrome – often thought of as a high functioning form of autism – and Pervasive Developmental Disorder Not Otherwise Specified.

Within this spectrum, children experience deficiencies in various forms. According to the tenth edition of The International Statistical Classification of Diseases and Related Health Problems (ICD-10), diagnostic criteria for childhood autism cover a wide range of symptoms. These include abnormal development in language skills before the age of three; qualitative impairment in social interaction, such as failure to use appropriate facial expressions; qualitative abnormalities in communicative skills, such as the idiosyncratic use of words or phrases; and

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[4] Fred R. Volkmar, ed., *Autism and Pervasive Developmental Disorders.* New York: Cambridge University Press, 1998, 3.

[5] Jill Boucher, 8.

[6] *Ibid.*, 29.

restricted repetitive patterns of behavior, including compulsive adherence to specific, nonfunctional routines.[7] These traits combined can truly debilitate an individual, most especially when that child lacks the ability to learn and use language effectively.

Unfortunately, while early intervention has been shown to be particularly helpful in treating autism, it is very difficult to diagnose children at an early age. "Because of the variability within typical development itself, even when slow development or lack of change is recognized, it is difficult to interpret." Furthermore, "[...] the current diagnostic instruments are still organized primarily with the skills of slightly older preschool-age children in mind."[8] Nevertheless, treatments for autism have shown success at many age levels. These include both physical and non-physical interventions. Physical interventions most commonly take the form of pharmaceuticals, including dopamine regulating agents, selective serotonin reuptake inhibitors, and Oxytocin. However, there are also complementary and alternative physical intervention methods (CAMs) such as those that utilize sensory stimulation.[9] "Non-physical interventions, including psychosocial treatments and education methods, most often develop from the experience of 'what works' in increasing a particular competence or for reducing and replacing a particular form of unwanted behaviour."[10]

Applied Behavioral Analysis (ABA) is perhaps the most popular non-physical intervention method. This method focuses on individual needs with repetition, an antecedent-consequent teaching formula, and carefully plotted progress charts.

> Beginning with demonstrations by Ferster (1961), Lovaas et al., (1966) and Bartak & Rutter (1971) that behavioural principles influences the behaviour of

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[7] Fred Volkmar, 26-27.

[8] Tony Charman and Wendy Stone ed., *Social and Communication Development in Autism Spectrum Disorders: Early Identification, Diagnosis, and Intervention*, New York: The Guilford Press, 2006, 35-36.

[9] Jill Boucher, 286-287.

[10] *Ibid.*, 287.

> these clients, there developed an appreciation of highly structured, carefully planned interventions to meet the needs of people with autistic disorder and related conditions. Since the mid-1960s the teaching technology for this population has grown increasingly sophisticated and effective.[11]

However, there is still doubt as to whether methods such as ABA are successful because of their specific design, or because they are intensive in nature, stress early intervention, actively involve the family, and have rigid structures.[12] Regardless, these methods are used across the United States, and individuals have shown marked improvement in function and social interaction as a result. Other widely used therapies and services include speech and language therapy, occupational therapy, social skills training, and music therapy.[13]

The estimated prevalence of autism has been on the rise since the 1980s. Back then, "classic autism was consistently estimated as affecting between 0.4 and 0.5 children in every 1,000."[14] More recently, studies have shown that about 1% of the population is affected by one of the Autism Spectrum Disorders. Although a set of narrower diagnostic criteria halves this rate, it remains well above the reported rates from a few decades ago.[15] One hypothesis for this increase is that new infant vaccinations, such as the measles, mumps, and rubella (MMR) vaccine, were causing children to develop autism. This theory, which was promulgated by a single author named Andrew Wakefield, caused a prolonged period of hysteria for the parenting population. However, the theory was disproven by several epidemiological studies, which all found a complete lack of evidence to link the MMR vaccine to autism. Other, more probable,

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[11] Fred Volkmar, 195.

[12] Jill Boucher, 300-301.

[13] Kathleen C. Thomas, Joseph P. Morrissey, and Carolyn McLaurin. "Use of Autism-Related Services by Family and Children." *Journal of Autism and Development Disorders*. Vol. 37 (Dec. 2007): 824.

[14] Jill Boucher, 72.

[15] *Ibid.*

theories about the increase of prevalence include a change in diagnostic practices, greater public awareness of autism, and better screening practices.[16]

It is important to understand this disorder, the state of currently available treatments, and the continuing rise of prevalence before evaluating autism policy. Policy is crafted in response to popular sentiment, and not necessarily in response to a specific group's true needs. Thus, policy does not always properly address the issue at hand in the most effective or productive manner possible. In regards to autism policy specifically, it is important to keep in mind that intensive treatments are most effective in the early years, that early diagnostic screening can make a huge difference in achieving early intervention, and that the variety of autistic symptoms necessitates a variety of individualized treatment methods.

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[16] *Ibid.*, 73.

U.S. Policy: The Beginning of a Movement

Similar to many other social movements in the United States, the first push for a change in autism policy began in the judicial branch. In 1990, a man named Daniel Kunin used the courts to fight for autism insurance coverage for his son, Alex. Kunin had incurred over $50,000 in medical bills while treating Alex's autism. However, Benefit Trust Life Insurance Company only agreed to cover $10,000, claiming that autism fell under "mental illness" within the insurance plan.[17] Although Kunin initially filed suit in state court, Benefit Trust argued that the case was a matter for the federal court since "the policy under which Kunin was insured was an "employment welfare benefit plan" governed by [the Employee Retirement Insurance Security Act of 1974, or] ERISA."[18] (20) When the case came before the United States Court of Appeals for the Ninth Circuit, the three-judge panel decided that the denial of benefits was arbitrary and capricious. Judge Reinhardt states in the opinion for *Kunin v. Benefit Trust life Insurance Co.*, "Under the law of all fifty states and the District of Columbia, where an unclear or ambiguous term is used in an insurance policy, the ambiguity must be construed in favor of the insured."[19] Thus, since Benefit Trust hadn't properly defined "mental illness" to cover autism or specified in the plan that autism would be covered in the same way as mental illnesses, the company's denial of benefits violated the Employee Retirement Income Security Act of 1974.

