



**Review and Evaluation of Proposed Legislation Entitled:
An Act Relative to Insurance Coverage for Autism
House Bill 3809**

**Provided for
The Joint Committee on Financial Services**

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Executive Summary

This report was prepared by the Division of Health Care Finance and Policy (DHCFP) pursuant to the provisions of M.G.L. c. 3 § 38C requiring DHCFP to review and evaluate the impact of a mandated benefit bill referred to the agency to a legislative committee. The Joint Committee on Financial Services referred House 3809 “An Act Relative to Insurance Coverage for Autism” to DHCFP for review.

Autism Spectrum Disorder

The term “Autism Spectrum Disorder” currently falls under the umbrella category of Pervasive Development Disorders (PDD) in accordance with the *Diagnostic and Statistical Manual of the Mental Disorders* DSM-IV-TR (fourth edition, text revision), which was first published in 1994 by the American Psychiatric Association and last revised in 2000.¹ There are three known Autism Spectrum Disorders (ASDs) including Autistic Disorder, Asperger syndrome, and PDD Not Otherwise Specified (PDD-NOS), including atypical autism. Two other rare, very severe disorders, including Rett syndrome and childhood disintegrative disorder, fall under the umbrella category of PDD but are not considered an ASD.

In the future, ASD may be its own category, based on the proposed draft diagnostic criteria for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) released by the American Psychiatric Association in February 2010. These proposed draft criteria recommend a new category of “autism spectrum disorders” which will incorporate the current diagnoses of autistic disorder (autism), Asperger’s disorder, childhood disintegrative disorder and pervasive developmental disorder (not otherwise specified). According to a report from the DSM-V Neurodevelopment Disorder Workgroup, a “single spectrum disorder” and “single diagnostic category” would be a better way to describe our current understanding about pathology and clinical presentation of the pervasive developmental disorders.²

The National Context

Autism Spectrum Disorder (ASD) has received national attention and reached national importance for at least three reasons, including: (1) the impact on the family; (2) the rising prevalence of ASD; and (3) the impact on society.

- Caring for children diagnosed with autism spectrum disorder takes a financial and emotional toll on families, according to Autism Speaks.³ Treatments can be intensive and expensive. It’s often difficult for families to pay out of pocket for services that are not provided by school districts or reimbursed by health insurers. The cost of the minimum-recommended number of 25 hours of therapy each week, which both the National Academy of Sciences and the American Academy of Pediatrics recommend, can run roughly \$75,000 a year.

- The prevalence of ASD is rising in this country without a definitive understanding of why this is occurring. According to a December 2009 report of the Centers for Disease Control and Prevention (CDC), 1 in 110 children are diagnosed with Autism Spectrum Disorder (ASD), including 1 in 70 boys. That rate represents a 57 percent increase from the CDC's report in 2007, which last reported that 1 in 150 children with a diagnosis of ASD.⁴ The CDC has not been able to attribute this increase to better, earlier and broader diagnosis of the disorder, concluding that it cannot "rule out" a true increase in the prevalence of ASD.
- The economic implications of ASD on society are significant. According to a 2006 study by the Harvard School of Public Health, the direct and indirect costs of taking care of an individual with autism over a lifetime can be \$3.2 million. Lost productivity and adult care contribute heavily to this estimate. The cost to society to care for all individuals with autism is estimated to be \$35 billion each year.⁵

Federal and state governments have responded in two major ways to address these issues. The federal government has been behind efforts to fund research. States have sought strategies that mandate that health insurance pay for treatments.

- In 2009, President Obama declared autism one of his top three public health priorities, with a commitment to support continued funding for biomedical research into the causes of ASD and cure for ASD. The National Institutes of Health (NIH) funds the majority of research on autism in this country.
- The Congress introduced the "Autism Treatment Acceleration Act (ATAA)" (S. 819) in 2009 in the Senate and H.R. 2413, the companion house bill, in the House of Representatives.⁶ If enacted, this federal legislation would require all insurance companies across the country to provide coverage for diagnosing and treating ASD.
- According to the National Conference of State Legislatures, at least 15 states have enacted "autism mandates" to require that fully-funded health insurers provide coverage for diagnosing and treating ASD.⁷ Many more states are considering an autism mandate, including Massachusetts.
- Many states having found that passage of the law proves to be only the first step in making treatments more available to individuals diagnosed with ASD. The second step is implementation of the law. Indiana's experience over the last 10 years demonstrates that the difficulty in enforcing a law that covers such a complex condition and treatments that are considered experimental by health insurers.
- Some states have relied upon the Medicaid Home and Community-Based Services Waiver Program to provide assistance to eligible individuals with autism. Massachusetts has such a program but serves only a relatively small number of individuals with ASD.
- Among self-insured health plans at least 21 corporations including such big names as Microsoft, Home Depot, Intel, Eli Lilly, and Deloitte offer insurance coverage for autism therapies, including applied behavioral analysis (ABA).⁸

Fully-funded health insurers are opposed to providing certain types of coverage for treating ASD because insurers view the treatments as educational and/or experimental, or the responsibility of early intervention (EI) programs and school districts. Clearly, EI programs and school districts play a critical role in providing early and intensive treatments to children under 3 years of age, and educating and caring for children between 3 and 22 years old. The key question remains, however: who should pay for treatments that are not provided by EI and school districts? Providing families with coverage for this gap in insurance coverage is the chief goal of H. 3809.

A compelling and common theme throughout all of the literature reviewed and interviews conducted was the critical emphasis placed on ensuring that children receive early and intensive intervention to treat the types and severity of symptoms that characterize ASDs.

The following report provides a review and evaluation of H. 3809 relative to a very complex neurodevelopment disorder about which there is much more to be understood.

Overview of Current Law and Proposed Mandate

Massachusetts does not currently mandate that health insurance provide coverage for the diagnosis and treatment of ASD. House Bill 3809 (H. 3809) would mandate coverage for the diagnosis and treatment of autism spectrum disorder (ASD). The proposed mandate would apply to the fully-insured market, Health Maintenance Organizations (HMOs), and Blue Cross Blue Shield plans, as well as the Group Insurance Commission (GIC).⁹

The proposed law would mandate that all required health insurers cover all care that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist who determines care to be medically necessary, including: (1) habilitative or rehabilitative care, including Applied Behavioral Analysis (ABA), (2) pharmacy care; (3) psychiatric care; (4) psychological care; and (5) therapeutic care. H. 3809 defines therapeutic care to mean “services provided by licensed or certified speech therapists, occupational therapists, physical therapists or social workers.” The proposed legislation applies across the lifespan, including coverage for both children and adults.

Health insurers typically exclude behavioral therapies such as applied behavioral analysis (ABA), because health insurers consider such services to be educational, habilitative and/or experimental in nature. Insurers provide coverage for other types of services, including pharmacy, psychiatric, psychological and therapeutic care such as speech and occupational therapies to treat ASD. However, according to expert opinion, insurance coverage for speech and occupational therapies could be limited relative to the demand for these types of services.¹⁰

H. 3809 also includes language to prevent the proposed mandate from having any effect on the “obligation to provide services” under an Individual Service Family Plan (IFSP), and Individualized Education Program (IEP), or an Individualized Support Program (ISP). The intent of this language is to ensure that early intervention (EI) programs, school districts, and the Department of Developmental Disabilities (DDS) maintain an obligation to provide services should the proposed bill become law. Nevertheless, DHCFP assumes that some level of cost shifting from these programs

to health plans would occur as a result of the proposed legislation. These assumptions are reflected in DHCFP's financial analysis of the mandate, although such shifts in costs away from school districts to health plans cannot be determined precisely.

Should H. 3809 become law, early and intensive interventions would become more available and affordable to family members, as health insurers pay for services that are not currently covered under an IFSP, IEP, or ISP. The proposed legislation may also reduce the disruption in services that children may now experience when they "graduate" from EI programs at age three and lose their coverage for ABA services.

It is important to note that the passage of H. 3809 may result in lower expenditures for the state for those specialty services that the Department of Public Health now pays for through EI program. At present, specialty services are funded 100 percent by the Department of Public Health (DPH). Current law makes EI as the payor of last resort, however.¹¹ This means that, should health insurers be required to cover ABA in the future, EI would be able to bill health insurers for certain specialty services, such as ABA. In turn, this would reduce the cost of these services to the state.

The proposed mandate would also require that services provided using ABA techniques are provided by Board Certified Behavioral Analysts (BCBA). That topic is discussed in more detail in this report. It is important to note that Massachusetts does not currently have specific certification or licensure requirements for ABA providers. Health insurers believe that the state matters must be addressed. Several health insurers proposed that the state establish licensing standards for these types of practitioners.¹²

Methodology for Financial Impact Analysis

DHCFP prepared this review and evaluation of H. 3809 by conducting interviews with legislative staff, insurers, providers, and officials in the education and autism communities; reviewing the relevant literature relative to the prevalence, diagnosis and treatment of Autism Spectrum Disorders; and conducting an actuarial analysis of the fiscal impact of H. 3809 (see appendix).¹³

DHCFP's analysis focused on how the use and costs of diagnosis services and treatments for ASD would be affected by H. 3809. The analysis was based on the following: (1) the prevalence of individuals diagnosed with ASD, (2) assumptions about the utilization and costs of services, and (3) coverage of services by insurers today among individuals diagnosed with ASD. More specifically, DHCFP's analysis primarily focused on the use and cost of habilitative and rehabilitative care, including ABA, because these services are currently excluded from coverage by health plans. The analysis considered the adequacy of the supply of providers to meet the expected response in demand.

DHCFP also considered the effect of H. 3809 on other types of services, including therapeutic services such as speech and occupational therapies. The key question is how H. 3809 would change the medical-necessity decisions on the part of the health plan since these are already covered services. Should H. 3809 become law, would health plans provide a more generous level of

therapies to individuals diagnosed with ASD? According to the expert opinion of providers, health plans typically provide limited coverage relative to the demand for these services for individuals diagnosed with ASD. However, the responses of the health insurers to DHCFP's survey indicate that health insurers are already currently providing these types of services using standards of medical necessity, including consideration of functional impairments that arise from the condition of ASD in this determination process. For this reason, DHCFP's actuaries concluded that H. 3809 would have no effect on the use and costs of therapeutic services to health plans (see Appendix).

Three different impact scenarios were developed – low, middle, and high – to present a range of the possible impact of the proposed mandate on premiums and total health plan expenditures for fully-funded health plans.

Results of Financial Impact Analysis

Over the next five years, the average projected increase in spending by fully-funded health plans that would result from H. 3809 ranges from .24 to .49 percent of premiums or \$34 to \$68 million. Per member per month (PMPM) impact ranges from \$1.22 to \$2.45.¹⁴ Note that these numbers exclude the impact on the Group Insurance Commission (GIC).

The five-year impact results are displayed in Exhibit 1. The results include three sets of estimates based on low, medium, and high impact scenario corresponding to .24%, .36%, and .49%, respectively, of premium. The five-year average of these three scenarios resulted in estimated increased total spending (including both claims spending and administrative expenses) of \$34 million, \$51 million and \$68 million, respectively.

Including the GIC in the five-year impact results that are shown in Exhibit 1 would increase the scenarios to account for medical expenses of GIC members by the following amounts, respectively: \$2.4 million, \$4.4 million and \$5.8 million, on average, over the next five years. Note again that the GIC results are not included in Exhibit 1 since the premium impact does not apply.

Exhibit 1: Estimated Cost Impact of H. 3809 on Fully Insured Health Care Premiums (2011-2015)

	2011	2012	2013	2014	2015	5-Year Total
Fully Insured Enrollment	2,330,000	2,328,000	2,326,000	2,325,000	2,323,000	
Low Scenario						
Annual Impact Claims (000s)	\$15,681	\$25,643	\$34,685	\$37,183	\$38,687	\$151,879
Annual Impact Administration (000s)	\$1,960	\$3,205	\$4,336	\$4,648	\$4,836	\$18,985
Annual Impact Total (000s)	\$17,641	\$28,849	\$39,021	\$41,831	\$43,522	\$170,864
Premium Impact (PMPM)	\$0.63	\$1.03	\$1.40	\$1.50	\$1.56	
Middle Scenario						
Annual Impact Claims (000s)	\$27,466	\$38,991	\$51,067	\$54,097	\$56,286	\$227,906
Annual Impact Administration (000s)	\$3,433	\$4,874	\$6,383	\$6,762	\$7,036	\$28,488
Annual Impact Total (000s)	\$30,899	\$43,865	\$57,450	\$60,859	\$63,321	\$256,394
Premium Impact (PMPM)	\$1.11	\$1.57	\$2.06	\$2.18	\$2.27	
High Scenario						
Annual Impact Claims (000s)	\$39,250	\$52,338	\$67,448	\$71,011	\$73,885	\$303,932
Annual Impact Administration (000s)	\$4,906	\$6,542	\$8,431	\$8,876	\$9,236	\$37,992
Annual Impact Total (000s)	\$44,157	\$58,880	\$75,879	\$79,888	\$83,120	\$341,924
Premium Impact (PMPM)	\$1.58	\$2.11	\$2.72	\$2.86	\$2.98	

Note: Please see actuarial assessment in the Appendix for details on assumptions for these estimates.

Introduction

Over the last decade, at least 15 states have enacted some type of autism mandate. Some states have enacted autism mandates that require insurers to provide coverage for the diagnosis and treatment of autism with annual benefits capped based on a dollar amount or limited based on age. Other states have enacted autism legislation without such caps or limits.¹⁵

H. 3809 proposes to mandate that health insurers provide coverage for the diagnosis and treatment of Autism Spectrum Disorder (ASD). The effect of the H. 3809 is to require that private insurers cover services that are currently excluded, namely applied behavioral analysis (ABA). It is less likely that H. 3809 would have a significant impact on increasing the supply of therapeutic care such as speech and occupational therapies covered by health plans. This proposed mandate would apply with no dollar cap or age limits. The proposed mandate would apply to all individuals covered under fully-insured commercial plans and the Group Insurance Commission (GIC).¹⁶

The remainder of this introductory section summarizes the scope of the current law and describes how private insurance coverage would change under the proposed bill.

Summary of Current Law

Current state law does not mandate that health insurers provide coverage for the diagnosis and treatment of ASD. The Commonwealth's Mental Health Parity Act of 2000, as amended in 2009, includes autism as a biologically-based mental disorder. The state's mental health parity law requires private insurers to provide medically-necessary mental-health benefits on a "non-discriminatory basis" for the diagnosis and treatment of biologically-based mental disorders.¹⁷ However, this law does not apply to treatments that health insurers currently consider to be educational and/or experimental in nature. According to the Division of Insurance, health plans may exclude care that is experimental under current law.^{18, 19}

Summary of Proposed Mandate

H. 3809 mandates coverage for the diagnosis and treatment of Autism Spectrum Disorder (ASD).²⁰ The proposed bill includes coverage for all care that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist who determines care to be medically necessary, including: (1) habilitative or rehabilitative care, including Applied Behavioral Analysis (ABA), (2) pharmacy care; (3) psychiatric care; (4) psychological care; and (5) therapeutic care. The language of the proposed mandate would prevent insurers from denying habilitative and rehabilitative care, such as ABA, because such care is considered educational and/or experimental by health insurers.

The proposed legislation also includes the requirement that services provided using ABA techniques are provided by Board Certified Behavioral Analysts (BCBA). See Box 1 for information about the supply of providers in Massachusetts.

This proposed mandate would apply to the fully-insured population, including those commercially insured, those enrolled in Health Maintenance Organizations (HMOs) and Preferred Provider Organizations (PPOs), Blue Cross Blue Shield plans, as well as those insured by the Group Insurance Commission (GIC).

In addition, the language of the proposed mandate addresses the relationship between health insurers and other sources of coverage for treating ASD, including the early intervention (EI) program of the Department of Public Health (DPH), the Department of Elementary and Secondary Education, and the Department of Development Disabilities (DDS). The language of H. 3809 specifically states that “nothing in this section shall be construed to have any effect on the obligation to provide services under an IFSP, IEP, or an ISP.” In effect, the proposed legislation requires that DPH, school districts, and DDS continue to create agreed-upon goals and provide services that are currently recorded in Individual Family Service Plans (IFSPs), in Individualized Education Plans (IEPs), and in Individualized Support Programs (ISPs).

Should H. 3809 become law, health insurers would pay for services that are not currently covered under an IFSP, an IEP, or ISP. Sponsors refer to these currently uncovered services as the “gap” in insurance coverage for individuals diagnosed with ASD.²¹

The proposed legislation would also allow EI programs to bill health insurers for specialty services that are not currently covered under health insurance. By law, EI is the payor of “last resort.”

School districts, which play a key role in treating ASD, would remain obligated to provide services under an IEP to children between 3 and 22 years of age. In accordance with the federal Individuals with Disabilities Education Act (IDEA), all children in Massachusetts are entitled to receive a free, appropriate public education (FAPE). The state is required to enforce this law. Still, wide variation exists in the level and quality of services provided to individuals with ASD among school districts, because of the way in which special education is funded in Massachusetts.²² This variation will also have a bearing on the demand for services covered under health insurances.²³

Box 1: Behavior Analyst Certification Board

H. 3809 requires that ABA be provided by board-certified analysts. The Behavior Analyst Certification Board, Inc. (BACB), located in Florida, offers two types of credentialing programs: BCBA and BCaBa. In the United States, there are approximately 7,500 supervisors and analysts certified by the BACB. Massachusetts has more ABA professionals than does any other state in the country that has passed an autism mandate law, or more than 600 or over 8 percent of the total supply.²⁴ That translates into 1 provider for every 16 individuals between the ages of 3 and 22 in Massachusetts, based on a total count of 9,973 students included in the category of “autism,” as reported by the Department of Elementary and Secondary Education.

Background

In this section, DHCFP provides: (1) an overview of ASD; (2) a synopsis of existing health insurance coverage by insurers in Massachusetts; (3) a description of the role of public early intervention programs and school districts in diagnosing and treating autism in relation to H. 3809; and, (4) a summary of federal and state activity on autism mandate laws, including nationwide efforts to address the need for improved research and insurance coverage for individuals.

Autism Spectrum Disorders

According to the National Institute of Mental Health (NIMH) of the National Institutes of Health (NIH), ASD is a range of neurodevelopment disorders including autism or classic autism, Asperger syndrome and PDD Not Otherwise Specified (PDD-NOS).²⁵ Some estimates indicate that roughly one third of people with ASDs are diagnosed with autism, one sixth with Asperger, while 50 percent are diagnosed with PDD-NOS.

ASDs can range from the very severe forms such as autistic disorder to the milder forms such as Asperger syndrome, with varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotyped patterns of behavior. Although ASD varies significantly in character and severity, it occurs in all ethnic and socioeconomic groups and affects every age group.

Autism Spectrum Disorder can be diagnosed as early as 18 months of age or younger in some children.²⁶ A diagnosis of ASD involves a two-step process including: (1) a developmental screening; and (2) a comprehensive evaluation by a multidisciplinary team involving a psychologist, a neurologist, a psychiatrist, a speech therapist, or other professionals who diagnose children with ASD. The diagnosis of an ASD is based “on a combination of behavioral characteristics of impairment in verbal and nonverbal communication skills and social interactions, and restricted, repetitive, and stereotyped patterns of behavior, and these can range in impact from mild to significantly disabling.”²⁷

Currently, there is no known cause for Autism Spectrum Disorders. There are a number of research efforts underway to review the biologic basis of ASD. There is also no known cure for an individual diagnosed with an ASD. The diagnosis of an ASD lasts throughout an individual’s lifetime with a mild to severe impact on an individual’s level of functioning.²⁸

Prevalence of Autism Spectrum Disorders

According to a reported published in December 2009 by the U.S. Centers for Disease Control and Prevention (CDC), an average of 1 in 110 persons in the United States has an ASD. Two years earlier, the CDC reported that 1 in 150 persons in the United States had an ASD.²⁹ See Box 2 for a discussion about the prevalence of ASD in Massachusetts.

The CDC cannot definitively indicate how much of that increase is true and how much is the result of other factors, including better detection efforts.³⁰ What is clear from this newly-published rate is that the rate of prevalence is much higher than previously recorded with far-reaching implications on society in general.

The CDC-funded Autism and Developmental Disabilities Monitoring (ADDM) Network monitors the prevalence of autism spectrum disorders in the United States based on information collected on 8-year old children in multiple areas of the United States. Age eight is considered by the CDC to be a “reasonable index age” at which to calculate prevalence in the United States, because research shows that most children with an ASD have been identified for some type of an evaluation or education service by this age.³¹

A summary of the key findings of the 2009 findings of the CDC-funded ADDM Network is listed below:

- All racial, ethnic and socioeconomic groups are affected.
- Boys are 4 to 5 times more likely to have an ASD than girls.
- Among identical twins, if one child has an ASD, then the other will be affected about 60 to 96 percent of the time.
- In non-identical twins, if one child has an ASD, then the other is affected about
- 0 to 24 percent of the time;
- Parents who have a child with an ASD have a 2 to 8 percent chance of having a second child who is also affected.
- It is estimated that about 10 percent of children with an ASD have an identifiable genetic, neurologic or metabolic disorder, such as fragile X or Down syndrome. Between 30-51 percent of the children who had an ASD also had an Intellectual Disability.¹¹

Box 2: Prevalence of ASD in Massachusetts

Relying on statewide statistics of ASD from the Department of Elementary and Secondary Education (ESE), the prevalence of ASD has been rising in Massachusetts. The statewide data for the 2008-2009 school year indicate that at least 1 in 90 students has been diagnosed with an ASD across all grades and ages from 3 to 22 years of age.³² For the purpose of comparing the CDC-reported rate of prevalence of 1 in 110 children to the state-specific rate for Massachusetts, the author calculated that 1 in 107 eight-year olds had a diagnosis of autism, based on data for 3rd graders enrolled in the public schools during the school year 2008-2009. The prevalence for autism is especially difficult to nail down. The state’s EI program estimates that 1 in 108 children under age three have or might have a diagnosis of ASD. EI estimates might overestimate the prevalence of ASD. EI tends to err on the side of caution.³³ EI reports a rate of 1 in 108 among 0-3 year olds. On the other hand, the ESE might actually underestimate the number of students diagnosed with an ASD in its reporting, because students with autism can also be classified in one of 13 categories used to comply with the federal Individuals with Disabilities Education Act (IDEA) Act.

Treatments for Autism Spectrum Disorders

Treating an ASD is complex and costly, because treatments must be intensive. The needs of individuals diagnosed with ASD are quite heterogeneous. There is no single protocol for treating an individual with ASD.

Many children receive a combination of interventions, including educational and therapeutic approaches, in response to the range of impact on a person's functioning. Other treatments may also be used to address a range of medical conditions including, but not limited to: motor and sensory impairments, seizures, immunological and metabolic abnormalities, sleep problems, and gastrointestinal symptoms. Complementary and alternative medicine, diet changes, or medications to manage or relieve symptoms of autism, are examples of other types of treatments that are sometimes used.

There are many strategies to address the functional deficits of an individual with an ASD. ABA is perhaps one of the best known strategies.³⁴ See Box 3 for more information about ABA. The Floortime Approach, developed by Dr. Stanley I. Greenspan, is another well-known strategy.³⁵

In accordance with the findings from the 2001 landmark report of the National Research Council of the National Academy of Sciences, early intervention is most important to educating children with ASD. Furthermore, the best treatment approach is to "tailor the treatment approach to the unique features of the individual child." The findings from this report also indicate that treatment programs include these features: (1) children should receive intervention as soon as a diagnosis of an ASD is seriously considered (early diagnosis); (2) interventions should be intensive in nature (between 25 and 40 hours each week); (3) a low student to teacher ratio is best, if not one-to-one; (4) families should be involved in the treatment program; and (5) treatment programs should include a high degree of structure. These findings have been reinforced by more recent studies and reports of the NIMH, the American Academy of Pediatrics (AAP), and the National Research Council (NRC), which endorse the following: (1) act early; and (2) provide interventions that provide structure, direction and organization.³⁶

Box 3: Applied Behavioral Analysis

ABA is a type of Early Intensive Behavioral Intervention (EIBI) intervention used to address the learning deficits in individuals diagnosed with autism.³⁷ ABA treatments involve a one-on-one child-teacher interaction and can range in intensity from 25 hours to 40 hours a week. The major goal of ABA is to minimize the core features and deficits associated with the diagnosis and maximize the functional independence and quality of life. ABA can be used to treat children and to treat adults. There are several techniques that can be used within ABA to teach these skills, including: discrete trial learning, natural environment training, task analysis, reinforcements, prompting and various visual supports.³⁸ At the Massachusetts-based New England Center for Children (NECC), a day and residential program for students diagnosed with an ASD, ABA, as methodology, is put into practice through the school day.³⁹ In this educational setting, curriculum protocols are used in every classroom to teach children with autism, based on the Autism Curriculum Encyclopedia (ACE), a computerized database which holds assessments, curriculum, and data analysis tools for teaching children with autism, based on ABA principles.⁴⁰

Survey of Health Insurers

Currently, health insurers in Massachusetts cover care to diagnose and treat ASD but at lower coverage levels than at the level and for the types of services being proposed under H. 3809.

DHCFP's consultants prepared a survey sent to seven health insurers in Massachusetts. All seven health insurers responded to this survey, including Blue Cross Blue Shield Plans, Fallon Community Health Plan, Harvard Pilgrim Health Care, Neighborhood Health Plan, Tufts Health Plan, Unicare, and United. Health plans also provided additional information, at the request of the consultants, to convey reasons for including, limiting or excluding care that the proposed legislation would cover.

The responses of the health plans were fairly similar. The following statements attempt to generalize the policies of the health insurers and are intended to clarify current health insurance coverage overall with respect to the diagnosis and treatments introduced by H. 3809:

- All but two of the insurers define Autism Spectrum Disorders (ASD) using identical codes, with two of the health plans potentially defining ASD more narrowly.
- All seven insurers indicated that they provide coverage for the diagnosis of ASD, including evaluations and assessments. One of the insurers, however, specifically excludes psychological and neuropsychological testing, because it is considered to be educational in nature. The other insurers might possibly exclude these tests too, but the responses from the other six plans are not sufficiently explanatory to say one way or the other.
- All seven insurers indicated that they do not provide coverage for treatments that are considered habilitative in nature, including ABA. All seven insurers indicated that they exclude ABA because such care is viewed by health plans as habilitative, educational or experimental in nature.
- Psychological and psychiatric services are covered for individuals diagnosed with an ASD in compliance with the Commonwealth's Mental Health Parity Act;
- Pharmacy services are covered for individuals diagnosed with an ASD.⁴¹
- All seven insurers indicated that they provide therapeutic care, including occupational, speech and physical therapies. Insurers indicated that medical-necessity determinations are based on psychiatric symptoms and the functional impairments that arise from them.

Health insurers also provided additional information to DHCFP relative to the view that health insurers hold about H. 3809. This additional information was provided by health plans in their survey responses.⁴² Two of the major concerns are raised, here, to ensure proper review and evaluation of H. 3809: (1) The proposed legislation would require health plans to cover all care that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist. That is viewed problematic by health plans, since health insurers believe that they will not have the right to review the medical necessity of the care being prescribed. (2) The proposed legislation would require health plans to contract with Board Certified Behavior Analysts. That is viewed as problematic by health plans, since there is currently no state licensing and credentialing process.

Coverage Under IDEA

In accordance with the federal Individuals with Disabilities Education Act (IDEA) Act, first enacted in 1975, all children in Massachusetts are entitled to receive a free, appropriate public education (FAPE). In 1990, autism was made part of IDEA. Part B of the federal law addresses the needs of children 3 through 22 years of age, while Part C of the federal law addresses the needs of infants and toddlers with disabilities from birth to 3 years of age.⁴³

- Part B. School districts are required to provide services to children and adolescents between 3 and 22 years of age in accordance with a written Individualized Education Plan (IEP). In general, children are placed in public schools (some children attend private schools) and services are provided during the school day and school year. A range of services might be provided including ABA, speech therapy, and occupational therapy. IEPs can be written for an extended day, or year around and school districts are responsible for providing all of the services provided under an IEP, with certain exceptions.
- Part C. Under the EI program, children under 3 years of age receive services in accordance with a written Individualized Family Service Plan (IFSP). These services are primarily provided in the child's home, and include a range of services including speech therapy, physical therapy, and occupational therapy. With respect to treating ASD, EI also provides specialty services, including ABA and "Floortime." Many of the services provided by EI under an IFSP such as speech, occupational and physical therapies are covered by health insurance. Specialty services designed to treat ASD, on the other hand, are fully funded by DPH.

In Massachusetts, coverage for treating ASD is provided by the EI program for children between birth and 3 years of age and by school districts for students between 3 and 22 years of age.

- Coverage under EI for treating ASD is fairly straightforward: EI provides "near-universal coverage" and services based on the needs of the individual.⁴⁴ Families may or may not secure services beyond the level provided under the IFSP by EI, which may or may not be covered by their health insurance.
- Coverage by school districts is less straightforward: school districts vary in what services they provide to students with ASDs, with some districts providing a richer or leaner set of services than other districts.⁴⁵ Families may or may not secure services beyond the level provided under the IEP by the school district, which may or may not be covered by their health insurance.

Sponsors of the proposed legislation refer to the demand for services stemming from the lack of uniformity on the part of school districts and need for coverage during non-school hours as the "gap."⁴⁶ Should H. 3809 be enacted, health insurers would be required to fill this "gap" in insurance coverage for treatments that are typically not covered under health insurance today by providing ABA services. Other types of services, including speech, occupational and physical therapies, might not change very much, with the caveat that demand could increase in the future in response to the

potential for school districts to reduce services provided under IEPs. See Box 4 for a description of the demand for services facing Boston.

Box 4: Increasing Demand for ABA in Boston

Across Massachusetts, cities and towns are facing increasing financial and programmatic demands in response to the increasing number of students with ASD. Statewide, the total number of students classified with “autism” has more than doubled from over 4,000 to about 10,000 in about 5 years.⁴⁷ Students with ASD account for close to 70 percent of the total increase in enrollment of special education students. These numbers are based on measuring the difference between the enrollment numbers in the 2002-03 and the 2008-2009 school years, and include all enrolled students between 3 and 22 years of age.

In 2009, Mayor Thomas M. Menino kicked off the city’s Autism Summit, calling for passage of H. 3809, in response to growing pressures within the city.⁴⁸ Boston has the highest number of students in the state classified with the diagnosis of “autism.”⁴⁹ The most recently reported count was 500. That translates into 1 in 100 students with ASD based on total enrollment. According to special educational officials in Boston, Boston has increased its supply of ABA professionals twelvefold over the last 10 years, from 3 to 36 professionals, and is in the process of hiring more professionals trained in ABA for the next school year.⁵⁰

This school district supports H. 3809 for many reasons including an increasing trend reported by the district to keep pace with the volume of “prescriptions” that school officials receive from the student’s medical practitioner. City special educational officials consider the some of the demand effects on school districts to be the result of coverage limitations under health insurance to treat ASD during non-school hours. These demand effects are not felt as greatly for other types of conditions where there are services that are provided by school districts during school hours and coverage under health insurance during non-school hours. Speech therapy is one such example.

Federal Activity

At the federal level, there is a significant amount of activity taking place. These activities have included both administrative initiatives around research into the causes of ASD and legislative initiatives to expand insurance coverage for treatments.

Autism Treatment Acceleration Act of 2009

In the 111th session of Congress, 2009-2010, the “Autism Treatment Acceleration Act (ATAA)” (S. 819) was introduced in the Senate by Senator Richard Durbin (D-IL), Senate Robert Casey (D-PA), and Senator Robert Mendez (D-NJ). The companion house bill, H.R. 2413, was introduced in the House of Representatives by Representative Mike Doyle (D-PA), Representative Chris Smith (R-NJ), Representative Eliot Engel (D-NY), and Representative Hank Johnson (D-GA). The following elected officials from Massachusetts have signed on to support this legislation, including: Senator

John F. Kerry (D-Massachusetts) and the late Senator Edward M. Kennedy (D-Massachusetts), as well as Representatives Barney Frank (D-MA) and Representative Jim McGovern (D-MA).⁵¹

The proposed federal legislation contains twelve sections in all, including Section 12 that requires that all insurance companies across the country provide coverage for all diagnoses and treatment costs relative to ASD. The proposed federal legislation does not contain any maximum caps on spending per year or per lifetime. The other 11 sections of the proposed federal legislation put forth different programs for autism, including funding and support for several demonstration projects, public education, a voluntary registry, and a national program of training.

The Combating Autism Act of 2006

In 2006, the U.S. Congress enacted a law “to combat autism” addressing areas of research, screening, intervention and education. The law provides almost \$1 billion over five years for ASD in support of: (1) activities to improve autism-related search including authorizing the Director of the National Institutes of Health to develop and implement a strategic plan for research related to ASD, and promoting the expansion, intensification and coordination of activities at NIH related to ASDs; (2) authorization and funding for the Developmental Disabilities Surveillance and Research Program through which the CDC collects epidemiological data; and (3) reauthorization for the “Autism Coordinating Committee” first established by the Children’s Health Act of 2000.⁵²

The Interagency Autism Coordinating Committee

The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee established for the purpose of coordinating all efforts within the Department of Health and Human Services (HHS) concerning ASD. The Children’s Health Act of 2000 first created the committee, and the Combating Autism Act of 2006 provided reauthorization for the IACC. The IACC includes all 5 NIH Institutes and representatives from other federal agencies, including Health Resource Services Administration (HRSA).⁵³

In January 2009, the IACC published its “Strategic Plan for Autism Research” “to focus, coordinate, and accelerate high-quality research and scientific discovery in partnership with stakeholders to answer the urgent questions and needs of people on the autism spectrum and their families.” Among the themes highlighted for research efforts were these needs: (1) recognition of the heterogeneity of people with ASD; (2) methods that can prevent the challenges and disabilities of ASD; (3) earlier detection including the need for “biomarkers” to identify ASD risk before the behavioral manifestations and the delayed developmental trajectory are established; (4) a lifespan perspective that encompasses the needs of individuals across a lifespan; (5) data sharing among researchers such as the example of the standardized data-sharing system under the purview of the National Database for Autism Research (NDAR); (6) resources including well-trained researchers; (7) public-private partnerships; and (8) community engagement in ASD research to capture the “first-hand experience” of families caring for individuals with ASDs.

The National Institutes of Health

NIH, the Nation's Medical Research Agency, is sponsor to two major research networks that are dedicated to understanding and treating autism. The first is the Collaborative Programs of Excellence in Autism (CPEA) Network, which conducts research to learn about the possible causes of autism, as well as diagnosis, early detection, behavioral and communications characteristics, and treatment of autism. The second is the Studies to Advance Autism Research and Treatment (STAART) Network. Boston University in Massachusetts is one of the eight designated STAART networks and is a CPEA site.⁵⁴

Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) plays a significant role in bringing autism to the forefront of this country's attention. Among the most noteworthy responsibilities of the CDC include these three major functions including: (1) the responsibility to monitor the prevalence of autism, (2) to understand risk factors associated with autism; and (3) to provide education.

- The CDC's Autism and Developmental Disabilities Monitoring Network (ADDM) is a group of programs that collects data from multiple communities throughout the United States in order to estimate the number of people with Autism Spectrum Disorders in the United States. Standardized surveillance methods are used to collect data at all ADDM sites, using the CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP).⁵⁵
- The Study to Explore Early Development (SEED) is a multi-year study funded by CDC. It is currently the largest study in the United States. The goal of SEED is to help identify factors that may put children at risk for ASDs and other developmental disabilities in an effort to learn more about the causes. Specifically, the goals include understanding more about: (1) the physical and behavioral characteristics of children with ASDs, children with other developmental disabilities, and children without a developmental delay or disability; (2) the health conditions among children with and without ASDs; and (3) factors associated with a child's risk for developing ASDs, including genes, health conditions, experiences of the mother during pregnancy, and the health and development of the child during infancy and the first few years of life.⁵⁶
- Finally, the CDC's "Learn the Signs. Act Early" campaign provides a variety of tools and materials to help parents recognize the signs of developmental disabilities such as autism. The campaign helps parents measure their children's developmental progress by monitoring how they play, learn, speak, and act. The site also includes useful campaign materials for health care providers, child care providers, and campaign partners.⁵⁷

TRICARE Enhanced Care Health Option (ECHO)

The Department of Defense (DoD) provides coverage for autism therapies, including Applied Behavioral Analysis (ABA), under the TRICARE Enhanced Care Health Option (ECHO) through the Enhanced Access to Autism Services Demonstration.⁵⁸ This demonstration, which went into

effect March 2008, is designed around improving access to services for eligible children with ASD. DoD refers to these services as special-education services. Individuals diagnosed with an ASD who qualify may receive a special-needs benefit capped at \$36,000 per year. This demonstration program, however, is not currently considered by the DoD as a basic medical treatment under the TRICARE but as a supplemental benefit managed under the ECHO demonstrations.