Many years passed after *Kunin* was decided before the next case regarding autism insurance benefits arose. Two notable cases – *Muratore v. United States Office of Personnel Management* and *Wheeler v. Aetna Life Insurance Co.* – made some headway for autism insurance coverage. However, it was not until 2007 that the specific question of Applied

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[17] Lorri Shealy Unumb and Daniel R. Unumb. *Autism and the Law: Cases, Statutes, and Materials.* Durham, NC: Carolina Academic Press, 2011, 12.
[18] *Ibid.*, 20.
[19] *Ibid.*, 12.

Behavioral Analysis was brought to the table. In *Tappert v. Anthem Blue Cross Blue Shield,* a Colorado court examined whether ABA could be considered a "medically necessary" treatment for individuals with autism. Anthem's insurance policy specifically stated that "medically necessary" treatments do not include experimental or investigational treatments, that the treatments need to be known to be effective and cost-effective, and that all treatments must be provided by a physician or certified healthcare provider.[20] Nevertheless, the Arbiter for the case concluded the following:

> It appears both from the greater weight of the references and credible testimony that ABA therapy is the standard of care in treating autism." [...] "It was uncontroverted that the ABA therapy has helped in the past and continues to help control Abby's [the Claimant's] self-destructive and outward aggressive behaviors. [...] Abby's ABA therapy was medically necessary because it controls Abby's self-destructive behaviors and outward aggression directed towards others.[21]

This conclusion was supported by the United States Surgeon General's 1999 assertion that decades of research had illustrated the effectiveness of applied behavioral analysis treatments in improving communication and social skills.[22]

"Notwithstanding that some early litigation efforts aimed at obtaining insurance coverage in isolated individual cases were successful, for a variety of reasons broad-based coverage remained largely unavailable at the turn of the millennium. Thus, advocates turned to legislative action."[23] At first, this legislative action focused on the inclusion of autism in state mental health parity laws. Although Maine, California, and various other states were successful in achieving this goal, the coverage that resulted was too minimal. If an insurance policy did not include mental health benefits, then individuals with autism would not be covered, and many insurance

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[20] Lorri Shealy Unumb, 41.
[21] *Ibid.*, 42.
[22] *Ibid.*, 12.
[23] *Ibid.*, 49-50.

plans that did include mental health benefits failed to include treatments such as Applied Behavioral Analysis.[24] Further, some of the earliest pieces of state legislation that required coverage for behavioral therapies put an incredibly restrictive cap on the treatment reimbursements. For example, Kentucky's 1998 statute states, "Coverage for autism shall be subject to a five hundred dollar ($500) maximum benefit per month, per covered child. This limit shall not apply to other health conditions of the child and services for the child not related to the treatment of autism."[25] Thus, the law put a $6000 annual cap on ABA therapy, even though such programs can cost up to $100,000 per year.[26]

Then, in 2001, Indiana's legislature passed the first truly effective autism insurance mandate, which required insurance plans to cover all physician-prescribed treatments for pervasive developmental disorders, regardless of the insured individual's age.[27] Years after the Indiana autism law's enactment, the Indiana Department of Insurance classified some of the law's coverage issues in a regulatory bulletin:

> It is the Department's position that behavioral therapies such as Applied Behavioral Analysis Services may not be subject to limitations that apply to therapies such as physical, occupational or speech therapy. Further, Indiana does not currently have a licensing requirement for persons who perform Applied Behavioral Analysis Services. It is, therefore, inappropriate at this time for an insurer or HMO to deny a claim based upon the fact that the provider of Applied Behavioral Analysis Services does not hold a license.[28]

In this way, Indiana closed the gaps and became the only state with meaningful health insurance coverage for individuals with autism. "Starting in 2006, however, autism insurance reform

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[24] Lorri Shealy Unumb, 56.
[25] *Ibid.*, 58.
[26] *Ibid.*
[27] Indiana Code §27-8-14.2-3,4.
[28] Lorri Shealy Unumb, 60-61.

caught the attention of policy-makers [elsewhere], and state after state considered the issue on their legislative agendas."[29]

Autism reform also gained some momentum on the national scale through Congress. Although almost no legislation regarding autism has been passed in Congress, two bills that have been introduced in the past few years are noteworthy. First was the Autism Treatment Acceleration Act of 2009. Although this legislation did not make it out of committee in either the House or Senate, the mere fact that such a proactive bill was introduced in both houses illustrates the greatly increased awareness of autism as a national issue. The Autism Treatment Acceleration Act was designed to "implement an Autism Care Center Program to provide grants and other assistance to improve the effectiveness and efficiency in providing comprehensive care to individuals diagnosed with autism spectrum disorders and their families."[30] Specifically, it directed the Secretary of Health and Human Services to provide grants, establish a National Registry, increase awareness and reduce autism-related stigmas, facilitate communication between autism spectrum disorder researchers and service providers, and collect research regarding best practices that improve care. Finally, the act would have amended the Employee Retirement Income Security Act of 1974 (ERISA) and the Public Health Service Act "to require group health plans to provide coverage for the diagnosis and treatment of autism spectrum disorders." Essentially, the text of this bill provided for a national mandate.

In the next congressional session, Pennsylvania Representative Michael Doyle came back to the House with a new autism bill, the Training and Research for Autism Improvements Nationwide (TRAIN) Act of 2010. Doyle was more conservative in drafting this second act, however. In stark contrast with his 2009 autism bill, TRAIN only aimed at securing grants for

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[29] *Ibid.*, 62.

[30] Official Summary, *Autism Treatment Acceleration Act of 2009* (HR 2413), 111th Cong, (2009).

individuals and establishing university centers for developmental disabilities education, research, and services.[31] It did not address autism insurance at all. The bill passed on the floor of the House of Representatives on September 23, 2010. Nevertheless, the TRAIN Act did not make it to the Senate to become law. In turn, autism policy reform advocates reverted to state legislation initiatives to bring about nationwide changes in autism insurance.

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[31] Official Summary, *Training and Research for Autism Improvements Nationwide Act of 2010* (HR 5756), 111th Cong, (2010).

A Closer Look: Five States' Autism Insurance Mandates [32]

Indiana's Autism Insurance Mandate

To this date, twenty-nine of the U.S. states have enacted meaningful autism insurance reform legislation: Arizona, Arkansas, California, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, Pennsylvania, Rhode Island, South Carolina, Texas, Vermont, Virginia, West Virginia, and Wisconsin. Several more states are currently pursuing autism insurance reform or have limited coverage via mental health parity laws. However, Indiana remains one of the only states with coverage that is almost entirely unrestricted.

Indiana's statute, which remains the broadest autism insurance coverage law in the country, covers any group health or accident insurance policy. Insurers that sell individual policies have to offer autism coverage to any interested buyers and only self-insured Indiana companies are exempt. Furthermore, Indiana code specifically states, "The coverage required under this section may not be subject to dollar limits, deductibles, or coinsurance provisions that are less favorable to an insured than [...those] that apply to physical illness generally under the accident and sickness insurance policy."[33]

Compared to other autism insurance statutes, Indiana's is incredibly short. Many believe that the law's brevity allows for vague language and, in turn, encourages individuals to seek specialized treatments that fit their specific medical needs. However, in March 2006, Indiana's Division of Insurance, the agency charged with implementing the autism insurance coverage

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[32] Indiana, New Jersey, Kentucky, Vermont, and Florida each illustrate one of the five major different approaches states can take when enacting autism insurance reform.

[33] Indiana Code §27-8-14.2-4.

mandate, issued a bulletin full of definitions and specifications to improve consistency across insurance providers, and to help insurance companies and health maintenance organizations comply with the law.[34]

New Jersey's Autism Insurance Mandate

In general, states with autism insurance coverage mandates specifically require insurers to provide coverage for the treatment of autism, which includes "applied behavior analysis, pharmacy care, psychiatric care, psychological care, therapeutic care, [...] and any care that is determined by a licensed physician to be medically necessary and evidence-based."[35] Unlike Indiana however, most of these states included strict limitations to the coverage provided. Limitations come in the form of maximum annual benefits, total lifetime benefit caps, age restrictions, age of diagnosis restrictions, caps related to the resulting increase of insurance premiums, and treatments covered; many of these have been added to bills in such a way as to effectively nullify any intended benefits. Consequently, the advocacy group Autism Speaks created a model autism insurance act in 2007. This model act recommends that the legislation (1) require insurance policies to cover individuals up to the age of 21, (2) specify that coverage will not be subject to visitation limits, (3) either leave yearly benefits uncapped or to set the annual limit between $36,000 and $50,000, and (4) include specific definitions according to the model, like "applied behavioral analysis," "autism service provider," and "medically necessary."[36] About ten of the U.S. states have a statute that closely resembles this model. New Jersey is one of these.

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[34] "Review and Evaluation of Proposed Legislation Entitled: An Act Relative to Insurance Coverage for Autism House Bill 3809," *Massachusetts Division of Health Care Finance and Policy*, (March, 2010), 18.

[35] Arkansas Act 196 (HB 1315 of 2011).

[36] Lorri Shealy Unumb, 67-69.

Enacted in August of 2009, New Jersey's law applies to anyone less than 21 years of age that has any kind of developmental disorder, including autism; it requires coverage for both the screening and diagnosis of these disorders. If the insured individual's primary diagnosis is autism, the law also requires coverage for applied behavioral analysis and occupational, physical, and speech therapies. Currently, the law caps annual benefits for any covered person at $36,000. This amount is subject to change each year according to "the change in the consumer price index for all urban consumers for the nation, as prepared by the United States Department of labor."[37] Only the New Jersey State Health Benefits Program, the School Employees' Health Benefits Program, and full-insured plans written in the state of New Jersey are subject to the law. Thus, self-funded plans under the federal ERISA law and insurance covering federal government employees are entirely exempt.[38]

Kentucky's Autism Insurance Mandate

Another path that states have taken in drafting their autism insurance legislation is the tiered system. For example, New Hampshire's law provides a maximum of $36,000 per year per insured individual up to the age of twelve, and then $25,000 per year per insured individual from age twelve to twenty-one. One argument for this kind of system is that it stresses early intervention, which is especially important in affecting a child's future development. However, Kentucky's law seems to exaggerate this belief with its annual cap of $50,000 for ASD individuals in large group health plans up to the age of seven, and then $12,000 – $1,000 per month – for those between the ages of seven and twenty-one. Moreover, the Kentucky law

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[37] New Jersey P.L. 2009 c. 115 (NJ Rev. Stat. §17:48-6ii).

[38] "Maximizing Coverage Under the New Jersey Autism & Other Developmental Disabilities Insurance Mandate: A Guide for Parents and Professionals," *Statewide Parent Advocacy Network,* 2011 http://www.spannj.org/cyshcn/core_outcome_3/Maximizing%20Coverage%20ASD%20&%20Other%20DD.pdf, (accessed April, 2012).

makes a distinction between large health benefit plans and individual or small group plans by capping benefits for all individuals up to the age of twenty-one in a small group plan at $1000 per month per individual.

The Kentucky act also goes into great detail when describing the required licensure for Board Certified Behavior Analysts and their assistants. In fact, out of the twenty sections that make up Kentucky's law, sixteen deal exclusively with licensure.[39] Although some states have decided not to create licenses for behavioral analysts before mandating insurance coverage, other states like Kentucky stress the importance of licensure in order to reinforce the medical legitimacy of behavior intervention practices and to ensure that patients receive care from a well-trained individual. In turn, the state can better evaluate the positive impact of these therapies and ensure that money is being spent in an effective manner. A good licensing process also ensures that patients have easy access to treatments like applied behavioral analysis because the process makes it harder for an insurance company or HMO to deny coverage for a certain type of treatment based on the healthcare provider's lack of certification.