Federal Employees Health Benefit Program

The FEHB Program provides benefits for services to individuals diagnosed with an ASD under the federal Mental Health Parity law just as it does for physical conditions. No other federal mandate exists that applies to the FEHB Program, relative to providing coverage for certain intervention or therapies that are specifically related to the diagnosis and treatment of individuals diagnosed with an ASD. The FEHB Program does not cover ABA, because it is considered experimental and does not meet standards of medical necessity under the federal program.⁵⁹

State Activity

Autism Mandates

There has been much focus on calculating the fiscal impact of autism mandate state by state. In this section, that is discussed in more detail. Most studies seem to converge around an increase in premiums of 1 percent or less as a result of an autism mandate.

Equally important, perhaps, is what happens after the law is passed. Some states have faced several difficulties in implementing the law.⁶⁰ Should H. 3809 be enacted, the Division of Insurance (DOI) in Massachusetts may very well face some of the same challenges that Indiana faced in creating a uniform interpretation of the law among health plans. See Box 5 for a case study of Indiana's experience in implementing its autism mandate law.⁶¹

- According to the National Conference of State Legislatures, at least 15 states across the country have enacted "autism mandate" laws to increase coverage for the treatment of autism over the last 3 years.⁶² That list includes: Arizona, Colorado, Connecticut, Florida, Illinois, Indiana, Louisiana, Montana, Nevada, New Jersey, New Mexico, Pennsylvania, South Carolina, Texas, and Wisconsin. Some states have enacted autism mandate laws with various types of coverage limitations, including age exclusions and/or dollar caps on the annual and/or lifetime benefit for treating ASDs. Pennsylvania, for example, enacted an autism mandate that includes a \$36,000 annual cap with no lifetime cap.
- Across the country, there have been several analyses conducted on behalf of states that indicate that autism mandates are expected to increase premiums by about 1 percent.⁶³ An estimate prepared by the Council for Affordable Health Insurance, which is opposed to an insurance mandate for ASD, reaches a similar conclusion. The CAHI analysis estimates that an autism mandate would increase the cost of health insurance by about 1 percent, but that the impact could be as high as 1-to-3 percent if the incidence in autism continues to increase

and if mandates cover more services.⁶⁴ In fact, that has occurred, since the CAHI published this estimate, from a rate of 1 in 150 persons to 1 in 110 persons.

Box 5: Implementation in Indiana

In 2001, Indiana enacted its health insurance mandate for Autism Spectrum Disorders (ASDs) and Pervasive Developmental Disorders (PDDs). Indiana's law is one of the most comprehensive in the country, and mandates insurance coverage for individuals with ASDs for any accident or health-insurance policy that is issued on a group basis (large or small). Insurers selling individual policies must offer the option to include coverage for ASD. However, Indiana's law took several years to implement. Indiana's Division of Insurance (DOI), the agency charged with implementing the autism mandate, has been key to implementing and enforcing the law that was enacted in 2001. According to Indiana's DOI, several reasons made the implementation the law cumbersome, including the vagueness of the law and the complex nature of ASD. In the years immediately following the enactment of the law, the practice of providing coverage for the treatment of ASD differed widely among health insurers. That led Indiana's DOI to take steps to clarify the law.

In March 2006, DOI issued Bulletin 136 to guide both insurance companies and HMOs on compliance with the law. This bulletin outlined many specifics that were absent from the law including: (1) a definition for PDD and that PDD is neurological condition; (2) a requirement that insurers provide coverage in accordance with the physician-approved treatment plans; (3) clarification that insurers and HMOs had the right to review the services included in the treatment plan, but that challenges to medical necessity would only be viewed as reasonable "if the review is by a specialist in the treatment of PDD"; coverage for services, including no limits on ABA; (4) limits on the frequency of reviewing treatment plans; and, (5) the requirement that insurers cannot deny ABA because the state does not have a licensing process for behavioral therapists. This bulletin proved instrumental in moving the law forward.

Nearly 10 years later, Indiana's DOI considers the law a success, since insurers and advocates are working together to form solutions, including creating a standardized plan across insurers.

Massachusetts

H. 3809

In Massachusetts, advocates and insurers, alike, have produced analyses that estimate the financial impact of H. 3809 on premiums. These estimates include consideration of the effect H. 3809 on ABA and non-ABA services, including therapeutic services. There are indeed assumption differences between the analyses that make comparisons difficult. On the one hand, an analysis performed by Oliver Wyman Actuarial Consulting, Inc., on behalf of Autism Speaks, was conducted before the prevalence of ASD was increased from 1 in 150 to 1 in 110.⁶⁵ On the other hand, an analysis performed by the Taylor Feldman Group, on behalf of health insurers in Massachusetts, is based on a more current prevalence of ASD but included self-insured plans in its estimate which are excluded from H. 3809.⁶⁶ Nonetheless, estimates conducted by advocates and opponents seem to agree that premiums would increase by less than 1 percent, on average, over the first 5 years of an autism mandate. These analyses are discussed in more detail in the Appendix of this report.

MassHealth

Massachusetts is one of many states in the country that has used the Medicaid Home and Community-Based Services Waiver Program as a way to provide assistance to individuals with autism. Under the Massachusetts' Children's Autism Spectrum Disorders Home and Community-Based Services Waiver Program, up to \$25,000 per child can be provided to a maximum of 110 children per year.⁶⁷ Services include an array of in-home services from Applied Behavioral Analysis to "Floor Time." In 2007, the Office of Medicaid and the Department of Developmental Service's Autism Division received approval from the Federal Centers for Medicare and Medicaid Services to provide Extended Habilitation Education Services. The approval was provided for three years. Under the terms of the waiver, eligible individuals must be under the age of 9 and eligible for ICF-MR Level of Care to be considered for the "waiver program."

Methodological Approach

Overview of Approach

DHCFP engaged a consulting team for this project, including the economics and actuarial firm of Compass Health Analytics, Inc. (Compass) to estimate the financial effects of the passage of H. 3809. Independent consultant Ellen Breslin Davidson of EBD Consulting Services, LLC (EBD) was hired to write the main report which included review and evaluation of the legislation, and Tony Dreyfus was hired to write the medical efficacy section of the report. The authors of this report thank Dr. Claire McCarthy and Dr. John Wong for their advice on the report. DHCFP, Compass, EBD and Dreyfus worked together to evaluate the likely effects of the proposed bill on existing health-insurance.

The following steps were taken to prepare the review and evaluation of H. 3809:

1. Conducted Interviews with Stakeholders.

DHCFP conducted interviews with stakeholders in the Commonwealth to ensure that it was accurately interpreting the proposed change in law, to understand the perceptions about how the law would be interpreted, if enacted, and expectations about its likely impacts. DHCFP completed interviews with the bill's lead sponsor, Representative Barbara L'Italien, and legislative staff including Jennifer Barrelle from the office of Representative Barbara L'Italien, and Lisa Pellegrino from the office of Representative Peter Koutoujian, and contacts from the fields of autism, health and human services, and education including: (1) experts from the New England Center for Children (NECC), Dr. Ann M. Neumeyer from the Lurie Family Autism Center/LADDERS, Susan Wilczynski, Director of the National Autism Center, and staff from the Behavior Analyst Certification Board; (2) health and human service experts Jean McGuire from the Executive Office of Health and Human Services, Janet George from the Department of Developmental Disabilities, Amy Bernstein from MassHealth, and Tracy Osbahr from the Department of Public Health; and finally, (3) special education experts Marcia Mitnacht, State Director of Special Education, the Department of Elementary and Secondary Education, and Carolyn Riley, Senior Director Special Education, the City of Boston. Meetings were also held with health insurers including Blue Cross Blue Shield of Massachusetts, the Massachusetts Association of Health Plans including representatives of member health plans, Unicare Life & Health, and United Healthcare; and, advocates, including Advocates for Autism and Autism Speaks.⁶⁸

2. Reviewed Literature.

DHCFP reviewed the literature to determine the context of the proposed mandate, including issues relative to the prevalence of autism, treatments, medical efficacy, and the federal and state landscape. This research included identification of parameters for estimating the cost impacts of H. 3809.

3. Prepared and Collected Survey Data from the Health Plans.

DHCFP requested that health plans respond to a survey developed by Compass and EBD to determine current coverage policies for Autism Spectrum Disorders.

4. Developed Baseline for Massachusetts.

DHCFP provided claims-level data from the health plans in the Commonwealth, using data from DHCFP's data warehouse, to establish a baseline of costs for those services that are currently covered by health insurance carriers. This data request was prepared by Compass, based upon the most recent definition of Autism Spectrum Disorder, as defined by the most recent edition of the Diagnostic and Statistical Manual of the Mental Disorders (DSM) published by the American Psychiatric Association.

Survey data was also used to affirm what was observed in the claims-level data. Baseline data from the health plans excluded early intensive behavioral therapies such as ABA, because private insurers do not currently provide coverage for that service. Baseline data was used primarily for the purposes of establishing costs for non-behavioral therapies.

5. Applied Assumptions and Sensitivity Analysis to Methodology.

Model parameters were developed from a comprehensive review of the literature, actuarial studies for other states and for Massachusetts by Oliver Wyman Actuarial Consulting, Inc. on behalf of the advocacy community and The Taylor Feldman Group on behalf of the insurance community, and Massachusetts-specific health plan baseline data collected from health plans to produce an estimate of the marginal premium cost of the proposed mandated benefits. The marginal premium cost estimate was driven by several components, including: (1) the prevalence of ASD; (2) the cost of behavioral therapies including ABA; and (3) administrative costs. Baseline premium costs were added to the marginal premium costs to estimate the total premium cost of the proposed mandate.

Approach for Determining Medical Efficacy

M.G.L. c. 3 § 38C (d) requires DHCFP to assess the medical efficacy of mandating the benefit, including the impact of the benefit on the quality of patient care and the health status of the population, and the results of any research demonstrating the medical efficacy of the treatment or service compared to alternative treatments or services or not providing the treatment or services. To determine the medical efficacy of H. 3809, DHCFP relied heavily upon the substantial research that has been conducted on the efficacy of available treatments for ASD.

Approach for Determining the Fiscal Impact of the Mandate

Legal Requirements

M.G.L. c. 3 § 38C (d) requires DHCFP to assess nine different measures in estimating the fiscal impact of a mandated benefit:

1. Financial impact of mandating the benefit, including the extent to which the proposed insurance coverage would increase or decrease the cost of the treatment or the service over the next five years;
2. Extent to which the proposed coverage might increase the appropriate or inappropriate use of the treatment or service over the next five years;
3. Extent to which the mandated treatment or services might serve as an alternative to a more expensive or less expensive treatment or service;
4. Extent to which the insurance coverage may affect the number or types of providers of the mandated treatment or service over the next five years;
5. Effects of mandating the benefit on the cost of health care, particularly the premium, administrative expenses and indirect costs of large employers, small employers and non group purchasers;
6. Potential benefits and savings to large employers, small employers, employees and non- group purchasers;
7. Effect of the proposed mandate on cost shifting between private and public payers of health care coverage;
8. Cost to health care consumers of not mandating the benefit in terms of out-of-pocket costs for treatment or delayed treatment; and
9. Effect on the overall cost of the health care delivery system in the Commonwealth.

Estimation Process

The steps required to identify the costs implied by this mandate were as follows:

- Estimate the size of the affected insured population, including reliance upon the prevalence of Autism Spectrum Disorder as reported by the CDC;
- Estimate the baseline claims costs for the affected benefits for services that are captured in the claims;
- Estimate the utilization and costs for habilitative and rehabilitative services including ABA, and non-habilitative and rehabilitative services, based on the percentage of individuals diagnosed with an ASD who would use services;

- Estimate the range of potential impact factors on claims costs should the mandate be enacted; and
- Estimate the impact of administrative expenses of the relevant insurers.

Following these steps, estimates were made for a five-year timeframe (2011-2015) for a range of “low case” to “high case” scenarios. Differences were driven by varying the demand response to changes in coverage for habilitative and rehabilitative care, including Applied Behavioral Analysis (ABA). The demand response was calculated taking into account the influence that severity and age will have on the demand for care. H. 3809 would provide coverage for services across the lifespan from children to adults, with adults expected to demand relatively less care than children. The analysis assumes that private insurance would cover ABA services based on the demand for early-intensive- behavioral therapies. That approach also internalizes a shift of ABA services currently provided by the EI program to private insurers.

For more detailed information on the methodological approach used to calculate the impact of H. 3809 (including the approach to calculating administrative costs), refer to the Appendix of this report.

Summary of Findings

Medical Efficacy

Medical Efficacy of Treatments for Autism

This section of the report is intended to summarize recent research on the efficacy of treatments for autism. In brief, the conclusion is that significant evidence exists for treatment efficacy. This evidence has led both practitioners and families to believe that current best-established therapies offer great promise for children with autism. At the same time, the evidence to date is not so fully conclusive to overcome all legitimate doubts about efficacy. Both current public debate and future research will help determine whether substantial new resources should be spent on available treatments to bring about the best outcomes for people with autism.

The sections below describe research challenges and major efforts in treatment research; report the results of major studies; and draw conclusions.

Challenges and major efforts in treatment research

Substantial clinical research has been conducted to examine the efficacy of treatments for autism. Researchers have faced numerous challenges, including the great variety in form and severity of autism spectrum disorders; the wide variety of treatments under consideration, including many behavioral therapies, drugs, and nutritional interventions; and the difficulty of specifying precisely what the treatments consist of, especially for behavioral therapies.⁶⁹

Research on autism treatments is so extensive that the medical efficacy section of this report is based on an examination of other efforts to review primary research. Conducting new work to examine the efficacy of autism treatments would require a large research effort and collaboration by a variety of experts and is well beyond the scope of this report.

Fortunately, several such large efforts have recently been undertaken to examine the research evidence and identify which approaches are supported by scientific evidence. Some of these studies have involved large panels of expert research reviewers evaluating large numbers of published articles with elaborate scoring systems. These studies show that interest in the efficacy of autism treatment can be found not only among families but also among state public officials, psychologists, pediatricians, psychiatrists, health service researchers, and the insurance industry. See Box 6 below for a list of our sources; citations in the text refer to this list.

Results of the Studies

These works conclude with a diversity of opinion about how well the efficacy of treatment is established for therapies based on applied behavior analysis or other behavioral approaches to therapy. A number of studies conclude that the efficacy of leading treatments for autism is well-established. The reliability of the evidence is questioned by two studies, with one concluding

that efficacy is not established for early intensive treatment and a second concluding that the evidence moderately supports the efficacy of leading treatments.

These differences of conclusion appear to stem in part from differences in what types of research were included for review. It is also possible that differences in the institutional and disciplinary backgrounds of the reviewers played some role. We first describe two analyses that question the reliability of the evidence. We then describe analyses that find efficacy is well-established.

The Studies

The most skeptical view among the studies listed above was provided by Rothenberg and colleagues, who concentrated on early intensive behavioral intervention (EIBI) and limited their review to a small number of studies that met their criteria about the structure of the experiments. Rothenberg and colleagues focused their review on only sixteen studies and concluded that “Overall, the quality and consistency of results of this body of evidence are weak. Consequently, no conclusions can be drawn from this literature on how well EIBI works. Weaknesses in research design and analysis, as well as inconsistent results across studies, undermine confidence in the reported results.”⁷⁰

In contrast with researchers in other groups, Rothenberg and colleagues decided not to consider evidence from the large number of studies known as “single-subject” design. In single-subject design studies, researchers examine data for individuals before and after treatment rather than examining differences between experimental and control groups. (The term “single-subject” is not meant to indicate drawing conclusions from an experiment with only one person, but that for a number of individuals the researchers examine how each individual changes over time.) While such studies have played an important role in research on psychological and educational interventions and also in some research on drug effectiveness, they are less accepted in the medical research community as conclusive evidence than the traditional experimental approach of studies comparing results between experimental and control groups.⁷¹ Rothenberg and colleagues argue that only group designs can indicate how well therapies will work in general for children with autism spectrum disorders.⁷² Other review efforts described below included single-subject studies, which may have contributed to the differences in their conclusion.

The study by Ospina and colleagues drew on a much larger body of research, consisting of 101 studies that were mostly clinical trials. It also combined data from different studies in “meta-analysis” for greater statistical advantage.

While Ospina and colleagues are cautious about how confidently we can view the evidence, they find considerable support for efficacy in the published literature. For many of the studies, Ospina and colleagues identify significant weaknesses in method or published description, limiting confidence in the results of individual studies that examined a wide variety of therapeutic approaches. Considering approaches based on applied behavioral analysis (ABA) such as discrete trial training and Lovaas therapy, the authors conclude that “The evidence

seems to provide some support for discrete trial training in terms of motor and functional skills but not for communication skills. Lovaas' therapy showed benefits when compared to 'no treatment' and evidence from meta-analysis of retrospective cohort studies showed greater effects for High versus Low intensity Lovaas."⁷³

Ospina and colleagues also examine earlier literature reviews and find that "studies of behavior analytic early intervention programs report substantial improvements, but the nature of improvements vary considerably across studies....They agree that the majority of recent primary studies of reasonable quality document some improvement associated with behavioral intervention, but it remains to be determined if any one early and/or intensive intervention program is more effective than another. Furthermore, there was insufficient evidence to establish a relationship between the amount (per day and total duration) of any form of treatment program to obtain desirable outcomes."⁷⁴

Several comprehensive efforts to examine research on a wide variety of treatments have come to more firmly positive assessments of the efficacy of the best treatments.