Vermont's Autism Insurance Mandate

Some state legislatures have based their acts on the argument that early intervention is not only more important, but key to treating autism. This type of legislation provides autism coverage only in the first three, six, or nine years of the insured child's life. Vermont's 2010 act, for example, "provides for the diagnosis and treatment of autism spectrum disorders, including applied behavior analysis supervised by a nationally board-certified behavior analyst, for children, beginning at 18 months of age and continuing until the child reaches age six or enters

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[39] 2010 Kentucky Act 150 (http://www.lrc.ky.gov/record/10rs/HB159.htm, HB 159 10RS).

the first grade, whichever occurs first."[40] However, within this short time frame, Vermont's autism insurance coverage has no maximum benefit cap. As such, parents who have young children with autism can seek out the most intensive therapies and programs without fear of bankruptcy. This approach has been shown effective in several studies, which show that with the correct treatments and early intervention, some young autistic children will be able to successfully filter back into a mainstream school system. Nevertheless, Vermont's Senate voted on March 26, 2012 for S.223 and unanimously approved the bill, which would eliminate the age cap and any annual reimbursement cap for applied behavior analysis. A representative in Vermont's House also submitted a bill that would lift the six-year-old age cap; H.736, however, would set a new cap at age twenty-two.

These initiatives are mainly due to a provision in the original piece of legislation, which provided for the evaluation of coverage for children up to the age of eighteen:

> No later than January 15, 2011, the agencies [of administration and of human services] and department [of education] shall report their findings and recommendations regarding expanding coverage of treatment for autism spectrum disorders to school-age children and the availability of providers. [...] In addition, the agencies and the department shall estimate the amount of savings and avoided costs to be realized by the state over time as a result of the insurance coverage requirement in Sec. 2 of this act.[41]

These and many other revised reports estimated that the expanded coverage would cost dramatically less than original reports had hypothesized.

Florida's Autism Insurance Mandate

Finally, there are states that follow the Autism Speaks' model, but put a lifetime cap on insurance coverage. As with Florida, states that use this kind of cap – namely, Louisiana and

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[40] Vermont Code, Title 8, Chapter 107, §4088i.

[41] Vermont Code, Title 8, Chapter 107, §4088i, Sec. 4.

New Mexico – set it at around $200,000. In Florida, since annual coverage is limited to $36,000, it is designed to cover about six years of intensive treatment. In this way, the legislation also encourages early intervention.

Florida's autism legislation comprises three components: a Medicaid waiver, the Developmental Disabilities Compact, and the autism insurance coverage mandate. The first of these provisions authorizes the Agency for Health Care Administration to seek federal approval for a Medicaid waiver that would provide coverage for various therapies and applied behavioral analysis for children under the age of six. It also limits Medicaid coverage for autism to $36,000 annually and $108,000 in total lifetime benefits. The second provision, also known as the "Window of Opportunity Act," requires the office of Insurance Regulation to create a compact between health insurers and HMOs to insure those with developmental disabilities. Thus, the final provision of the act, which outlines the autism mandate, is designed simply to fill in the gaps. This mandate benefits children under the age of eighteen who were diagnosed with a pervasive developmental disorder, as defined in the Diagnostic and Statistical Manual of Mental Disorders, by the age of eight.[42]

Florida's law also provides several exemptions to the autism mandate. For example, any insurance company or HMO that signed the Developmental Disabilities Compact by April 1, 2009 is exempt, in addition to employers with fewer than fifty employees and self-insured plans.

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[42] Florida Stat. Ann. §627.6686.

Table 1: States with Autism Insurance Coverage in the United States

The following table presents a list of states in 2011-2012 with autism insurance coverage laws, and distinguishes between their different system approaches, caps, and age limitations.

State	System Approach	Age Limitation	Benefit Cap
Arizona	Tiered Coverage	1 to 9 years 9 to 16 years	$50,000 annually $25,000 annually
Arkansas	Model Coverage	18 years	$50,000 annually
California	Federal Plan	Same as PPACA	Same as PPACA
Colorado	Early Intervention	3 years	$5,725 annually
Connecticut	Tiered Coverage	1 to 9 years 9 to 13 years 13 to 15 years	$50,000 annually $35,000 annually $25,000 annually
Florida	Lifetime Maximum	18 years	$200,000 lifetime $36,000 annually
Illinois	Model Coverage	21 years	$36,000 annually
Indiana	Broad/Unlimited Coverage	None	None
Iowa	Model Coverage	19 years	$36,000 annually
Kansas	Tiered Coverage	1 to 7 years 7 to 19 years	$50,000 annually $12,000 annually

State	System Approach	Age Limitation	Benefit Cap
Kentucky	Tiered Coverage Licensure	1 to 7 years 7 to 21 years	$50,000 annually $1,000 monthly
Louisiana	Lifetime Maximum	17 years	$140,000 lifetime $36,000 annually
Maine	Early Intervention	5 years	$36,000 annually
Massachusetts	Broad/Unlimited Coverage	Same as with physical conditions	Same as with physical conditions
Missouri	Model Coverage Licensure	18 years	$40,000 annually and may be exceeded
Montana	Tiered Coverage	1 to 8 years 9 to 19 years	$50,000 annually $20,000 annually
Nevada	Model Coverage	18 years but up to 22 years if in high school	$36,000 annually
New Hampshire	Tiered Coverage	0 to 12 years 13 to 21 years	$36,000 $27,000
New Jersey	Model Coverage	21 years	$36,000
New Mexico	Lifetime Maximum	19 years but up to 22 years if in high school	$200,000 lifetime $36,000 annually
New York	Broad Model Coverage	None	$45,000 annually
Pennsylvania	Model Coverage	21 years	$36,000

State	System Approach	Age Limitation	Benefit Cap
Rhode Island	Model Coverage	15 years	$32,000
South Carolina	Model Coverage	16 years	$50,000
Texas	Early Intervention	9 years	None
Vermont	Early Intervention	18 months to 6 years or first grade	None
Virginia	Early Intervention	2 to 6 years	$35,000 annually for applied behavioral analysis
West Virginia	Tiered Coverage	18 months to 18 years	$30,000 annually for first three years, $2,000 monthly after
Wisconsin	Broad/Unlimited Coverage	None	None

The Costs: An Overview

"One of the greatest impediments for autism advocates attempting to reform insurance laws has been not only the potential impact on insurance premiums for the general public but also the impact on state budgets."[43] However, many actuarial estimates and reports regarding the aforementioned autism insurance coverage mandates predict that the new laws will cause at most a 1% increase in insurance premiums and will save the state a large amount of money in the long run. This long-term economic benefit relates to the reduced reliance of autistic individuals on expensive state-provided services after receiving medical and therapeutic treatments as children. Specifically quantifying the potential savings, however, is tricky:

> A wise spectrum of health care, education, and social service agencies provide diagnostic services, therapeutic interventions, and medical care related to autism [...]. Sharing of information or data across agencies is limited. In additional, most of the costs borne by families of children with autism occur outside the market and are difficult to quantify. These facts make it challenging to obtain a comprehensive measure of autism-related expenses. [44]

Nevertheless, some researchers and consultants have begun to evaluate the impact of specific mandate bills by calculating the likely impact on premiums, the prevalence of autism, the cost of providing specific therapies like applied behavioral analysis, and the average lifetime cost of a fully dependent versus independent autistic adult. Although these cost-benefit analyses vary according to policy, area, and actuarial methods, most of them illustrate that state autism insurance coverage mandate policies will result in positive economic gains over the next few decades.

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[43] Lorri Shealy Unumb, 157.

[44] Deanna L. Sharpe and Dana L. Baker, "The Financial Side of Autism: Private and Public Costs," In *A Comprehensive Book on Autism Spectrum Disorders*, ed. Mohammad-Reza Mohammadi, (InTech: 2011), 276.

Premiums and Prevalence

Many of the methods that calculate the percentage of rate impact on insurance premiums calculate it as a function of the prevalence of autism. Recently, the Center for Disease Control reported that the prevalence statistic has risen to 1 in every 88 children. However, *treated* prevalence – the statistic of autistic individuals that seek out and receive therapies and treatments – is much lower. Although some reports use a statistic of 1 in 150, research and survey data have shown that the treated prevalence of autism in the United States is actually around 1 in 500.[45] In one method of calculating the percentage rate of impact, researchers multiply whatever prevalence statistic they determine most accurate by the number of insured children in the relevant area, the average annual medical expenditures for children with autism, and the cost to insurance companies of implementing autism mandate regulations. In a 2009 study on Pennsylvania's autism insurance mandate, "estimated increases in healthcare premiums ranged from 0.19% (assuming a treated prevalence of 2 per 1,000 children and annual expenditures of $10,000), to 2.31% (assuming a treated prevalence of 6.7 per 1,000 children and annual expenditures of $36,000)," which for many reasons includes a generous overestimation of potential costs.[46]

Societal and Long Term Costs Related to Autism

Identifying the factors that contribute to the overall costs of autism is difficult because specific costs result from each of the following categories: direct medical expenses, direct nonmedical – usually educational – expenses, and indirect expenses resulting from the lower

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[45] James N. Bouder, "Cost Analysis – HB 958 of 2008 (As Amended 4/30/08)," May 2008, 3-4.

[46] James N. Bouder, Stuart Spielman, and David S. Madell, "Brief Report: Quantifying the Impact of Autism Coverage of Private Insurance Premiums," *Journal of Autism and Developmental Disorders*. Vol. 39 (Feb. 2009), 954.

productivity and wages of both autistic individuals and the family members that care for them. Autism finance specialist Michael Ganz, who considered all of these categories in his 2007 report on the societal costs of autism, determined that the incremental cost of autism was about \$3.2 million per capita in 2003 dollars.[47]

In general, autistic children have higher healthcare costs than children without the diagnosis. In fact, a 2006 study using data from a large group health care plan in California demonstrated that children with an autism spectrum disorder had higher average total clinic, pediatric, and psychiatric outpatient visits; were more likely to be hospitalized; were twice as likely to use medications for gastrointestinal or psychotherapeutic medications; and required more expensive services and medications, all of which resulted in an average total cost per member that was nearly three times higher than children without ASD.[48] Furthermore, another 2006 study, which based its results on data from multiple national surveys, found that the medical costs of autistic children were over seven times higher than the annual medical expenses of other children.

Special educational services are also a cost that society bears for autistic children. In fact, they are the basis for another kind of cost-benefit analysis, which compares the costs of keeping a child in special education classes through his or her high school career with the costs of providing a pre-school intensive treatment program that helps a certain percentage matriculate into normal schooling. Chasson et al.'s 2007 study on Texas illustrates this idea. According to their research, Texas provides an average of \$198,000 every year for the special education of each individual between the ages of four and twenty-two. The actual total cost of this special

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[47] Marc Lambright, "Actuarial Cost Estimate: Vermont Senate Bill S.262, An Act Relating to Insurance Coverage for Autism Diagnosis and Treatment," *Agency of Human Services, Department of Education and Agency of Administration*, Oliver Wyman Actuarial Consulting Inc., February 2011, http://www.leg.state.vt.us/reports/2011ExternalReports/265773.pdf, 18-19.
[48] Deanna L. Sharpe, 277.

education per year per person is $360,000, adding up to a grand total of $3.6 billion annually, of which the state provides $1.98 billion. According to the study, over half of this money could be saved with the implementation of an early interventional behavioral program.[49]

One can also evaluate the difference between what special education costs, in addition to regular education, and what a basic education would cost on its own. According to The Special Education Expenditure Project, which was conducted for the U.S. Department of Education in 2000, average annual expenditures for the special education of children with autism is about ten times greater than the average annual expenditures for a regular education program.[50]

Other expenses and services that factor into the total cost of autism are harder to quantify and compare. Although some costs, "such as the value of lost leisure and employment time, and lost income can be estimated, [...] other costs such as increased stress, disruption of family life, or reduced time with other family members can only be recognized."[51] Consequently, almost all of the cost-benefits that are conducted underestimate the savings that result from early intensive medical, educational, and therapeutic services.