One such effort by the National Autism Center (NAC) recruited large numbers of expert reviewers to examine 775 research studies for their scientific validity and implications for the efficacy of treatments for autism in those up to age 21. The NAC review considered a large number of different kinds of therapies many of which are based on applied behavioral analysis or other types of behavioral therapy. Therapies were identified as beneficial "when there is sufficient evidence that we can be confident favorable outcomes resulted from the treatment" and as established when "several well-controlled studies have shown the intervention to produce beneficial effects."⁷⁵

The NAC review found that a number of different treatments were effective: "We identified 11 treatments as Established (i.e., they were established as effective) for individuals with Autism Spectrum Disorders (ASD)...There is compelling scientific evidence to show these treatments are effective; however, even among Established Treatments, universal improvements cannot be expected to occur for all individuals on the autism spectrum."⁷⁶

A second large effort to assess studies, by the State of Maine, using "laypersons, state agency staff, providers, and researchers, reviewed more than 150 studies of 43 different treatments for children with ASD."⁷⁷ The Maine study concluded that "The research clearly indicates that there are effective treatments for some core deficits and related challenges of ASD. For instance, comprehensive behavioral treatment has some of the most compelling evidence which emphasizes the importance of early and intensive intervention for children with ASD."⁷⁸

Another recent effort by Eldevik and colleagues concentrated more narrowly on early intensive behavioral intervention. These researchers reviewed studies, used meta-analysis, and attempted to improve on methodological weaknesses of prior reviews. Eldevik and colleagues focused on 34 studies including nine that used comparison or control groups. Their meta-analysis examined effects on intelligence and behavior, for which they found, respectively, large and moderate effects. "Our results support the clinical implication that at present, and in the

absence of other interventions with established efficacy, Early Intensive Behavioral Intervention should be an intervention of choice for children with autism.”⁷⁹

In slightly earlier work for a clinical report in *Pediatrics* (2007), Myers and Johnson also found substantial evidence to support the efficacy of treatments and described the kinds of gains that early intervention can bring: “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.”⁸⁰

Implications for Choice of Therapy

Some researchers argue that therapies developed with ABA have the strongest evidence base. Granpeesheh and colleagues, for example, conclude that “The only treatment that has been supported by substantial empirical research is treatment based on applied behavior analysisABA has been supported by several hundred single case experiments and an increasing number of between-groups studies....ABA treatment programs for individuals with autism are supported by a significant amount of scientific evidence and are therefore recommended for use.”⁸¹

The work by Ospina and colleagues to evaluate research across a wide range of behavioral therapeutic approaches also identifies ABA-based treatments as the most supported by current evidence, but cautions that “As no definitive behavioral or developmental intervention improves all symptoms for all individuals with ASD, it is recommended that clinical management be guided by individual needs and availability of resources.”⁸² The study by the National Autism Center evaluates effectiveness for a large number of different therapies, with many of those judged effective based on ABA or behavioral psychology; the report details the age groups, diagnoses, skills and behaviors for which they are most appropriate.

Meanwhile, families are faced with a great variety of other approaches, some using drugs, others using non-standard therapies, that offer hope and risks for children with autism, as reviewed for example by Rossignol.⁸³

Drawing Conclusions

The application of the research on autism treatments for public decision-making remains challenging. Researchers have attempted to establish the efficacy of a great variety of treatments created to help individuals with a complex, highly varied condition. Psychologists, statisticians, researchers who are expert in analysis of experimental evidence and lay people have brought their expertise and backgrounds, including biases, to the analysis. On the one hand, many of the people involved in producing the original research or reviewing it are themselves experienced therapists who may be inclined by background to identify efficacy in therapeutic work. On

the other hand, statisticians and investigators focused on medical efficacy research bring a professional skepticism and systematic methods for evaluating research; they have supported and questioned the strength of the evidence for efficacy.

Research in the next years will likely continue to bring more rigorous evaluation of the more-established and less-established treatments for autism. Future research may or may not strengthen the evidence base for the most established treatments, and may or may not address all the legitimate concerns of those who are skeptical about the efficacy of treatments. We can probably look forward to more evidence-based guidance about the benefits of different durations and intensity of therapies, and about the effectiveness of complementing established therapies with other efforts to treat children with autism.

Weighing the large review efforts of current research described above, we think it fair to say that the best-established treatments for autism have shown substantial evidence of efficacy. Skepticism about efficacy and a desire to focus treatment resources on the most effective therapies are useful guides to public discussion and should serve to encourage more efficacy research. From the point of view of parents and care providers who have the most pressing obligation to consider the best interests of children with autism, the evidence now seems strong enough to support substantial provision of therapy as being very likely in the best interests of the child. We believe that the broader public community of those who may assume some of the financial burden of this care can also regard the evidence as substantial.

Box 6: Recent Large Efforts to Analyze and Present Research on the Efficacy of Autism Treatments

Beaulieu, "Interventions for Autism Spectrum Disorders; State of the Evidence," Report of the Children's Services Evidence-Based Practice Advisory Committee, Maine Department of Health and Human Services and Department of Education, 2009.

Eldevik and colleagues, "Meta-Analysis of Early Intensive Behavioral Intervention for Children with Autism" (Journal of Clinical Child and Adolescent Psychology, 2009).

Granpeesheh and colleagues, "Applied behavior analytic interventions for children with autism: a description and review of treatment research" (Annals of Clinical Psychiatry, 2009).

Myers and Johnson, "Management of Children with Autism Spectrum Disorders" (Pediatrics Clinical Report, 2007).

National Autism Center, "National Standards Project Findings and Conclusions; Addressing the Need for Evidence-Based Practice Guidelines for Autism Spectrum Disorders," 2009.

Ospina and colleagues, "Behavioural and developmental interventions for autism spectrum disorder: a clinical systematic review" (Public Library of Science One, 2008).

Rothenberg and colleagues, "Early Intensive Behavioral Intervention Based on Applied Behavior Analysis among Children with Autism Spectrum Disorders" (Assessment Program Technology Evaluation Center of Blue Cross Blue Shield Association, 2009).

Financial Impact of Mandate

1. DHCFP is required to assess the extent to which the proposed coverage would increase or decrease the cost of the treatment or the service over the next five years.

There is no reason to expect that the mandated coverage of ABA would change the *unit* treatment costs for treating autism. However, it is reasonable to expect that those who may have been forgoing services would get ABA services if covered. In addition, the responsibility for the payment for services will change. See the responses to questions #5 and #9, in this section, for a more comprehensive explanation of the financial impact of H. 3809 and the increase in premium costs that would result.

2. DHCFP is required to assess the extent to which the proposed coverage might increase the appropriate or inappropriate use of the treatment or service over the next five years.

There is no evidence available for DHCFP to quantify the extent to which the proposed coverage might affect the appropriate or inappropriate use of the treatment or service over the next five years. Should H. 3809 become law, however, it is estimated that more individuals with ASD would receive care for diagnosing and treating ASD.

Several factors, however, complicate an assessment of the potential for the increase in the appropriateness or inappropriate use of the treatment or service over the next years, including: (1) persons diagnosed with ASD are a heterogeneous group with symptoms ranging from mild to severe; (2) treatment plans are best developed around the needs of the individual, making any universal treatment protocol difficult to establish; and (3) diagnosis of ASD lasts a lifetime, with needs changing over the lifespan.

3. DHCFP is required to assess the extent to which the mandated treatment or services might serve as an alternative to a more expensive or less expensive treatment or service.

DHCFP anticipates that the mandated services could serve as an alternative to treatments or services that are currently covered by health insurance. That is based on the understanding that individuals do not receive the level of mandated treatment or services that they demand. The mandated services could serve as a more or less expensive service depending upon what types of services are provided by the health plans today in lieu of the mandated services. However, many children with ASDs would receive therapies that will prevent the need for more expensive treatments or services in the future.

4. DHCFP is required to assess the extent to which the insurance coverage may affect the number or types of providers of the mandated treatment or service over the next five years.

The proposed legislation requires that mandated services provided using ABA techniques are provided by Board Certified Behavioral Analysts (BCBA). We would expect H. 3809 to lead to an increase in the number and type of providers of the mandated treatment or service to meet the increase in demand for ABA over the next five years.

5. DHCFP is required to assess the effects of mandating the benefit on the cost of health care, particularly the premium, administrative expenses and indirect costs of large employers, small employers and non-group purchasers.

DHCFP estimated the fiscal impact of the bill (see Appendix I) relative to the effect this mandate bill would have on care for Autism Spectrum Disorder.

- Estimated impacts of H. 3809 on Massachusetts health care premiums for fully-insured products were calculated assuming that the five-year average premium (2011-2015) for a fully-insured member is \$498 on a per member per month basis.
- Low, middle and high scenarios assumed varying prevalence. All scenarios assumed an increase in the demand for care for habilitative and rehabilitative services, including Applied Behavioral Analysis.
- Utilization rates for low, middle and high varied based on assumptions about the percentage of diagnosed children who would use services and their relative severity and costs.
- The combination of these assumptions, as well as administrative expense assumptions produced estimates of the total cost of the mandated benefits.
- These estimates exclude consideration of other areas of potential savings, such as reduced costs to school districts, among individuals diagnosed with an Autism Spectrum Disorder.
- Baseline premium levels were subtracted from the estimated total premium cost, producing estimated five-year average impacts on the premium of \$1.22, \$1.84, and \$2.45 Per Member Per Month (PMPM), to determine the cost increase due to the proposed mandate.
- The PMPMs are multiplied by the fully-insured population projection for the corresponding year to arrive at estimated annual impact dollar.

The five-year impact results are displayed in Exhibit 2. The results include three sets of estimates based on low, medium, and high impact scenario corresponding to .24%, .36%, and .49%, respectively, of premium. The five-year average of these three scenarios resulted in estimated increased total spending (including both claims spending and administrative expenses) of \$34 million, \$51 million and \$68 million, respectively.

Exhibit 2: Estimated Cost Impact of H. 3809 on Fully Insured Health Care Premiums (2011-2015)

	2011	2012	2013	2014	2015	5-Year Total
Fully Insured Enrollment	2,330,000	2,328,000	2,326,000	2,325,000	2,323,000	
Low Scenario						
Annual Impact Claims (000s)	\$15,681	\$25,643	\$34,685	\$37,183	\$38,687	\$151,879
Annual Impact Administration (000s)	\$1,960	\$3,205	\$4,336	\$4,648	\$4,836	\$18,985
Annual Impact Total (000s)	\$17,641	\$28,849	\$39,021	\$41,831	\$43,522	\$170,864
Premium Impact (PMPM)	\$0.63	\$1.03	\$1.40	\$1.50	\$1.56	
Middle Scenario						
Annual Impact Claims (000s)	\$27,466	\$38,991	\$51,067	\$54,097	\$56,286	\$227,906
Annual Impact Administration (000s)	\$3,433	\$4,874	\$6,383	\$6,762	\$7,036	\$28,488
Annual Impact Total (000s)	\$30,899	\$43,865	\$57,450	\$60,859	\$63,321	\$256,394
Premium Impact (PMPM)	\$1.11	\$1.57	\$2.06	\$2.18	\$2.27	
High Scenario						
Annual Impact Claims (000s)	\$39,250	\$52,338	\$67,448	\$71,011	\$73,885	\$303,932
Annual Impact Administration (000s)	\$4,906	\$6,542	\$8,431	\$8,876	\$9,236	\$37,992
Annual Impact Total (000s)	\$44,157	\$58,880	\$75,879	\$79,888	\$83,120	\$341,924
Premium Impact (PMPM)	\$1.58	\$2.11	\$2.72	\$2.86	\$2.98	

Note: Please see actuarial assessment in the Appendix for details on assumptions for these estimates.

6. DHCFP is required to assess the potential benefits and savings to large and small employers, employees, and non-group purchasers.

It is unlikely that this mandate would produce savings in costs to private insurers, employers and employees.

7. DHCFP is required to assess the effect of the proposed mandate on cost shifting between private and public payers of health care coverage.

The proposed mandate applies to fully-insured carriers, Health Maintenance Organizations (HMOs), and Blue Cross Blue Shield plans, as well as the GIC. DHCFP can expect three types of shifts: (1) from self-pay to health insurers; (2) from the EI program to health insurers; and (3) from school districts to health insurers to the extent that school districts modify the provision of services under IEPs. H. 3809 proposes that nothing in the legislation would affect the obligation of services provided under an IEP; nonetheless, treatments provided by school districts during non-school hours might shift to private insurance. Yet, there is no evidence to inform how much of a shift would occur.

8. DHCFP is required to assess the cost to health care consumers of not mandating the benefit in terms of out-of-pocket costs for treatment or delayed treatment.

It is reasonable to suggest that consumers would realize lower out-of-pocket costs should H. 3809 be enacted to the extent that consumers are bearing the cost of ABA services and other alternative therapies that are not covered by any other source, including health plans and school districts. Data are unavailable, however, to determine exactly how much of the “gap” in coverage is being paid today by families. DHCFP may be able to anticipate less delay in receiving appropriate treatments today, due to the presence of insurance coverage in the future, and less interruption in treatment for children graduating from EI when they turn three. Data are unavailable to determine how much treatment is delayed today and how much service interruption occurs for children.

9. DHCFP is required to assess the effects on the overall cost of the health care delivery system in the Commonwealth.

The estimated impact on health insurance premiums and spending is included in Exhibit 2 above. Should H. 3809 be enacted, the overall cost of the health care delivery system in the Commonwealth will change. DHCFP anticipates an increase in the overall level of utilization of treatments, including a shift from school districts to health insurers.⁸⁴ The overall cost of the health care delivery system will also increase because H. 3809 applies to GIC plans, and those results are not shown in Exhibit 2 above.

The Appendix includes a discussion about the effect on health care costs from GIC plans. Including the GIC in the five-year impact results in Exhibit 2 would increase the scenarios to account for medical expenses of GIC members by the following amounts, respectively: \$2.4 million, \$4.4 million and \$5.8 million, on average, over the next five years.

It is important to note that DHCFP’s assessment of the effects of the overall cost of the health care delivery system in the Commonwealth does not address the financial impact on society from expanding access to early and intensive intervention to treat individuals with ASD. More specifically, DHCFP’s assessment does not include the potential for society to realize savings from increasing access to ABA. School districts, other public agencies and families would experience financial benefits in the short run and over the life span of individuals diagnosed with ASD from individuals diagnosed with ASD receiving earlier and more continuous treatment programs.

DHCFP offers these considerations relative to the potential for savings to give some additional context to the numbers in this report. Many ask if intensive and expensive therapies are worth the cost to society. According to one recent study by Harvard University Professor Gantz, the author concludes that each child in the U.S. with autism will cost society about \$3.2 million in medical and non-medical costs over his or her lifetime.⁸⁵

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Appendix: Actuarial Review of Massachusetts House Bill 3809, An Act Relative to Insurance Coverage for Autism

**Actuarial Assessment of House Bill 3809:
An Act relative to Insurance Coverage for Autism**

Prepared for

**Commonwealth of Massachusetts
Division of Health Care Finance and Policy**

Prepared by

Compass Health Analytics, Inc.

March 11, 2010



**Actuarial Assessment of House Bill 3809:
An Act relative to Insurance Coverage for Autism**

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This report was prepared by James Highland, PhD, MHSA, Lars Loren, JD, Lisa Manderson, ASA, MAAA, and Andrea Clark, MA.

**Actuarial Assessment of House Bill 3809:
An Act relative to Insurance Coverage for Autism**

EXECUTIVE SUMMARY

House Bill 3809, before the 2009-2010 Session of the Massachusetts Legislature, mandates insurance coverage for the diagnosis and treatment of autism spectrum disorders (ASDs). The Massachusetts Division of Health Care Finance and Policy (the Division) engaged Compass Health Analytics, Inc. to provide an actuarial estimate of the effect that enactment of the bill would have on the cost of health care insurance in Massachusetts.

Compass analyzed the language of H.B. 3809 and its relationship to existing mandate laws to determine the net effect of the proposed bill on coverage requirements. We conclude that the primary impact of the bill is to broaden the set of currently mandated therapies to include intensive behavioral therapies such as Applied Behavioral Analysis (ABA) for children with ASDs. A survey of carriers also identified these services as the primary service type in the bill not currently covered by available insurance products. Compass also analyzed historical commercial payer claim data provided by the Division for 2007 and 2008 for individuals diagnosed with an ASD, and found a typical proportion of the population with an ASD diagnosis but confirmed that claims are not currently being paid for ABA and similar intensive therapies. Cost estimates for this analysis are focused on ABA; further below and in the body of the report we provide a detailed analysis of the rationale for concluding that incremental costs for other services are not material to the results. To estimate the cost of the newly mandated therapies, Compass used a population-based approach which can be summarized as follows:

$$\begin{aligned} \text{Estimated Cost} &= \text{Population Count} \\ &\times \text{Treatment Prevalence} \\ &\times \text{Incremental Cost per Child Treated} \end{aligned}$$

The population for purposes of this analysis is the approximately 2.3 million persons insured by fully-insured products subject to the Commonwealth's statutory and regulatory authority. We used a variety of methods to estimate both the "treatment prevalence" for ABA (that is, the proportion of that population that would receive ABA-type services) and to estimate the incremental cost per child treated of providing those services.

To estimate treatment prevalence of ABA for ASDs, it is important to be careful to distinguish this estimate from the diagnosed prevalence for ASDs, and from the epidemiological prevalence of ASDs estimated by the federal CDC and others. Not all those with an ASD may be diagnosed, and not all those diagnosed may receive ABA services. To estimate ABA treatment prevalence, Compass first reviewed the literature regarding the prevalence of ASDs and compared it to (i) the prevalence of individuals with any diagnosis of an ASD in the Division's claim data, to (ii) data available from Commonwealth programs that provide ABA treatment for children with ASDs, and to (iii) data on treatment prevalence where ABA is covered in other states. The values from these various sources were roughly compatible for prevalence related to diagnosis, although data from other states where coverage is in place suggest that the prevalence of treatment with ABA, even when available and covered by insurance, is significantly below both the diagnosed prevalence as evidenced by claims and below the epidemiological population prevalence estimates.

Compass also estimated the cost per child treated of providing the mandated therapies, beginning with estimates from past studies, but adjusting them to reflect that in practice not all children receiving services will receive the intensive high-acuity modality. The cost per child estimates for the recommended "intensive delivery model" often cited in the literature were adjusted to reflect more accurately the full distribution of cost per child that occurs in practice. It is the average of this cost per child distribution that we are interested in, and we assume that the average decreases the larger the treatment prevalence is assumed to be as decreasingly severe cases are added. The sources cited

above for treatment prevalence were also helpful in estimating these cost-per-child distributions.

As noted above the methodology just described focuses on ABA and related services. After careful review of H.B. 3809, existing mandates, Massachusetts claim data and data from other states we concluded that the incremental claims costs for speech, occupational, and physical therapies were immaterial for several reasons. First, carriers currently include benefits for these services in the products on the market. Second, carriers indicate that their medical necessity criteria for these therapies are based on functional limitation and not on diagnosis; H.B. 3809 does not change functional status levels or criteria. Third, current law mandates coverage for autism with parity to coverage for other medical conditions already, so H.B. 3809 does not change benefit limits for these services. Fourth, when looking at system-wide data and all individuals with an autism diagnosis (as opposed to a specific clinic where use of these services is emphasized) there is a very low proportion of ASD-diagnosed individuals using these therapy services in Massachusetts, and even fewer elsewhere where coverage for ABA is required (possibly due to a substitution effect). As a consequence, despite the apparent additional authority granted to providers by the bill for individuals with an ASD, we do not expect the passage of H.B. 3809 to change the demand and coverage for these therapies to a degree that exceeds the uncertainty already captured by the range of our estimates.