Applied Behavioral Analysis Programs

According to data collected from Sharpe and Baker's 2007 Family Experiences with Autism survey, "One of the most salient sources of financial pressures [... is] the high cost of therapy, especially Applied Behavioral Analysis."[52] This service is generally calculated by the

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[49] Gregory S. Chasson, Gerald E. Harris, and Wendy J Neely, "Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism," *Journal of Child and Family Studies.* Vol. 16 (Jan. 2007), 408-409.

[50] Gregory S. Liptak, Tami Stuart, and Peggy Auinger, "Health Care Utilization and Expenditures for Children with Autism: Data from U.S. National Samples," *Journal of Autism and Developmental Disorders*, Vol. 36 (July 2006), 875.

[51] Deanna L. Sharpe , 281.

[52] *Ibid.*, 283.

hour, and requires a review of staffing, wages according to state, and overhead cost assumptions. In addition, ABA is provided for more hours for younger children, such that children under the age of eight are provided 1,500 hours of ABA annually, while children ages eight to twelve are provided about 670 hours annually. Considering that ABA costs about $54 an hour in New Jersey, a 2009 study reported that ABA costs around $34,000 annually for all ages in that state.[53]

When considering the affect of covering ABA treatments in a state insurance mandate, one must keep in mind that only a small percentage of diagnosed autistic individuals will actively employ this service. For example, "In Minnesota, a state that is widely regarded as having some of the most extensive ABA coverage and services in the nation, provider data indicates ABA utilization of approximately 20% of diagnosed three to six year olds."[54]

Other Considerations

Other factors that affect all of the insurance mandate plans in a similar manner include the fact that these mandate plans generally have low initial costs, which is due to lack of awareness and a limited number of providers; that average costs will decrease for autistic individuals as they age if they receive the proper education and treatments early on; and that the quantifiable "effectiveness" of services like Applied Behavioral Analysis is still being evaluated, thus forcing studies to allow for "minimal" to "maximum" benefit and saving estimates.

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[53] Marc Lambright, "New Jersey State Health Benefits Program Actuarial Cost Estimate for Assembly Committee Substitute for Assembly, No. 2238 – An Act concerning for the treatment of autism and other developmental disabilities," Oliver Wyman Actuarial Consulting, Inc., April 2009, http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/NJ%20cost%20analysis.pdf, 10.

[54] "Actuarial Cost Estimate: Vermont Senate Bill S.262, An Act Relating to Insurance Coverage for Autism Diagnosis and Treatment," 12.

Economic Comparison: Three Cost-Benefit Analyses [55]

Uncapped Coverage

In contradiction to the theory that uncapped autism insurance coverage is too great of a burden for society to bear, recent actuarial reports have shown that even unlimited plans will not result in unmanageable costs. Several reports have been conducted regarding the cost-benefit, cost effectiveness, cost utility, and cost offset of these laws, most of which provide for a "low," "middle," and "high" cost scenario estimate. These categories are based on the percentage of autistic children that are diagnosed before a certain young age, the average annual cost of Applied Behavioral Analysis, the average cost of other additional medical costs, and the percentage of premium increases.[56] One example is the actuarial cost estimate done for Vermont's *original* Senate Bill 262, which had neither an age nor maximum benefit cap. This report assumed a treated prevalence rate of 1 in 150, ABA service use by between 40% and 66.7% of diagnosed autistic children for an average of 30 hours a week, and an average ABA therapy cost per hour of about $45. It also assumed that the cost of non-ABA medical costs would range between $2,000 and $4,000.[57]

In order to estimate long-term effects, the report uses its "middle" cost scenario estimate of an $18.50 annual claim cost per covered person and a $21.80 premium increase for each of three categories: individual, small group, and large group markets. In total, these markets cover 161,000 people in Vermont. Since the average premium per person is $3,913, the claim cost as a percentage of the premium would be 0.47% and the premium increase as a percentage would be

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[55] Uncapped coverage, model coverage, and early intervention coverage represent three of the major approaches to autism insurance reform. Analyses for the other two approaches have been omitted because there are fewer comprehensive actuarial reports for the states that have adopted those policies.

[56] "Actuarial Cost Estimate: Vermont Senate Bill S.262, An Act Relating to Insurance Coverage for Autism Diagnosis and Treatment," 2.

[57] *Ibid.*, 15.

0.56%. This "middle" estimate comes from the assumption that 50% of diagnosed autistic individuals will start using ABA, that ABA programs will cost about $45,000 per year, and that annual non-ABA costs will remain around $3,000. However, the report also reemphasizes that the researchers "expect that costs would be lower in the years immediately following the passage of S.262 [as originally drafted] based on experiences in other states that have mandated [Autism Spectrum Disorder, or] ASD benefits, lags typically seen I accessing new benefits, and the limited supply of ABA providers."[58] Economic analyst Bouder concludes the report by stating, "We would expect that the costs of ABA treatments covered under S.262 could be recovered through reductions in educational and medical expenditures alone."[59]

Model Coverage

When first introducing an autism insurance coverage law, state legislators often propose an uncapped bill like Indiana's. However, legislatures on the whole are wary of these mandates, thinking them too costly. As a result, most of the bills are restricted in one way or another. Nevertheless, states that use Autism Speaks' model insurance coverage place a safeguard cap *above* what many studies estimate as the average annual cost of applied behavioral analysis services and an age cap at adulthood. These kinds of caps allow for comprehensive coverage while ensuring that costs will not rise above a certain point.

A 2009 report on Pennsylvania's model law attempts to provide an accurate estimate of this data. The following shows the researchers' rate impact formula with a key:[60]

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[58] "Actuarial Cost Estimate: Vermont Senate Bill S.262, An Act Relating to Insurance Coverage for Autism Diagnosis and Treatment," 16-17.

[59] *Ibid.*, 20.

[60] Bouder, James N. "Cost Analysis – HB 958 of 2008 (As Amended 4/30/08)." *Autism Votes.* May 9, 2008. http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-

$$\%RI = \frac{\left(\frac{f}{\Sigma f} \times F\right) \times \left(\bar{x} \times A\right) \div MLR}{PR}$$

$\%RI$ = Estimated Percentage Rate Impact
f = Frequency of Children in State (Aged 2-20) with Autism Based on Treated Prevalence Data
Σf = Sum of all Frequencies of Children in State (Aged 2-20) Based on Estimates from U.S. Census Bureau
F = Estimated Number of Insured Children in State (Aged 2-20) with Full-Insured, non-ERISA Exempt Health Coverage
$\bar{x}$ = Mean Annual Per Capita Expenditure for Services for Children with Autism Adjusted for Changing Conditions
A = Assumed Load Factor for First Year Administrative and other Incidental Costs Associated with Proposed Mandate
MLR = Medical Loss Ratio
PR = Total Health Insurer Premium Revenue

Using this formula, Bouder et al.'s study found that the average family would likely pay an additional $0.54 a month as a result of Pennsylvania's autism insurance coverage mandate. Furthermore, the study calculated that even in a "worst-case scenario," which would include a prevalence of 1 in 150 and the use of exactly $36,000 per year per child, the increase in family contributions would only reach $6.53 a month. Even in this very unlikely scenario, premiums would increase, at most, 2.5%.[61]

Also in 2009, the Oliver Wyman Actuarial Consulting group developed an estimate of the costs of New Jersey's autism insurance coverage mandate for the New Jersey State Health Benefits Program. This report assumed similar figures to Vermont's actuarial report, except with an average cost per hour of ABA therapy at about $54. Using these assumptions, the report's "High" cost scenario posited an annual cost of $33,788, its "Middle" cost scenario posited an

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1B1C0BE5334B%7D/Bouder_LA_HB_958_-_Engrossed_Cost_Analysis_FINAL_-_050908_with_Exhibits.pdf, Exhibit "A," 12.

[61] "Brief Report: Quantifying the Impact of Autism Coverage of Private Insurance Premiums," 956.

annual cost of $30,000, and its "Low" cost scenario posited an annual cost of $25,000.[62] These estimates resulted in annual cost per enrollee increases of $23. 40, $16.60, and $11,10 respectively.

Early Intervention Coverage

Although Early Intensive Behavioral Intervention (EIBI) coverage is much more restrictive than the two forms of autism insurance coverage cited above, it is an efficient way to help autistic individuals while maximizing limited funds. According to one of the earliest studies on EIBI, conducted by Jacobson et al. in 1998, the economic benefits are clear:

> The average cost benefit of providing public K-12 education to a normally developing child in Pennsylvania (career income to age 55 minus the cost of education) is about $1.6 million. Subtracting the estimated cost of EIBI [...] the net savings for a child with PDD who achieves normal functioning is $1.5 million. In contrast, the net cost in Pennsylvania of a child who obtains partial effects to age 55 is the cost of services for 52 years less income from supported work, or about $3.4 million, while the net cost of a child who obtains little or no benefit from EIBI is $4.4 million. Thus, the net savings for the child who achieves partial effects is roughly $1 million.[63]

Chasson et al. piggybacked this study in 2007 by evaluating the EIBI program in Texas. The new study incorporates special education costs (averaging about $20,000 per child per year, but for which Texas allocates $11,000), EIBI costs (averaging about $22,500 per child per year), EIBI effectiveness, prevalence estimates, and service usage. The following equation and key represents this study's formula for computing projected savings associated with EIBI for all children with autism in Texas:[64]

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[62] "New Jersey State Health Benefits Program Actuarial Cost Estimate for Assembly Committee Substitute for Assembly, No. 2238 – An Act concerning for the treatment of autism and other developmental disabilities," 9-11.

[63] John W. Jacobson and James A. Mulick, "System and Cost Research Issues in Treatments for People with Autistic Disorders," *Journal of Autism and Developmental Disorders*, Vol. 30, No.6 (2000): 587.

[64] Gregory S. Chasson, 406.

$$C = S(18)(10,000) - [E(3)(10,000) + S(.28)(15)(10,000)]$$

C = total savings for all children with autism in Texas
S = Annual special education costs (either state-budgeted or actual)
E = Annual EIBI costs
10,000 = Conservative estimate of children with autism in Texas
18 = Necessary years of special education for children who do not receive EIBI (age 4–22)
3 = Average number of years of EIBI (age 4–22)
.28 = Proportion of children who receive EIBI but fail to mainstream into regular education (72% offset)
15 = Necessary years of special education for children who receive EIBI but fail to mainstream into regular education (age 4–22)

With this equation, Chasson et al. found that a child who receives three years of EIBI and resultantly uses 72% less services requires $84,300 less from state-budgeted funds. Furthermore, "comparing the reported *actual* cost of a special education program to a three-year EIBI program (and a 72% special education offset), savings of $208,500 per child are achieved."[65] Finally, Chasson's study shows that higher up-front costs can be recovered within five years, and that subsequent savings can yield a net gain of almost $1 billion in state-budgeted funds over a span of eighteen years.[66]

In 2010, Vermont created an EIBI insurance coverage program when it enacted Act 127, *An Act Relating to Insurance Coverage for Autism Diagnosis and Treatment.* This act required private insurance and Medicaid coverage of autism diagnosis and treatments, including applied behavior analysis, for children between the ages of eighteen months and six years. A fiscal analysis of this act, published in 2011, estimates that the potential savings per child could reach between $40,000 and $100,000 within fifteen years, depending on reduction in duplicative

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[65] Gregory S. Chasson, 408.
[66] *Ibid.*, 408-410.

services.[67] The analysis also takes into account participation. For example, if all 183 diagnosed autistic children under the age of six receive treatment, it is estimated that the cumulative positive impact of early intervention over fifteen years would be over $7,400,000 and up to $20,000,000. However, if only ten of those children receive treatment, cumulative savings would only reach between $400,000 and about $1,000,000.[68]

In order to calculate these estimates, this analysis assumed that "20 percent of children receiving treatment would no longer require additional Medicaid or Special Education Services; 50 percent would require 20 percent less services; and 30 percent would experience no improvement."[69] It also based its estimates on Medicaid, special education, and joint program expenditures for children with ASD. In 2009, these totaled to almost $55,000,000 for children between the ages of six and seventeen.[70]

When evaluating the effect the mandate would have on individuals with private insurance health plans, the Act 127 analysis considered the following facts and figures: (1) the percentage of children under age six that are enrolled in a private health plan subject to the private coverage mandate is approximately 16%, (2) EIBI consists of up to forty hours of weekly intensive year-round teaching beginning in preschool for two to three years, and (3) about 74% of children who do not receive EIBI, versus about 20% of those who do, will likely be placed in a full-time special education class.[71]

In conclusion, the analysis of Vermont's coverage mandate for early intensive behavioral intervention states the following:

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[67] "Report to the Legislature of the State of Vermont, Act 127: An Act Relating to Insurance Coverage for Autism Diagnosis and Treatment," *Agency of Human Services, Department of Education and Agency of Administration*, February 2011, 3.
[68] *Ibid.*, 5.
[69] *Ibid.*
[70] *Ibid.*, 14.
[71] *Ibid.*, 16.