There are additional considerations in calculating the incremental costs required by H.B. 3809. One key issue is that we must consider who, other than insurers providing fully-insured products, will be paying for ABA services for the members of those products. If we were to use the basic population-based estimate directly, we would in effect be assuming that all costs for the fully-insured population would be paid for by the carriers. However, school districts in Massachusetts currently pay for significant amounts of ABA and related services for children with an ASD. If the bill were to pass, the degree to which ABA costs currently paid for by school districts would be shifted to health insurance payers, especially as time passes and school districts become more familiar

with the effect of the bill, is difficult to determine precisely¹. Therefore we have incorporated a range of estimates for how much the schools would continue to bear (and therefore how much should be subtracted from the population-based estimate) to arrive at overall impact estimates on commercial premiums. We made no such adjustment for services paid for by Early Intervention programs, assuming that all costs would shift to commercial payers since DPH is the payer of last resort. We also allow that expense for ABA would likely be damped for the first few years as providers ramp up to meet the demand. Finally, Compass added adjustments for administrative expense and risk/profit estimates for insurers to arrive at the total cost to premium payers.

The average net premium cost of H.B. 3809 over the next five years for fully-insured plans that would be subject to the proposed mandate ranges from approximately \$34 million to \$68 million per year, adding 0.24 to 0.49 percent to premiums. The table below summarizes the five-year effect on costs.

Summary Table

	-2011 -	-2012 -	-2013 -	-2014 -	-2015 -	- Average -
Members	2,330,000	2,328,000	2,326,000	2,325,000	2,323,000	
Med Exp Low (\$K)	\$ 15,681	\$ 25,643	\$ 34,685	\$ 37,183	\$ 38,687	\$ 30,376
Med Exp Mid (\$K)	27,466	38,991	51,067	54,097	56,286	45,581
Med Exp High (\$K)	39,250	52,338	67,448	71,011	73,885	60,786
Premium Low (\$K)	\$ 17,641	\$ 28,849	\$ 39,021	\$ 41,831	\$ 43,522	\$ 34,173
Premium Mid (\$K)	30,899	43,865	57,450	60,859	63,321	51,279
Premium High (\$K)	44,157	58,880	75,879	79,888	83,120	68,385
Low PMPM	\$ 0.63	\$ 1.03	\$ 1.40	\$ 1.50	\$ 1.56	\$ 1.22
Mid PMPM	1.11	1.57	2.06	2.18	2.27	1.84
High PMPM	1.58	2.11	2.72	2.86	2.98	2.45
Est Mo. Premium	\$ 442	\$ 468	\$ 496	\$ 526	\$ 558	\$ 498
Premium % Rise Low	0.14%	0.22%	0.28%	0.28%	0.28%	0.24%
Premium % Rise Mid	0.25%	0.34%	0.41%	0.41%	0.41%	0.36%
Premium % Rise High	0.36%	0.45%	0.55%	0.54%	0.53%	0.49%

¹ The bill's language could be interpreted to require schools to continue paying for services, but the language does not appear to be definitive. Services outside the school day would likely shift and in general "creep" would be difficult to avoid.

Note particularly that the need to ramp up provider systems and the time lag in any shifting of costs from special education to health insurers dampens costs in the early years, and ongoing average costs will be higher.

The impact on plans provided to state employees by the Group Insurance Commission (G.I.C.), which are also subject to mandate, is assumed to have the same PMPM impacts as noted above, and at an assumed membership (not including Medicare eligible retirees) of 233,000, annual costs would range from \$2.3 million in 2011 to \$5.6 million in 2015, not including incremental administrative costs.

It is important to note that the annual medical care cost estimates contained herein should be considered in the context of potential societal savings outside the medical care system, including those realized in education, social security payments, and in workplace productivity.

In presenting these results, we recognize that other analyses have been made available to the Legislature, including one sponsored by Autism Speaks, performed by Oliver Wyman, and one sponsored by the Massachusetts Association of Health Plans, performed by the Taylor Feldman Group. Each of those analyses, and this one, uses different assumptions and methods. Appendix A summarizes the differences with detailed explanations of the calculations used to make the reports' results comparable. The five-year average "middle scenario" results appear below².

We note that when the middle scenarios are adjusted to a comparable 5 year average, our results of \$51 million are significantly below Taylor Feldman's approximate \$82M annual cost, and somewhat below the \$58 million estimated by Oliver Wyman. Though not computable from the information presented, the comparable amount calculated from the Oliver Wyman report (\$58 million) appears to include costs for ABA (which constitute our entire \$51 million estimate) perhaps somewhere in the \$30-\$40 million

² Note that many of the figures from the other studies referenced were not explicitly presented in those reports and are approximated for comparison, including removal of costs associated with self-insured plans not subject to benefit mandates.

range (see Appendix A), with some of the remainder for non-ABA services such as speech therapy.

Comparison of Analyses of H.B. 3809

Report Sponsor	Autism Speaks	Massachusetts Health Plans	DHCFP
Author	Oliver Wyman	Taylor Feldman Group	Compass Health Analytics
Likely average annual cost , from report	\$60M (2009 dollars, not 5-year)	\$123M (2010-2014 average including self-insured)	\$51M (2011-2015 average)
Approximate 2011-2015 average annual cost, adjusted for membership, premium, FI only	\$58M	\$82M	\$51M
2011-2015 average PMPM with retention	\$2.09	\$2.95	\$1.84
2011-2015 percent of premium	0.42%	0.59%	0.36%
Underlying assumptions:			
Estimated Prevalence of treatment for ASDs	6.7 per thousand	9.0 per thousand	4.5 - 9 per K treatment prevalence
Member base	Fully insured members (~2.2M)	All privately insured (~4.1M)	Fully-insured members (~2.3M)
Insurers' retention (non-claims) % of premium	15%	None estimated	12%
Non-ABA services	Included	Included	Immaterial net impact (see section 3.4)

The primary factors explaining the lower results in this report are that adjustments were made for all of the following factors³: (i) inclusion of evidence on the degree to which treatment prevalence for ABA tends to be significantly lower than epidemiologic prevalence of ASDs even when coverage is present (see section 5.3); (ii) lower average cost for treatment to reflect the bill's allowance for credentialed professionals to supervise less expensive staff in delivery of service (see section 5.4); (iii) lagged response in demand (awareness) and supply (provider capacity) typical of benefit expansions (see section 5.7); (iv) no inclusion of incremental costs for occupational and other therapies due to existing coverage for functional problems requiring use of these services (see

³ The other reports adjusted for some but not all of these factors.

Section 3.4) and (v) reductions to full population-based estimates on commercial claims costs to reflect current school district spending on these services continuing at least in part (see section 5.6)⁴. Less significant, but also partly responsible for lower premium cost estimates, were a reduction to reflect patient cost sharing (a small fraction of the cost will be borne by individuals rather than the insurer), as well as the use of 12% insurer retention, consistent with recent evidence on administrative costs and profit.

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⁴ The bill could be interpreted to require no costs to be shifted from school districts; the Compass analysis assumes that some services shift over time, as discussed in more detail in the body of the report.

**Actuarial Assessment of House Bill 3809:
An Act relative to Insurance Coverage for Autism**

1. INTRODUCTION

House Bill 3809, before the 2009-2010 Session of the Massachusetts legislature, mandates insurance coverage for the diagnosis and treatment of autism spectrum disorders (ASDs). The Massachusetts Division of Health Care Finance and Policy (the Division) engaged Compass Health Analytics, Inc. to provide an actuarial estimate of the effect that enactment of the bill would have on the cost of health care insurance.

Assessing the cost impact entails analyzing the incremental impact of the law on spending for those insurance plans subject to the proposed law. This in turn requires estimating costs under the provisions of the proposed law and comparing that projection to costs under current statutes and current benefit plans, for the relevant services.

Under current law, insurers offering health insurance in Massachusetts are already required to provide at least some services to treat ASDs:

- The current Massachusetts mental health parity law⁵ lists autism among the biologically-based mental illnesses for which insurers must provide coverage on a non-discriminatory basis (as defined above).
- Some early intervention services for children under three are mandated, with dollar limitations, by laws requiring dependent coverage for children⁶.
- Finally, the federal Wellstone-Domenici Mental Health Parity Act of 2008⁷ requires large group health plans (over 50 members) to cover treatment for mental illness on the same terms and conditions as all other illnesses.

Finding in H.B. 3809 an incremental effect on insurers, beyond existing mandates, requires that the bill expand mandated services and/or materially change insurers' ability

⁵ G.L. c. 175, § 47B, G.L. c. 176A, § 8A, G.L. c. 176B, § 4A, G.L. 176G, § 4M, G.L. c. 32A, § 22. Current mental health parity law does not require coverage for unlimited visits.

⁶ G.L. c. 175, § 47C, G.L. c. 176A, § 8B, G.L. c. 176B, § 4C, G.L. 176G, § 4. Coverage for medically necessary early intervention services, up to \$5,200 per year.

⁷ 29 U.S.C. § 1185a (section 712 of ERISA). The 2008 act expands on a 1996 act that required parity, but only for annual and lifetime dollar limits.

to review utilization and deny coverage for medical necessity reasons. The degree to which the law incrementally affects covered services and application of medical necessity criteria is discussed in Section 2.

The estimate of incremental cost requires converting the proposed law's requirements into estimates of incremental benefit use and prices paid for those benefits. Section 3 discusses a variety of important considerations in translating H.B. 3809's language into estimates of incremental benefit use and in estimating average prices paid for those benefits. Section 4 describes the basic methodology used for the analysis while Section 5 walks through the steps of the analysis and its results.

2. INTERPRETATION OF H.B. 3809

Interpreting H.B. 3809 entails specifying which insured populations are required to follow its provisions, what benefit requirements are being added, and how rules for determining when those benefits are and are not payable are affected.

2.1 Insurance entities subject to H.B. 3809: Fully-insured plans and GIC

H.B. 3809 amends the statutes that regulate insurers providing health insurance in Massachusetts. The bill has the following five sections, each addressing statutes dealing with a particular type of health insurance policy:

- Section 1: Insurance for persons in service of the Commonwealth (creating G.L. c. 32A, § 24)
- Section 2: Accident and sickness insurance policies (creating G.L. c. 175, § 47U)
- Section 3: Contracts with non-profit hospital service corporations (creating G.L. c. 176A, § 8AB)
- Section 4: Certificates under medical service agreements (creating G.L. c. 176B, § 4S)
- Section 5: Health maintenance contracts (creating G.L. 176G, § 4R)

Sections 2 to 5 apply to individual and group policies issued within or without⁸ the Commonwealth. All sections mandate coverage for residents of the Commonwealth and to policyholders having a principal place of employment in the Commonwealth.

Health insurance plans operated as self-insured entities (i.e., the employer policy holder retains the risk for medical expenditures and uses the insurer to provide administrative functions) are subject to federal law, and not to state-level mandates. Note Section 1 of the bill directs the commissioners of the Commonwealth's own largely self-insured employee plan (the Group Insurance Commission, or GIC) to provide autism coverage.

2.2 Benefits covered: Applied behavioral analysis the key incremental benefit

H.B. 3809 mandates coverage for the diagnosis and treatment of autism spectrum disorder⁹ in individuals, with no limitation on age, on a "non-discriminatory basis", meaning the policy can contain no annual or lifetime dollar or unit of service limitation for autism treatment less than any limitation that applies to physical conditions. Furthermore, autism coverage will be subject to no limits on visits to an autism services provider.

The bill includes in the treatment of ASDs the following types of services:

- a) Habilitative or rehabilitative care
- b) Pharmacy care
- c) Psychiatric care
- d) Psychological care
- e) Therapeutic care

Except for item (a), habilitative or rehabilitative care, the services on this list are typically covered by Massachusetts health insurers. In some contexts beyond this bill, habilitative

⁸ This analysis does not attempt to deal with whether H.B. 3809 has any effect on policies issued outside of the Commonwealth, even if their members include Massachusetts residents.

⁹The bill defines "autism spectrum disorder" to mean any of the Pervasive Developmental Disorders (PDD) as defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), including Autistic Disorder, Asperger's Disorder, and PDD Not Otherwise Specified.

services are defined as not medical but educational. However, H.B. 3809 defines item (a) as “professional, counseling, and guidance services and treatment programs, including applied behavior analysis supervised by a Board Certified Behavior Analyst, that are necessary to develop, maintain, and restore, to the maximum extent practicable, the functioning of an individual”.¹⁰ Thus, the services for which coverage is mandated in the bill explicitly include intensive therapies such as Applied Behavioral Analysis (ABA), which most commercial policies do not currently cover, rendering irrelevant, for purposes of this analysis, questions of whether such services are “educational” and therefore arguably outside traditional interpretations of “medical” service. Similarly, its mandated inclusion as a benefit also largely removes consideration of efficacy as an issue in this cost estimation. Since efficacy is a key consideration in whether benefits are included in health insurance policies for coverage, and the coverage is mandated, there is no question about whether coverage would be included. Where efficacy may be situation or sub-population specific, it becomes a medical necessity issue, which we discuss next.

2.3 Benefit interpretation: Providers “determine care to be medically necessary”

Among the terms and conditions under which insurers typically cover healthcare services is the requirement that the service be “medically necessary”; that is, any covered benefit will be paid for by the insurer only if the service meets medical necessity criteria.¹¹ So, for example, while a hip replacement is a covered benefit, it would not be medically necessary for a completely healthy 20 year old.

Most benefit mandates refer to “medically necessary services.” H.B. 3809 also contains language addressing medical necessity, however, its language provides that covered care must be “prescribed, provided, or ordered for an individual diagnosed with one of the autism spectrum disorders by a licensed physician or a licensed psychologist who determines the care to be medically necessary”. Whether the bill regards the prescriber’s determination of medical necessity as sufficient or merely necessary is open to question.

¹⁰ Subsection (f) 6 of each of the major sections of H.B. 3809. The structure of the paragraph implies that the requirement for supervision by a Board Certified Behavior Analyst applies only to applied behavioral analysis and not to other habilitative or rehabilitative services.

¹¹ We assumed existing mandate laws retain this requirement, and that it would apply to H.B. 3809 as well.

It allows the interpretation that the physician/psychologist is the arbiter of medical necessity, not subject to the review of the insurer. We expect that many providers will deem ABA to be efficacious and will in many situations deem it medically necessary. However, the bill does not explicitly address the insurer's role in determining medical necessity, arguably leaving the general terms of the policy intact, and those terms typically allow the carrier to review medical necessity and utilization. We doubt the practical effect of the mandate would be to remove all oversight from the hands of the insurers (especially after insurance regulatory bodies provide additional guidance). But we acknowledge the bill's language leaves open the possibility that insurers' ability to restrain utilization would be somewhat limited.¹²

2.4 Summary of key points in interpretation of H.B. 3809

For the purposes of this analysis, Compass assumes the intent of H.B. 3809 is to expand the services covered in fully-insured products for the treatment of ASDs and to loosen the standards under which insurers cover the services. Specifically:

- The mandate applies to fully-insured commercial policies regulated by the Division of Insurance and plans covering government employees (GIC).
- H.B. 3809 explicitly includes, in mandated services habilitative and rehabilitative services, intensive therapies, such as ABA, intended to improve the functioning of children with ASDs. These services are not typically covered by commercial health insurance policies.
- Despite (and without evaluating either side of) disagreements in the literature about the efficacy of ABA and related therapies, for purposes of this analysis Compass assumes the bill's authors find that at least some of these therapies are efficacious and not experimental, and that providers will often deem them medically necessary. And furthermore we assume the bill's language provides a significant degree of control by a prescribing physician or psychologist about whether the therapies are medically necessary, and that the bill's language leaves open the possibility that insurers' ability to restrain utilization would be somewhat limited.

¹² H.B.3809 includes no reference to external standards. Bills in other states, e.g., H.B. 569 in New Hampshire, sometimes incorporate standards, such as the autism treatment standards of the American Academy of Pediatrics, which might impose some limits on utilization.

Several important considerations in applying these interpretations to the analysis are discussed in the next section.

3. FACTORS AFFECTING THE ANALYSIS

Given the interpretations of H.B. 3809 discussed in Section 2, there are several specific issues to consider in translating that interpretation into an analysis of incremental cost.

3.1 Efficacy of treatments for ASD

As noted in Section 2, H.B. 3809's inclusion of ABA and "habilitative care" removes for this analysis the issue of whether ABA is medical or educational, and shifts significant control over determination of medical necessity to the provider. The analysis of the full impact of H.B. 3809, in support of which this analysis appears, summarizes current views on the efficacy of ABA and similar intensive therapies in the treatment of autism. For purposes of this analysis, we assume that in specifying ABA and similar therapies in the body of H.B. 3809, the bill's author finds such therapies to be efficacious.

Even if these intensive therapies are efficacious for some portion of the population with an ASD, they are not necessarily efficacious for all portions, and this analysis will attempt to account for those variations. In particular, we will assume that carrier utilization review will tend to restrain the use of these therapies on populations, such as adults, for which little or no evidence of efficacy exists.

3.2 ABA and related therapies: Provider supply

Coverage and provider networks are well-established for most of the services listed in H.B. 3809, including medical and psychological services. And carrier surveys performed for this analysis re-emphasize that carriers typically cover physical, speech, and occupational therapy services. But as noted above, H.B. 3809 defines "habilitative or

rehabilitative care" to include ABA, a service typically not covered under most commercial plans.

Assuming most of the services incrementally mandated by H.B. 3809 would be ABA and similar services, limitations in the supply of ABA practitioners might affect the cost of the mandate to insurers by limiting the number of clients who could receive service in a given period, effectively restraining utilization.