ABA services for school-age children are likely to result in improvements in functioning and reduce the level of need for some services currently covered by Medicaid. However, studies on the long term impact of intervention provided to children Age 6 to 17 are limited and complex, which makes it challenging to draw conclusions about the potential for long term savings as a result of treatment for school-age children.[72]

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[72] "Report to the Legislature of the State of Vermont, Act 127: An Act Relating to Insurance Coverage for Autism Diagnosis and Treatment," 17.

Where to Go from Here:
Filling In the Gaps and Improving Efficiency

Self-Funded Health Insurance

As previously stated, even the least limited of the state autism insurance coverage mandates have gaps, most notably those left by self-insured plans. These plans are provided by large private employers who choose to pay claims from their own money rather than purchase a typical insurance policy for their employees; as a result, they are governed by the Federal Employee Retirement Income Security Act, which is outside of state jurisdiction. Government-sponsored plans also fall under ERISA, and thus are not subject to state mandates for autism insurance coverage.[73] Since these plans make up a huge percentage of the market, "Of the Americans whose insurance is provided through their employers, more than half are covered by health benefit plans that are not subject to state regulation."[74] The only way to fill this gap is with a congressional autism insurance coverage mandate.

Moves for Federal Reform

On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act, which was amended a week later by the Health Care and Education Reconciliation Act of 2010. "Of interest to the autism community is the inclusion of mental health and substance abuse disorder services, including behavioral health treatment as well as preventive and wellness services and chronic disease management in the so-called 'essential benefit list.'"[75] Furthermore, this law could drastically reduce the opportunity for HMOs and insurers to impose pre-existing

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[73] Lorri Shealy Unumb, 189.

[74] *Ibid.*, 161.

[75] Deanna L. Sharpe, 288.

condition exclusions, excessive delays before the commencement of coverage, or incredibly low caps on annual and lifetime benefits. However, even this federal mandate is limited in scope; in fact, it only applies to plans that will be offered by state-based exchanges and plans offered in the individual and small group market. "Existing coverage, plans offered in large group market outside of exchanges, and self-insured plans will not be required to supply the essential benefit package to the insured."[76]

Back to the States

As the federal mandate is restricted, and as it is unlikely that Congress will enact more comprehensive health care legislation any time soon, state initiatives must continue to lead reform in order to make national policy changes. There are still autism insurance coverage laws that restrict coverage to a bare minimum, not to mention the states that have yet to enact any autism reforms at all. According to available data, these states are losing money in the long run while at the same time depriving some of their most vulnerable citizens of the education and therapies they need to eventually become independent and productive citizens.

Implementation Issues

Autism insurance reform is still relatively new in the United States. Consequently, states continue to learns about, and adapt to, issues that arise in the implementation process of these laws. A few major issues have included identifying who qualifies as an eligible provider of autism-related services, whose determination of "medical necessity" prevails, how much research is needed to prove that a therapy is "evidence-based," and exactly which policies are

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[76] Deanna L. Sharpe, 289.

subject to the law.[77] These issues create unintended gaps in coverage, and must be addressed as quickly as possible.

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[77] Lorri Shealy Unumb, 214.

Conclusion

Autism Spectrum Disorder is a complex and crippling disease that affects individuals of every race and ethnicity. As of now, there is no cure for autism. However, there are treatments that have been shown to make a huge difference in the lives of autistic individuals. Governments must maximize on these treatment opportunities to aid those with pervasive developmental disorders and, in turn, aid society by saving money for taxpayers and states.

"Research on expenditures related to ASD underscore the fact that the disorder imposes high costs on immediate family as well as society."[78] These costs are from both direct and indirect sources. Although it may still be too early to evaluate whether it is more economically efficient to mandate coverage for therapies like applied behavioral analysis beyond a certain age or education level, it is clear that the autism insurance coverage laws outlined in this thesis all save money for both families and the state. As the prevalence rate of autism rises, the resultant costs will become more and more salient of an issue. Thus, it is vital to take action as soon as possible via state and federal legislatures.

Comprehensive state autism insurance coverage policies work because they allow autistic individuals to access the care necessary for them to reach their full potential. In this way, many autistic children will be able to mainstream back into regular schooling, thereby saving state funds on special education programs; will potentially hold steady employment down the road; will require fewer medical resources over the course of their lives; and will be less of a burden on family members, who can better use their time for careers or leisure activities, both of which help stimulate the economy.

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[78] Deanna L. Sharpe, 291.

In the coming years, and even months, current policies will be modified or rewritten such that specific details in this thesis will become inaccurate or moot. I am glad for that. State legislatures must learn from each other's experiences and adapt. A cost-benefit analysis according to in-state data for one particular policy can be helpful, but true success will be achieved by comparing results with those achieved by different policies in other states. Over time, if enough legislatures take this to heart, state policies will become more consistent. There may be reason to argue that a state's policy should depend on its population size, prevalence of autism, and majority's ideological stance. However, I believe that economics will prevail in this case; it is simply a matter of discovering which policy results in the greatest long-term savings for the state while maintaining reasonably low insurance premiums. Thankfully, this will likely occur when autistic individuals are receiving enough of the appropriate kinds of care to help them become more independent citizens. Thus, when it comes to autism insurance coverage, it truly can be a win-win situation.

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