H.B. 3809 requires mandated ABA services to be supervised by a Board Certified Behavior Analyst, specifically a behavior analyst credentialed by the Behavior Analyst Certification Board (BACB), nonprofit corporation located in Florida. Such certification typically requires a master's degree with appropriate coursework and substantial experience in the therapeutic techniques specific to ABA. Massachusetts has approximately 637 board-certified ABA practitioners, of which 576 are masters or doctorate level Certified Behavior Analysts, and the remainder carry a lower, bachelors-level certification.¹³

The delivery of ABA services often involves more than one level of practitioner, with a highly-credentialed practitioner evaluating the person in need of service, specifying the treatment, and monitoring the delivery of the service and the progress of the client. The actual delivery of the therapy, typically one-on-one and time-consuming, is often performed by less highly-credentialed practitioners working under supervision. H.B. 3809 requires insurers to cover properly-prescribed ABA services supervised by a (master's-level or higher) Board Certified Behavior Analyst, and sets no requirements for other practitioners involved.

Current Massachusetts law does not require BACB certification for persons supervising ABA. And in some cases, ABA services are currently supervised by practitioners with

¹³ See www.bacb.com. Counts shown include certificants not listed in the online registry. Not all are necessarily actively practicing ABA at this time.

other credentials, notably some licensed by the Board of Registration of Psychologists.¹⁴ H.B. 3809 requires only that properly-prescribed services supervised by a certified practitioner must be covered by commercial insurance policies. The bill does not preclude an insurer from covering ABA supervised by a psychologist or practitioner credentialed through some other process (though that is also true at present and so we would not expect the bill to have an incremental cost impact on services from non-certified practitioners).¹⁵

If the 576 certified behavior analysts in Massachusetts were responsible for supervising therapy for the approximately 6,600 children with an ASD in fully insured plans¹⁶ (approximate count, regardless of whether diagnosed), the ratio of children to practitioners would be a little over 11:1. Projecting the ability of these practitioners to absorb new demand is difficult in that there are a number of offsetting factors. On one hand, the treatment regimen is time-intensive and practitioners have ongoing practices and would not drop all their current work and turn to ABA practice for this population (though some ABA work would be occurring already as out-of-pocket service and would now be covered). But on the other hand, delegation is allowed to staff with lower credential levels to deliver this service under supervision, and not all diagnosed children will be referred or in treatment at the same time. So the actual average caseload is not knowable, but assuming the geographic distribution of analysts does not limit the availability of services¹⁷, it is unlikely the supply of supervisory analysts will constrain the availability of services should it pass, beyond a reasonable startup period following the effective date of the mandate (discussed in the “Timing” section further below).

¹⁴ Interview with Director, Office of Specialty Services, Massachusetts Department of Public Health, 12/30/09.

¹⁵ Another pair of bills before the Legislature, H.B. 181 and S.B. 47, would impose criminal penalties on anyone practicing ABA without a license. These bills establish two levels of practitioner, at the doctorate and master’s levels, and define the scope of practice of ABA to include conducting ABA-based therapy, as well as planning and supervision services. We will not determine at this time whether the bills allow for someone other than a doctorate or master’s level practitioner to deliver, with supervision, the one-on-one, time-consuming behavioral therapy at the core of ABA, but if they do not, they could constrain the supply of ABA providers. For purposes of this analysis of H.B. 3809, we cannot assume these proposed licensing bills are in effect, and must ignore their potential effect on the practitioner supply.

¹⁶ Roughly, 10 per thousand from approximately 660,000 children in the FI pool.

¹⁷ This assumption might be supported by recent studies showing greater prevalence of ASDs in more educated areas. See, e.g., <http://www.npr.org/templates/story/story.php?storyId=122256276>

Of greater concern is the supply of (typically less highly-credentialed) practitioners to provide the bulk of the ABA services. Data on this group are less clear. While growth in the supply of practitioners, in response to greater demand resulting from the mandate's passage, will eliminate any shortage over time, it is reasonable to assume that the effect on covered costs of any large increase in the demand for services will be delayed somewhat as new resources become available.

Therefore, this analysis will assume the supply of supervising ABA practitioners is not likely to affect the cost of H.B 3809 to insurers to a significant degree.

- H.B. 3809 allows for delivery of intensive one-on-one services by non-certified practitioners, leveraging the supply of supervisory practitioners
- H.B. 3809 affects only ABA services for fully-insured commercial health plans, setting no requirements for other insurance plans, and practitioners credentialed by boards other than the BACB can supervise ABA for services covered by insurers other than those targeted by H.B. 3809 (including Medicaid).
- Given the near-universal nature of the current early intervention program, which includes an ABA component, we do not expect the provider supply to limit payments for children in that age range since those services are already being provided and only the payment source will shift.

We will, however, incorporate estimates for the potential delay caused by limits in the growth of the supply of less highly-credentialed practitioners.¹⁸ During the first few years expense will be constrained as the provider system becomes engaged to meet the demand for services.

3.3 ABA and related services: Demand and cost shifting

We expect that the availability of commercial coverage will, over time, increase awareness level, referral frequency, and access to services, and factors for this gradual increase are included in our estimation process that is discussed in detail in sections 4 and 5. Another key factor in estimating demand is the current availability of a variety of publicly financed programs for the ASD population. This must be considered at the

¹⁸ Incorporating ABA providers into provider networks will also place a transitory incremental administrative burden on insurers.

outset, because any population-based cost estimates of ASDs must subtract costs that will be paid for by public programs. In addition, the allocation of ASD services across public and private programs affected by the passage of H.B. 3809 is likely to vary over time; therefore the timing of any cost shifting should be considered.

A person with an ASD might currently receive the services listed in H.B. 3809 from any of several public or private programs in health care, education, or other social support systems. The extent to which coverage mandated under the bill might offset costs currently borne by public health care or education programs will be part of any debate about the bill.

H.B. 3809 is not likely to affect greatly the allocation of traditional medical services among commercial insurance or public programs, since commercial coverage for these is not altered by the bill. In contrast, mandating commercial coverage for ABA and other intensive therapies might alter the current allocation between insurers and public programs for these therapies.

Depending on his or her age, income, clinical needs, or degree of disability, a person with an ASD might receive publicly-funded ABA (or similar) services from the Early Intervention Program (Office of Specialty Services in the Department of Public Health), the MassHealth autism waiver, or special education programs provided by local school districts.

Early intervention programs

The Department of Public Health provides a near-universal program of early intervention for children up to 36 months of age. Within that department the Specialty Services program provides ABA and similar services, which served 1,321 children at a cost of \$11.2 million in FY 2009.

Roughly 60% of these children are commercially insured.¹⁹ Some of these children receive services for which H.B. 3809 will require commercial insurers to pay. DPH is the payer of last resort and will look to commercial insurers for the costs of these services for eligible children. Given that DPH will shift whatever costs it can, we do not need to estimate, for the purpose of this analysis, the shifted dollars, since we will be estimating the costs of serving these children as part the cost of serving the general insured population.²⁰

It is likely, given DPH's advocacy and active involvement in meeting the needs of this population, that the ramp-up time for exploiting the mandate will be less for these very young children than for other portions of the population with an ASD. We account for this effect in our analysis of the time ABA spending will take to ramp up after the effective date of the mandate bill.

Autism waiver

Through MassHealth, Medicaid provides some funding for services for children with an ASD. For a limited number of children (up to 110) under the autism waiver, some of these services may include some ABA, and MassHealth, as the payer of last resort, would look to commercial insurers for the costs of these services if any of the recipients had commercial insurance. However the Department of Health and Human Services estimates that few of these children have commercial insurance.²¹ Therefore a substantial cost shift from public to private resources is unlikely. And even if it occurs, given that DPH will shift whatever costs it can, we do not need to estimate, for the purpose of this analysis, the shifted dollars, since we will be estimating the costs of serving these children as part the cost of serving children in the general insured population.

¹⁹ Interview with Director, Office of Specialty Services, Massachusetts Department of Public Health, 12/30/09. We do not know how many are in fully-insured or GIC plans subject to the terms of H.B. 3809.

²⁰ Nonetheless, we can crudely estimate that if 60% of the children are insured, and 60% of that pool is fully-insured and therefore affected by the bill, and 70% of the Specialty Services budget – an estimate from the Office – is used for ABA, then approximately \$2.8 million would shift. Note this is very rough because the per-capita demand for service may not be the same for Medicaid and commercially-insured populations, and self-insured plans might pick up ABA coverage over time.

²¹ Interview with staff of MassHealth, DDS, 1/7/10.

Special education programs

Local education authorities (LEAs, e.g., school districts) in Massachusetts provide substantial services to children with an ASD. The type and amount of services provided by school districts to these children varies widely across LEAs, but many provide at least some ABA and related services to children either in preschool programs or in programs for school-age children in settings ranging from special classes to residential placement. Estimates of special education spending in general, and of the number of children with autism, are available; however the amount of spending on ABA and similar services is not.

Many of the children receiving ABA from an LEA live in households covered by commercial insurance. To the extent that schools continue to pay for ABA, estimates of cost based on overall commercial population treatment prevalence and cost per treated child will double count those dollars that would continue to be paid by the schools. As a result, we must estimate the approximate amount schools will continue to pay, and subtract it from our first-pass “gross estimates,” which are based on population-wide parameters.

H.B. 3809 provides that it “will not be construed as affecting any obligation to provide services to an individual under an individualized family service plan, an individualized education program, or an individualized service plan.” For purposes of this analysis we cannot determine if the language of the bill refers only to existing programs and service plans, or to the LEAs’ general obligation to provide these services in the absence of H.B. 3809. The bill’s authors might anticipate little, if any, shift from the schools to insurers, meaning we should deduct, from population-based estimates of cost of ABA services for all commercially-insured children, the cost borne by the LEAs. However, it seems unlikely that, over time, no costs will shift. Officials in LEAs involved in drafting individualized education plans will understand the effects of the mandate and will have an incentive to shift costs as new plans are drafted. At the least, the costs of any services

provided for school-age children by the LEA, but outside of the school day, are likely to shift.

We do not have data on actual school expenditures for ABA. Instead, we will make a range of assumptions about the portion of the cost of ABA for school-age children that will be borne by the schools and include that range in those factors affecting the range of our final estimate. Any shifting of costs from schools to private payers is likely to be gradual and we will incorporate this into our timing estimates.

Demand unmet by current programs and demand growth

While we must account for and adjust for the services that will continue to be paid for by existing programs, passage of H.B. 3809 will likely trigger a significant increase in the measured demand for services to treat an ASD in Massachusetts. Despite the availability of public programs in many parts of the state, the lack of uniformity across school districts and the cost of funding ABA and similar therapies out-of-pocket suggest that there are a significant number of children with an ASD not receiving care that would be covered under the mandate. Allowance for demand growth for commercial insurers is included in our estimate. Our estimate does not account, however, for the possibility that families with a child with ASD may choose to move to Massachusetts, or seek out employers with a policy issued in Massachusetts, to help alleviate their financial burden.

3.4 Services other than ABA

The average child with an ASD might have medical costs, other than ABA costs, that are greater than costs incurred by the average child from the general population.²² Even if true, existing health benefits, including typical coverage provisions and those required by

²² The study performed by Oliver Wyman for Autism Speaks cites studies finding that insurers paid for non-inpatient medical services for children with ASDs at a rate approximately three times the average for all children. Actuarial Cost Estimate: The Commonwealth of Massachusetts House Bill 3809. Oliver Wyman, May 4 2009.

mental health parity mandates, already cover these services and so these costs would not be incrementally caused by H.B. 3809.

H.B. 3809 requires that insurers cover, in a non-discriminatory fashion, a full range of services related to the treatment of an ASD. However, existing federal and state mental health parity mandates, particularly the state mandate²³, already identify autism as a biologically-based mental illness that must be covered on a non-discriminatory basis.

Note we have assumed that H.B. 3809 likely grants the prescriber some additional discretion in determining what treatment is medically necessary, and in theory a provider might prescribe non-ABA services that might not pass current carrier utilization review, thereby raising costs. However, responses to the carrier survey, in describing the criteria for evaluating medical necessity, particularly for restorative therapies (OT, PT, speech), emphasized the evaluation of functional limitations as the issue in determining medical necessity, rather than the clinical condition causing those limitations.

Finally, it is possible that coverage for ABA services might in effect drive down use of other services. This might occur because some therapy services may now be used in part as an imperfect substitute for non-covered ABA services, and in part because early use of ABA may reduce later demand for these other services.

Weighing these considerations, we assume H.B. 3809 does not, on net, imply incremental costs for these other services. In order to test this assumption, we analyzed 2008 claim data from the Division's database of fully insured individuals. We found that only about 8% of individuals with an autism diagnosis had a restorative therapy claim, and the mean claim amount among those was approximately \$1,600, for a mean among all individuals with an ASD diagnosis of \$115. Since it appears to be rare for individuals to use these services and rarer still to approach typical benefit limits, and since criteria for accessing these services are based on functional rather than diagnostic criteria, the data appear to

²³ G.L. c. 175, § 47B, G.L. c. 176A, § 8A, G.L. c. 176B, § 4A, G.L. c. 176G, § 4M, G.L. c. 32A, § 22. Current mental health parity law does not require unlimited visits.

support the assumption that the cost impact owing to H.F. 3809 for other services is immaterial.

3.5 Timing factors

This analysis provides an estimate of the cost of this mandate for five years from its effective date. Our analysis will account for:

- Membership trends
- Cost inflation: We assume an annual per-service cost increase of four percent, measured from 2010 and raising the value for 2011 and on.²⁴
- Supply and demand: As noted, while the supply of providers will eventually be adequate to meet the demand for ABA and related services, it will take time to reach that level. Likewise, potential clients and their families will take time to exploit the mandate's provisions. Therefore we assume costs will be constrained in the first few years.
- Shift from education: Any shift in ABA costs from school systems to insurers will take several years to occur.

3.6 Societal benefit

Supplementing these calculations, the full analysis of H.B. 3809 to which this report is attached addresses the broader issues of potential societal benefit from the bill. The medical care costs that are the subject of this actuarial analysis should be considered in the context of potential societal savings outside the health care system, including those realized in education, social security payments, and in workplace productivity.

Measurement of these benefits is outside the scope of this analysis.

²⁴ Slightly higher than the 3.5 percent trends reported for HMO's in www.mass.gov/lhqcc/.../2009_04_01_Trends_for_Fully-Insured_HMOs.doc and <http://www.mass.gov/Eoca/docs/doi/Consumer/MAHMOTrendReport.pdf>

4. METHODOLOGY

4.1 Analysis steps

This analysis takes the following approach to evaluating the potential costs of H.B. 3809:

1. Estimate the population covered by the mandate; i.e., identify the types of policies affected and estimate the number of covered individuals.
2. Measure past use (per member) and expenditures for ASD-related services for members with an ASD in Massachusetts.
3. Obtain estimates of prevalence of ASDs, by age group. Corroborate with other sources.
4. Estimate (ranges for) the per user cost of services for ASD, by age group
5. Estimate the gross program costs by combining prevalence and cost per user data
6. Estimate the portion of ABA service costs that will remain within school systems, by age group
7. Estimate (ranges for) the net change due to the mandate in medical expenses billed to health insurers for the next five years, including consideration of ramp-up factors
8. Estimate the net effect on health insurance premiums by accounting for insurers' administrative expenses and margin

Two critical factors in estimating the net cost to the health care system of H.B. 3809 are the prevalence of ASDs within the population and the incremental cost of newly mandated services (ABA). Estimates of these factors are subject to substantial variation; in this analysis we establish a reasonable range of costs that the Division and the Legislature can use in evaluating the bill.

4.2 Data sources

The primary data sources used in the analysis were:

- Government reports and data, including information on delivery of services for ASD in other states, and academic literature, cited as appropriate.

- Claims: The Division provided Massachusetts data from its all-payer claim database for claims containing any ASD-related diagnosis for almost all plans affected by H.B. 3809.
- Membership data: The Division provided membership data for the plans represented in the all-payer claim data. We also used other studies prepared for the Division, supplemented with U.S. Census data to derive trends by age group.

The step-by-step description of the estimation process below addresses limitations in some of these sources.

5. ANALYSIS

5.1 Estimating the insured population affected by the mandate

H.B. 3809 applies to residents of the Commonwealth and to policyholders having a principal place of employment in the Commonwealth, covered under individual and group health insurance policies regulated by the Commonwealth, under which the policy holder is fully-insured (not self-insured), and to people insured under one of the plans operated by the G.I.C.

We estimate the number of people affected by the mandate at 2.3 million, including members of fully-insured plans, but excluding the G.I.C. plans.²⁵ This number is smaller than the approximately 4 million Massachusetts residents covered under non-government health plans, as estimated by the Kaiser Family Foundation.²⁶ As noted, H.B. 3809 does not apply to self-insured plans (other than the G.I.C.) and residents covered thereby are not included in this analysis. Also, H.B. 3809 effectively applies to insurance regulated by (issued in) Massachusetts, and residents who commute to other states and are insured

²⁵ The Division's membership data, representing the plans contributing to its all-payer claim database, contains 2.9 million, of which 1.7 million are fully-insured and 1.2 million self-insured. Non-residents who work in Massachusetts and are insured by policies issued in Massachusetts are included in the population affected by the mandate and in the 2.3 million; however they are not present in the Division's data. We will assume that age and other breakdowns we obtain from the Division's data apply proportionately to the nonresidents as well.

²⁶ Kaiser Family Foundation, "Massachusetts: Health Insurance Coverage of the Total Population, states (2007-2008)", accessed 1/26/10, <<http://www.statehealthfacts.org/profileind.jsp?ind=125&cat=3&rgn=23>>

in those states are generally not included in insurance roles, nor in this analysis. Finally, this analysis does not include individuals with Medicare coverage and commercial “medigap” policies, as these policies are tied to Medicare benefits and cover patient cost-sharing within the Medicare benefit structure. We have excluded populations over age 64.

To the extent that employers who purchase self-insured plans want to offer employees plans that meet the standards to which fully-insured plans are held, H.B. 3809 may have the effect of increasing coverage of ABA services, and therefore premiums, for self-insured plans. However, this analysis will focus on the direct effect of the mandate.

Table 1 shows the estimate of the relevant insured subpopulations, excluding fully-insured G.I.C. plans.²⁷

Table 1: Membership (projected 2011)

Age	Members
Adult (<65)	1,669,000
Child 5-19	502,000
Child 0-4	159,000
Total	2,330,000

5.2 Measuring current claims costs for persons with an ASD diagnosis

Using carrier claim data, provided by the Division, we measured the amount paid per user for 2008 claims carrying an ASD-related diagnosis.²⁸ Table 2 provides a brief summary, showing the per-user amounts paid for current standard therapies (physical, speech, and occupational), behavioral health services, other services, and pharmacy.

²⁷ The membership data use age breakouts defined by the Division for its all-payer claim database.

²⁸ The carriers differed somewhat in how they define a diagnosis of ASD. After review we used the most common definition across carriers, i.e., an ICD code beginning with 299. Variations from this definition were found in smaller carriers and make little difference in the averages across all carriers. We assume no claims with 2008 service dates remain unprocessed.

Table 2: Per User Amount Paid for 2008

Plan	Age	User Count	Therapies (OT, ST, PT)	Behavioral Health	Other Medical	Total
Commercial FI						
	Adult (<65)	727	\$ 6	\$ 614	\$ 631	\$ 1,251
	Child 5-19	5,253	124	567	1,022	1,712
	Child 0-4	1,151	148	509	1,308	1,964
All members		7,131	\$ 115	\$ 563	\$ 1,023	\$ 1,701

The main lesson of Table 2 is that per-user expenditures by commercial insurers for behavioral health services and standard therapies for people with a diagnosis of autism are relatively low, particularly when compared to the cost of ABA and other intensive therapies potentially mandated by H.B. 3809, discussed below. These data were also used as one source of assessing the prevalence of ASD diagnoses in Massachusetts.

5.3 Prevalence of ASDs and estimated user counts for ASD services

Population Prevalence

Epidemiological estimates of the prevalence of ASDs among children in the US have evolved over the years as understanding of the set of related disabilities improves, and even now the range of estimates reflects not only the experimental design and population of each study, but also how expansive a definition of autism and ASDs each author takes. Measures and estimates cited in studies encountered in this analysis range from 4.5 to 9.1 per thousand (approximately 1 of 250 to 1 of 110), with the CDC weighing in near the upper end of the range, measured for eight-year-olds.²⁹ The upper part of the range

²⁹ Centers for Disease Control and Prevention, “Autism Spectrum Disorders”, <<http://www.cdc.gov/ncbddd/autism/index.html>>. Maryland Autism and Developmental Disabilities Project, <http://www.cdc.gov/NCBDDD/autism/states/Maryland_ADDM.pdf>. Ganz, Michael L., “The Lifetime Distribution of the Incremental Societal Costs of Autism”. *Archives of Pediatric & Adolescent Medicine* 2007; 161(4): 343-349. Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150. Durham, NC: Abt Associates, Inc., June 18, 2008, P5.

includes the widest set of ASD-related disabilities and the full range of impairment to functioning, i.e., the group includes both low-functioning and high-functioning individuals who have relatively high and low treatment costs, respectively.

We can compare these epidemiological estimates to calculations of prevalence in the Massachusetts commercial population using claim data provided by the Division. If we divide the number of users (as defined above with diagnosis codes) by the membership value from the same database to calculate an effective prevalence rate for children ages 5-19, we arrive at a value of approximately 10.5 per thousand. The calculation method inflates the value somewhat;³⁰ a more accurate measure is probably 20 percent less or approximately 8.4 per thousand. Values in this range suggest the “prevalence” for children with an ASD diagnosis represented in the claim data corroborates the population prevalence estimated from epidemiologic data. It is important to note that, as with the CDC estimate, this calculation includes a wide range of individuals, including those that have only one claim during the year.

Special education roles in Massachusetts schools also provide a value for comparison. The Special Education Planning and Policy Development Office estimated that 9,800 school-age children (in public and charter schools in 2008-09) had an ASD, out of a school age enrollment of 959,000. This suggests a prevalence of about 10.2 per thousand, close to the higher published values, such as those from the CDC.³¹

³⁰ The value measured from claims is somewhat inflated. First, the calculation includes members with even one claim for the year, but the membership value (denominator) is a sum of member months; i.e., if a member was a member for only six months he or she contributes only 0.5 to the total. Therefore the denominator is smaller (and the prevalence larger) than it would be if measured on a basis consistent with the numerator and each member counted as one. Second, if a member changes plans during the year he or she may appear as two members, inflating the numerator. We do not have data from the Division to quantify the inflation, but we can estimate the magnitude of the first effect by looking at other insured populations, which suggest we should reduce the prevalence by about 20%.

³¹ <http://profiles.doe.mass.edu/state_report/mcas.aspx> and linked pages. While we cannot rule out the possibility that stigma or systemic incentives may decrease or increase the chances that a child with ambiguous symptoms may be diagnosed with an ASD, the likely magnitude of any such effect is not large enough to render the comparison invalid.

Treated prevalence

It is important to distinguish prevalence based on epidemiologic data from the other measures of prevalence used in this analysis. For example we would expect the prevalence measure in the claim data to be somewhat lower than the epidemiologic prevalence, because not all children will have been diagnosed, or not all may have had a claim showing an ASD diagnosis within the window of time defining the claim data. As we saw, the claim-based prevalence (which no doubt has “false positives”) is somewhat lower than the epidemiological prevalence (8.2 vs. 10.2).

More importantly, not all children with an ASD diagnosis will receive treatment with ABA or similar therapies. As we consider the children treated for ABA, we will speak of a “treatment prevalence” specific to that set of therapies. Some of the “prevalence” values that we will see in other data sources, and use in this analysis, reflect this more limited definition.

Examining data from the Medicaid program in Pennsylvania, which due to a Medicaid eligibility loophole in the past included all children with an ASD, including those with commercial coverage in their families, we measured the ratio between “diagnosed” prevalence in claims (as measured in the Massachusetts data discussed above) and “treated” prevalence in claims for intensive therapy services such as ABA (which is covered under Pennsylvania Medicaid). Many individuals had claims with an ASD diagnosis but did not have ABA-type services. The resulting ratio was on the order of 60 percent, suggesting we could see ABA treatment prevalence values that are as low as 5 to 6 per thousand, similar to the Ganz study’s findings for Pennsylvania of 4.5 per thousand³². A summary of data from Wisconsin, Minnesota, and California concluded that only about 1/3 of children with an ASD who had coverage available to them accessed services³³. Though the data were quite specific, the sources for the information

³² Ganz, *op. cit.*

³³ Larrison, E.V., “The Cost of Autism, Health Care, and the Cost-Effectiveness of Intensive Early Behavioral Intervention,” The Lovaas Institute for Early Intervention, February, 2009.

were not clearly documented, so we did not include in our ranges the 3 per thousand value this conclusion would imply.

Specific prevalence values for young children

For young children (less than five) the prevalence observed in the claim data is roughly 70 percent of that observed for children 5 to 19. An autism diagnosis might not be made until the child in question reaches the age appropriate for an important developmental milestone³⁴, so we should expect a lower treated prevalence.

In comparison, the Specialty Services program in the Massachusetts Department of Public Health, which provides specialized early intervention services, including ABA, to children under 3, provided such services to 1,321 children with an ASD in fiscal year 2009. Given a population in the relevant age range of approximately 143,000 the program identifies 9.2 per thousand as having an ASD. The Department allows that the program casts a wide net, identifying children who have risk factors for ASD, such as a sibling with the disorder.³⁵

Specific prevalence value for adults

In theory, the prevalence of ASD-related disabilities among the adult population should be somewhat close to that among children (theories of relatively recent increases in major environmental causes aside). However, we have found no well-documented estimates of the prevalence among adults. The claim data provide little value in this measure; they identify adults with an ASD far less frequently than they do for children – less than 0.5 per thousand.

³⁴ The CDC reports that the median age of diagnosis ranges from 41 to 60 months.
<<http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>>

³⁵ Interview with Director, Office of Specialty Services, Massachusetts Department of Public Health, 12/30/09.

We have no evidence that passage of H.B. 3809, even though it mandates services for all people with an ASD regardless of age, will cause the number of diagnosed adults to increase or that those diagnosed, now or in the future, will be receive treatments beyond those they already receive. Occupational therapy, potentially useful to address specific adult living skills, is already covered in many cases. But the efficacy and medical necessity of intensive behavioral therapy are likely to be more at issue and subject to challenge in utilization review. Furthermore, we expect, more so than might be the case for children, that the supply of providers capable of providing ABA to adults may effectively limit the treatment available. Finally, we expect that once people with a severe form of an ASD are no longer dependents covered by their parents, their participation in the commercial insurance market, the target of this mandate, will be relatively smaller.

Perhaps some adults might benefit from a wider range of covered therapies, but we expect any increase in treatment costs to be tempered for the reasons noted, and to be much smaller than the uncertainties introduced by other factors in this analysis. Therefore, for this analysis we assume that H.B. 3809 will have a negligible effect on the cost of providing services to the adult population with ASDs.

Summary of prevalence values

Table 3 summarizes the approximate prevalence data from various Massachusetts-specific sources.

Table 3: Estimates of Prevalence of ASDs (per 1,000)

	Literature prevalence	Claim data	MA Early Interven.	Special Education
Adult (<65)	Not found	0.3		
Child 5-19	4.5 - 9.1	8.4		10.2
Child 0-4	Not found	5.8	9.2	

Data from Pennsylvania, which has provided coverage for all children with ASDs since the late 1990s, indicates that treatment prevalence for ABA-type therapy is no higher than 5 to 6 per thousand.

5.4 Cost of therapy services mandated by H.B. 3809

As discussed above, we interpret H.B. 3809 as mandating coverage for ABA and similar intensive therapies not currently mandated. Commonly cited estimates for the cost of year-round intensive therapy such as ABA run well over \$45,000 per year.³⁶ However, some individuals with an ASD have a level of disability that requires treatment of lower intensity, resulting in substantially lower per-ser cost for those users. Unfortunately, few published sources provide useful information on actual experience for the statistical distribution of the costs of treating individuals across the full range of disabilities, and we must instead rely on some reasonable, coupled with the limited data from actual state experience. In practice the data available on actual costs per treated individual over the full range of childhood ages are far lower than the theoretical maximums calculated from intensive service delivered by fully credentialed staff.

Studies on ABA Costs

Citing studies by Jacobson and Hildebrand, the Ganz analysis³⁷ estimates an average cost of over \$42,000 per year for the intensive therapies targeted primarily at children from diagnosis at about age three until they enter school at age six or seven. For older children Ganz estimates therapy costs of approximately \$5000 per year. Ganz's analysis, which examines the costs of autism across all support systems, shows costs shifting to special

³⁶ Ganz, *op cit.* Jacobson JW, Mulick JA, Green G. Cost-benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. *Behav Intervent.* 1998;13:201-226. Hildebrand DG. Cost-Benefit Analysis of Lovaas Treatment for Autism and Autism Spectrum Disorder (ASD). Vancouver, British Columbia: Columbia Pacific Consulting; 1999. A January 2010 analysis of H.B. 3809 prepared for Massachusetts health plans by the Taylor Feldman Group estimates the cost of year round therapy at 25 hours per week to be over \$65,000. A May 2009 report on this bill prepared for Autism Speaks by Oliver Wyman estimates the cost at \$45,000 to \$65,000. Cited costs inflated to current dollars as necessary for comparison.

³⁷ Ganz, *op cit.*

education for school age children, presumably displacing some of the intensive therapy that might be funded by the health care system. Weighting the cost of the intensive therapy for each age group from the Ganz study with the age breakdowns for Massachusetts insured membership provided by the Division yields Table 4. Note that costs have been inflated by four percent per year for the three years since the study was published.

While this may provide a value for the cost of treating a child with a moderate to severe disability, we cannot take the value as applying to the population across the full range of severity.³⁸ However it informs our assumptions below.

Table 4: Weighted Average Cost of Intensive Therapies for Children from Ganz Study

	Age group distribution	Estimated cost
Child 10-19	62%	\$5,600
Child 5-9	28%	\$26,400
Child 3-4	10%	\$47,200
Weighted cost		\$16,000

These results are similar to the \$14,000 per child per year that Ganz cites from the Pennsylvania Medicaid program.

At least two estimates of the cost of H.B.3809 have been made available to the Division. A January 2010 analysis prepared for Massachusetts health plans by the Taylor Feldman Group estimated a likely five-year cost of ABA at \$566 million for 8,500 children ages two to 18 with ASD³⁹, resulting in an average (across all ages) of roughly \$13,000 per year per child with an ASD. It further assumes that only 70% of children with an ASD are treated with ABA, meaning the cost per treated child is closer to \$19,000.

³⁸ The prevalence assumption accompanying the cost estimate was only 2.8 per thousand; however, prevalence played a role in the analysis different than it played in other analyses discussed and the estimate is not genuinely comparable. Ganz, *op cit.*, from spreadsheet supplement at http://www.costsofautism.com/index_files/page0004.html, citing Fombonne J Autism Devel Dis 2003.

³⁹ Autism Treatments, Roles, Projected Costs: Massachusetts H.B. 3809. Davis, CA: The Taylor Feldman Group, January 25, 2010. The report assumes four years of intensive therapy at \$65,000. The count of children includes some not in insured groups affected by this mandate.

In comparison, a May 2009 report prepared for Autism Speaks by Oliver Wyman⁴⁰ assumes lower costs and an age-dependent estimate of the portion of children in ABA treatment, starting at 50% and declining as the child ages, resulting in a lower cost per child with an ASD, somewhere in the \$7,000 to \$10,000 range. (Calculation details underlying the report and the ABA cost per treated child are not available.) The Oliver Wyman study also assumes an older, subsequently revised, CDC prevalence rate of 6.7 per thousand. Therefore the study's estimate of the cost of mandated ABA is lower than that of the Taylor Feldman study.⁴¹

The studies identified above construct cost estimates for ABA built on estimates of the distribution of the severity of the disorder across the population, the duration and intensity of treatment for each level of severity, and the cost of a unit of therapy. Given the scarcity of real-world data for validation, all these estimates can span large ranges. Settling on an estimate for this analysis is a matter of applying judgment in weighing those underlying assumptions, tempered as possible with real-world data.

State program data

The Abt Associates evaluation of the costs of services for children with autism in Pennsylvania cites an average cost to the Pennsylvania medical assistance program (for FY 2009) of \$14,300 per year per child with ASD, including costs of ABA.⁴² This value is not a perfect predictor of costs to commercial insurers in Massachusetts; it is derived from a Pennsylvania program, meaning it reflects Pennsylvania medical assistance

⁴⁰ Actuarial Cost Estimate: The Commonwealth of Massachusetts House Bill 3809. Oliver Wyman, May 4 2009.

⁴¹ The reports differ on key assumptions; Appendix A provides a summary of the differences. For example, using an hourly rate of \$51.90, the Autism Speaks study calculates an annual cost for intensive service of close to \$65,000, but assumes that to be the worst case, settling on \$55,000 as most likely. The Taylor Feldman study uses \$55 per hour to arrive at \$65,000 and takes it as the most likely value. The mean rate for early intervention specialty services provided by DPH is approximately \$47 per hour, and the Department says the rate has not changed in many years. Interview with Director, Office of Specialty Services, Massachusetts Department of Public Health, 12/30/09. The private sector rate is likely to be higher.

⁴² Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150. Durham, NC: Abt Associates, Inc., June 18, 2008. p 36.

policies and provider rates (thought it does serve the commercially insured population⁴³) and may not reflect the Massachusetts health care market, and it may include services other than ABA. Nonetheless, it offers some corroboration of the model-based estimates.⁴⁴ The “treated” prevalence reflected in the Pennsylvania analysis was approximately 4.3 per thousand⁴⁵, or roughly half the current CDC epidemiologic rate, and close to the range of treated prevalence we might expect to see, based on the discussion above. This program has been in place since prior to 2000, and so is fully mature and implemented.

As noted above, the Massachusetts Department of Public Health provides a near-universal program of early intervention for children up to 36 months of age. The program last year provided ABA and similar services to 1,321 children at a cost of roughly \$11.2 million per year, or roughly \$8,400 per served child. Of that, the Office of Specialty Services estimates that roughly 70% is for ABA, suggesting a per child ABA cost closer to \$6,000 per year. The 1,321 children treated suggest a 9.2 prevalence rate, but also as noted, that value may be higher than a value that accurately reflects how well ASDs can be diagnosed in very young children. Finally, children under three (and their families) have limits to how much therapy they can effectively receive per day, so we should not take this number as any sort of upper limit on the cost of serving older children.⁴⁶

5.5 Combining treated prevalence and cost per user to estimate cost ranges

As noted, not every child with an ASD will need the maximum level of service and the cost per child for intensive therapy will drop as we include a greater proportion of

⁴³ Prior to the implementation of Pennsylvania Act 62 on July 1, 2009, all children with ASDs were eligible for Medicaid coverage regardless of other eligibility criteria.

⁴⁴ While we cannot predict precisely how much more service will cost in Massachusetts, the average rate for DPH Specialty Services of \$47 per hour, and a mean Medicaid rate for the related services in Pennsylvania in the mid \$30's, suggest the \$14,300 could go up 35% or so to \$19,000 in Massachusetts.

⁴⁵ Calculated by dividing the number of children with an ASD served by the PA Dept. of Public Welfare by the population of children in the appropriate age. Children served include Medicaid beneficiaries and children from families who were privately insured whose insurers excluded coverage for ASD diagnoses.

⁴⁶ Interview with Director, Office of Specialty Services, Massachusetts Department of Public Health, 12/30/09.

children who have been identified as having an ASD-related disability. Tables 5A, 5B, and 5C display the interaction between prevalence and average cost per child and their impact on service costs for ABA-type therapies. Note that these results generate gross results, before application of factors which dampen the costs such as costs paid by school districts and ramp-up effects (discussed further below).

Table 5A applies to the population of children ages 5 and up, 5B applies to the population ages three and four, and 5C to the population under three. The shaded area on each table defines likely combinations of treatment prevalence and cost per user based on the foregoing discussions, and creates the range of our estimate. For example, in Table 5A, with a treatment prevalence (i.e., engagement in the treatment system) of 5.5 per thousand, our estimated cost of \$25,000 per child yields a total cost of about \$69 million. As we expand the assumed population of children with an ASD receiving active treatment, up to the maximum of 10 per thousand, we would expect lower per user costs as less acute cases are added. Table 5A provides a set of cells which hold possible scenarios, with those judged to be most realistic shaded. Neighboring cells are shaded because of uncertainties along either the cost per user dimension or the prevalence dimension. The least and most expensive highlighted scenarios form low and high ends of our range of estimates for the group.

Tables 5B and 5C show corresponding estimate ranges for younger children. To some extent, isolating these populations is a consequence of constraints in the age ranges available in membership data. However, because of the typical age of diagnosis, the existence of early intervention programs, and how these populations interact with school systems, the behavior of the transitional three to four age range merited the isolation.

The median age of diagnosis falls into the three to four age range in Table 5B, and we expect relatively higher costs per treated user since this is the start of the prime age for ABA and similar treatments, and diagnoses for some of the less severe conditions on the autism spectrum (such as Aspergers) tend to occur later.

Table 5A: Estimates of Average Cost of Therapies – Children 5-19

Members	502,000				
Treatment Prev. (per K)	4.0	5.5	7.0	8.5	10.0
Total users	2,008	2,761	3,513	4,266	5,019
Cost per user					
\$ 10,000	\$ 20,077,000	\$ 27,606,000	\$ 35,134,000	\$ 42,663,000	\$ 50,192,000
15,000	30,115,000	41,408,000	52,702,000	63,995,000	75,288,000
20,000	40,154,000	55,211,000	70,269,000	85,327,000	100,384,000
25,000	50,192,000	69,014,000	87,836,000	106,658,000	125,480,000
30,000	60,231,000	82,817,000	105,403,000	127,990,000	150,576,000
Low per member	\$ 99.98				
High per member	\$ 139.98				

Table 5B: Estimates of Average Cost of Therapies – Children 3-4

Members	64,000				
Treatment Prev. (per K)	4.0	5.5	7.0	8.5	10.0
Total users	254	350	445	541	636
Cost per user					
\$ 10,000	\$ 2,544,000	\$ 3,497,000	\$ 4,451,000	\$ 5,405,000	\$ 6,359,000
15,000	3,815,000	5,246,000	6,677,000	8,108,000	9,538,000
20,000	5,087,000	6,995,000	8,902,000	10,810,000	12,718,000
25,000	6,359,000	8,743,000	11,128,000	13,513,000	15,897,000
30,000	7,631,000	10,492,000	13,354,000	16,215,000	19,077,000
Low per member	\$ 79.48				
High per member	\$ 139.09				

Table 5C: Estimates of Average Cost of Therapies – Children 0-2

Members	95,000				
Treatment Prev. (per K)	3.0	3.5	4.0	4.5	5.0
Total users	286	334	382	429	477
Cost per user					
\$ 4,000	\$ 1,145,000	\$ 1,335,000	\$ 1,526,000	\$ 1,717,000	\$ 1,908,000
7,000	2,003,000	2,337,000	2,671,000	3,005,000	3,338,000
10,000	2,861,000	3,338,000	3,815,000	4,292,000	4,769,000
12,000	3,434,000	4,006,000	4,578,000	5,151,000	5,723,000
15,000	4,292,000	5,008,000	5,723,000	6,438,000	7,154,000
Low per member	\$ 31.63				
High per member	\$ 45.18				

In Table 5C, the prevalence rates are lower; this reflects the need to apply the rates to the entire membership in the 0-2 range, at least half of whom are too young for any diagnosis. The lower per user costs in Table 5C reflect the therapy loads observed in the Early Intervention program.

Summing the minimums and maximums from the shaded portions of Tables 5A, 5B, and 5C yields an approximate annual potential cost range of \$58 million to \$83 million. Table 6 summarizes Tables 5A, 5B, and 5C, and identifies a midpoint “likely” value within the range of estimates.

Table 6: Summary of Estimated Gross Costs of Mandated Services (2010 Dollars)

		\$/Member	Cost of Services
Children (5-19)			
Members	502,000		
Low estimate		\$ 100	\$ 50,192
Mid estimate		120	60,231
High estimate		140	70,269
Children (3-4)			
Members	64,000		
Low estimate		\$ 79	\$ 5,087
Mid estimate		109	6,995
High estimate		139	8,902
Children (0-2)			
Members	95,000		
Low estimate		\$ 32	\$ 3,005
Mid estimate		38	3,649
High estimate		45	4,292
Total			
Members	661,000		
Low estimate		\$ 88	\$ 58,284
Mid estimate		107	70,874
High estimate		126	83,463

5.6 Portion of ABA service costs that will remain within school systems

The gross estimates presented above are based on prevalence and estimated cost per user for all children with fully-insured coverage. Many of these children currently receive services from their school district. Local education authorities (LEAs, e.g., school districts) in Massachusetts provide substantial services to children with an ASD, many with commercial insurance. The type and amount of services provided to these children varies widely, but many LEAs provide at least some ABA to either preschool children or to school-age children or both. The potential for shifting costs of ABA from the schools to insurers exists, but to the extent the costs remain in the schools, they will not contribute to the costs borne by insurers. Variation among LEAs means that some children may not currently receive the therapy for which the mandate would provide coverage, and the mandate might place the cost for this unmet demand on insurers, while in other LEAs children might receive therapy, but some portion of it may shift to insurers.

For example, looking across the full range of LEAs, if two thirds provide substantial services, and within those, half the cost of services was to remain borne by the LEA, then we would reduce the burden on insurers of ABA for school age children by a third. Quite possibly the schools will provide more than that. For the purpose of this analysis, we will assume the commercial insurer exposure to cost of ABA for school-age children may be reduced by 30 to 50 percent from the gross estimates. Any shifting of costs from schools to insurers is likely to be gradual; we will assume the schools will retain an even larger portion in the first few years.

The effects of this estimate are shown in Table 7.

Table 7: Estimated Cost of Mandated Services

Children (5-19)	-2011 -	-2012 -	-2013 -	-2014 -	-2015 -	- Total -
Members	502,000	498,000	495,000	493,000	492,000	
Provider supply limit	-20%	-10%	0%	0%	0%	
School ABA portion	75% - 50%	60% - 40%	50% - 30%	50% - 30%	50% - 30%	
Low estimate (\$K)	\$ 10,440	\$ 19,388	\$ 27,836	\$ 28,832	\$ 29,925	\$ 116,421
Mid estimate (\$K)	19,836	30,051	41,197	42,672	44,289	178,045
High estimate (\$K)	29,232	40,715	54,559	56,512	58,653	239,670
Children (3-4)	-2011 -	-2012 -	-2013 -	-2014 -	-2015 -	
Members	64,000	64,000	64,000	64,000	65,000	
Provider supply limit	-20%	-10%	0%	0%	0%	
School ABA portion	50% - 25%	40% - 20%	40% - 20%	20% - 10%	20% - 10%	
Low estimate (\$K)	\$ 2,116	\$ 2,971	\$ 3,433	\$ 4,761	\$ 5,029	\$ 18,310
Mid estimate (\$K)	3,836	4,952	5,722	7,067	7,464	29,040
High estimate (\$K)	5,555	6,932	8,011	9,373	9,900	39,771
Children (0-2)	-2011 -	-2012 -	-2013 -	-2014 -	-2015 -	
Members	95,000	96,000	96,000	97,000	97,000	
Provider supply limit	0%	0%	0%	0%	0%	
School ABA portion	0% - 0%	0% - 0%	0% - 0%	0% - 0%	0% - 0%	
Low estimate (\$K)	\$ 3,125	\$ 3,284	\$ 3,416	\$ 3,589	\$ 3,733	\$ 17,148
Mid estimate (\$K)	3,794	3,988	4,147	4,358	4,532	20,820
High estimate (\$K)	4,464	4,691	4,879	5,127	5,332	24,492
Total						
Low estimate (\$K)	\$ 15,681	\$ 25,643	\$ 34,685	\$ 37,183	\$ 38,687	\$ 151,879
Mid estimate (\$K)	27,466	38,991	51,067	54,097	56,286	227,906
High estimate (\$K)	39,250	52,338	67,448	71,011	73,885	303,932

5.7 Increase in covered costs to be paid by health insurers

Applying the estimated per-user costs to the projected annual insured membership for the next five years yields the range of estimated costs shown in Table 7. The table reflects changes in projected membership and an assumption of 4% per year for inflation in the cost of services. The amplitude of the range reflects the uncertainties, discussed above:

- The treatment prevalence of ASD
- The extent to which the cost of treating less severely disabled individuals drops off from the relatively high cost of treating the most disabled
- How much school systems will continue to bear the burden of ABA costs
- The extent to which the provider supply constrains costs in the first few years as it ramps up to handle the demand for services

Table 7 does not reflect cost sharing (copays, etc.) that might reduce what insurers pay.

5.8 Effect on health insurance premiums

To convert medical cost estimates to premiums, costs were reduced to reflect member cost-sharing (copays, deductibles, etc.) and increased to reflect insurer retention (administrative costs and profit). We would expect lower cost-sharing ratios given the size of these per user expenditures, but recent surveys of the Massachusetts insurance market suggest very low values.⁴⁷ We assume 1 percent on average.

Using historical retention data, we estimated retention ratios – the portion of premiums that represent administration costs and profit for bearing risk on the covered members – of approximately 12%. Table 8 displays the resulting net effect on premiums, showing the net increase measured on a per-member per-month (PMPM) basis and an increase as a percentage of estimated premiums.

The estimated average PMPM cost of H.B. 3809 over five years is \$1.22 to \$2.45, increasing substantially over the five years as the provider system ramps up and ABA costs shift to insurers. We estimate that H.B.3809 would increase premiums by 0.24 to 0.49 percent for the members affected by the mandate, again, increasing with time.

⁴⁷ Premium Levels and Trends in Private Health Insurance Plans. Table C1: “Most Popular Benefit Plans in Private Comprehensive Insurance Products”. DHC FP, Oliver Wyman, February 2010.

Table 8: Estimated Incremental Impact of H.B. 3809 on Insurance Premiums

	-2011 -	-2012 -	-2013 -	-2014 -	-2015 -	- Average -
Members	2,330,000	2,328,000	2,326,000	2,325,000	2,323,000	
Med Exp Low (\$K)	\$ 15,681	\$ 25,643	\$ 34,685	\$ 37,183	\$ 38,687	\$ 30,376
Med Exp Mid (\$K)	27,466	38,991	51,067	54,097	56,286	45,581
Med Exp High (\$K)	39,250	52,338	67,448	71,011	73,885	60,786
Premium Low (\$K)	\$ 17,641	\$ 28,849	\$ 39,021	\$ 41,831	\$ 43,522	\$ 34,173
Premium Mid (\$K)	30,899	43,865	57,450	60,859	63,321	51,279
Premium High (\$K)	44,157	58,880	75,879	79,888	83,120	68,385
Low PMPM	\$ 0.63	\$ 1.03	\$ 1.40	\$ 1.50	\$ 1.56	\$ 1.22
Mid PMPM	1.11	1.57	2.06	2.18	2.27	1.84
High PMPM	1.58	2.11	2.72	2.86	2.98	2.45
Est Mo. Premium	\$ 442	\$ 468	\$ 496	\$ 526	\$ 558	\$ 498
Premium % Rise Low	0.14%	0.22%	0.28%	0.28%	0.28%	0.24%
Premium % Rise Mid	0.25%	0.34%	0.41%	0.41%	0.41%	0.36%
Premium % Rise High	0.36%	0.45%	0.55%	0.54%	0.53%	0.49%

G.I.C. data membership data, distinct from the other membership covered under commercial plans, was not available broken down at the same level of detail as was the general commercial membership. However we can estimate a medical expense range for the G.I.C. by applying the medical expense per member month used for the fully-insured population. (We will not attempt to estimate administrative costs or premium impact.) Note G.I.C. membership is an estimate of members excluding those on Medicare. Table 9 illustrates.

Table 9: Estimated Impact of H.B. 3809 on GIC Claims

	-2011 -	-2012 -	-2013 -	-2014 -	-2015 -	- Total -
Members	223,000	223,000	223,000	223,000	222,000	
Med Exp Low (\$K)	\$ 1,501	\$ 2,456	\$ 3,325	\$ 3,566	\$ 3,697	\$ 14,546
Med Exp Mid (\$K)	\$ 2,629	\$ 3,735	\$ 4,896	\$ 5,189	\$ 5,379	\$ 21,827
Med Exp High (\$K)	\$ 3,757	\$ 5,013	\$ 6,466	\$ 6,811	\$ 7,061	\$ 29,108
Low PMPM	\$ 0.56	\$ 0.92	\$ 1.24	\$ 1.33	\$ 1.39	
Mid PMPM	\$ 0.98	\$ 1.40	\$ 1.83	\$ 1.94	\$ 2.02	
High PMPM	\$ 1.40	\$ 1.87	\$ 2.42	\$ 2.55	\$ 2.65	

CONCLUSION

We estimate the cost of H.B. 3809 to policy holders of fully-insured policies will range between \$171 million and \$342 million over the next 5 years, raising premiums by 0.24 to 0.49 percent on average over that time. The proportionate difference between the low and high estimates is large. This uncertainty is driven by the lack of solid data on the distribution of the severity of ASDs among the affected population and the possibility of cost-shifting from school systems, and other factors discussed in the analysis.

We believe there is enough uncertainty in the treatment protocols, availability of provider capacity, and final determination of medical necessity that would evolve in Massachusetts if H.B. 3809 is enacted that the Legislature should deliberate with the understanding that costs could be in the higher end of this range of estimates. Furthermore, because assumptions in the analysis dampen the cost of services in the early years, extrapolating these costs into the future requires care. Costs beyond the five year horizon will be significantly higher than the five-year averages reflected in this analysis.

APPENDICES

Appendix A: Comparison of Analyses of H.B. 3809

Appendix A: Comparison of Analyses of H.B. 3809

This table compares the results of the three analyses of the financial impact of H.B. 3809 available to the Legislature. The values herein are approximate only and intended to convey general ranges based on reasonable interpretation of the reports. To put all three reports on an equal footing, the table contains values adjusted for membership and other factors, as explained in the notes following the table. In some cases, determining the values required assumptions about the methodologies the reports used, also explained in the notes. Unless otherwise specified, the values refer to the “likely” portion of the range of estimates.

Report Sponsor	Autism Speaks	Massachusetts Health Plans	DHCFP
Author	Oliver Wyman (OW)	The Taylor Feldman Group (TF)	Compass Health Analytics
Likely average annual cost over 5 years, from report ^a	Report shows \$60M, in 2009 dollars, for one year (range: \$40M to \$88M)	\$123M average for 2010-2014 (range: \$25M to \$284M)	\$51M average for 2011-2015 (range: \$34M to \$68M)
Average annual cost 2011-2015 adjusted to reflect FI membership and retention (non-claims costs)	\$58 million ^b	\$82 million ^e	\$51 million
2011-2015 average PMPM increase, including retention (non-claims costs)	\$2.09 ^c	\$2.95 ^f	\$1.84
2011-2015 average percent increase in premium	0.42 % ^d (weighted mean of 5 yearly values)	0.59 % ^g	0.36 %
Underlying assumptions:			
Member base ^h	Fully insured members (~2.2 million)	All privately insured (~4.1 million)	Fully-insured members (~2.3 million)
Prevalence of ASDs, from report ⁱ	6.7 per thousand	9.0 per thousand	4.5 - 9 per thousand treatment prevalence
Cost of a year of intensive therapy, from assumptions listed in report	\$45,000 - \$55,000 - \$65,000	\$37,000 - \$66,000 - \$94,000	Included in range of estimates of severity in relation to prevalence
Portion of children treated with ABA, from assumptions listed in report	Depends on age; 50% of young children and then declining	50% - 70% - 80%	Included in range of estimates of severity in relation to prevalence
Estimated cost of ABA (w/out retention)	Not derivable, but likely lower. ^j	\$67M per year average 2011-2015 ^k	\$46M per year average 2011-2015
Cost of ABA per child with ASD	Not derivable, but likely lower. ^l	Approximately \$13,000 ^m	Included in range of estimates
Non-ABA services resulting from bill	\$3,400 per year per child for other medical expenses	Models for OT, PT, and speech therapy, add \$10M/year to likely scenario	Net impact immaterial. See section 3.4 for discussion.
Role of special education	Not reflected in calculations	Not reflected in calculations	Insurer’s costs for ABA lower due to schools’ funding services (see sect. 5.6)
Insurers’ retention percentage =((administration + profit)/premium) =(1- (claims/premium))	15%	None estimated in report; \$82 million estimate above includes 12% add-on not included in report.	12%

Notes to Appendix A Table:

- a. Each report presented an estimated annual cost with a minimum and maximum. All reports assume costs ramp up over the first years following enactment. Note the Taylor-Feldman (TF) range encompasses all the others.
- b. Applying the percents of premium from the Oliver Wyman (OW) report (page 15, see d below) to Compass's premium projections for 2011-2015 yields a total expense of \$292M, or \$58M per year on average.
- c. Divide the \$58M in b above by Compass's average membership for 2011-2015, and divide by 12.
- d. The OW report (page 15) estimated the effect of H.B. 3809 over the 5 years following enactment, by specifying a set of yearly percent of premium values, ascending as expenses ramped up. Compass calculated the premium for each year from 2011 to 2015 using its membership and premium projections and calculated the average of OW's five yearly values, weighted by the premium values over that same period.
- e. The following adjustments were made: (i) the TF report value of \$123M was reduced to remove costs for the self-insured membership (self-insured plans not subject to the mandate), using Compass's fully-insured membership value (~2.3M), (ii) 12% retention (non-claims costs) was assumed (less than OW's value of 15%), and (iii) because TF used the years 2010-2014, the TF health care inflation factor of 5% was applied to raise the value to the level of the 2011-2015 period.
- f. Total expense for the 2011-2015 period (which reflect an additional year of inflation) was divided by Compass's membership for the period.
- g. The PMPM was divided by Compass's projection for 2011-2015 average monthly premium (~\$498) to get the approximate % of premium.
- h. These are the average membership numbers shown in the reports. Note the TF value reflects fully- and self-insured plans, although self-insured plans are not subject to the mandate. The adjusted values in the upper part of the table use the Compass membership numbers as a standard.
- i. The OW report reflects a prevalence number since updated by the CDC. The prevalence numbers are shown for reference; they are used in the models in different ways.
- j. This value is not rigorously derivable from the OW report. However applying the assumptions explicitly listed in the report, including the percentage of children treated at each age range and likely costs, suggests a value considerably lower than the total expense in the base year of the report (\$51M, without retention), possibly as low as the low \$30M's. The difference is, presumably, made up of non-ABA service costs.
- k. TF shows \$566M for ABA. Adjusted for membership (but not non-claims costs) and one year of inflation, produces an average of \$67M for 2011-2015.
- l. This value is an estimate of the cost of ABA services per child with ASD. (This is different than the cost per treated child.) See the derivation of the ABA cost in note j above. The per-child cost is likely below \$10,000 per year. These values are estimates based on assumptions about the methodology.
- m. Divide TF's average annual ABA cost (\$113M) by the approximately 8500 children with an ASD in the current age range on its ABA Likely Scenario spreadsheet.

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