

**JOINT LEGISLATIVE AUDIT AND REVIEW COMMISSION  
OF THE VIRGINIA GENERAL ASSEMBLY**

**EVALUATION OF PROPOSED  
MANDATED HEALTH INSURANCE BENEFITS**

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**Evaluation of House Bill 83:  
Mandated Coverage of  
Autism Spectrum Disorders**

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**September 2008**

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JLARC provides evaluations of proposed health insurance mandates in accordance with Sections 2.2-2503 and 30-58.1 of the *Code of Virginia*.

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**Evaluation of House Bill 83:  
Mandated Coverage of  
Autism Spectrum Disorders**

**JLARC SUMMARY**

House Bill 83 of the 2008 General Assembly Session would mandate coverage for the diagnosis and treatment of autism spectrum disorders (ASDs) in individuals under the age of 21. Treatment for ASDs is defined as medically necessary habilitative, rehabilitative, pharmacy, psychiatric, psychological, and therapeutic care that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist for an individual diagnosed with an ASD. Intensive behavioral interventions, including Applied Behavior Analysis (ABA)-based therapies, are among the therapies that would be covered by HB 83.

**MEDICAL EFFICACY AND EFFECTIVENESS**

Speech, physical, and occupation therapy are generally accepted by the medical and educational communities as being effective treatments for individuals with ASDs. In addition, medical experts and the American Academy of Pediatrics (AAP) indicate that the effectiveness of ABA-based therapy has been well documented, although the extent to which the effectiveness of other behavioral treatments has been documented varies. In general, the AAP indicates that any treatments used should be based on sound theoretical constructs, rigorous methodologies, and empirical studies of efficacy.

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## **SOCIAL IMPACT**

Data provided by the Department of Education indicates that there are approximately 7,500 children in Virginia with an ASD. Services to treat ASDs are provided through the Early Intervention System and the public schools. However, families, medical experts, and providers of ASD services indicate that some children require services in addition to those provided through the schools. One third of health insurance plans indicate that they cover ASD-related treatment, but far fewer cover treatment for ABA-based therapy. For those families that do not have insurance coverage for ASD services, the cost of obtaining services may result in a considerable financial hardship depending on the severity of their child's condition.

## **FINANCIAL IMPACT**

The median estimated premium impact of HB 83 is \$4.88 per month for standard coverage, which is within the range of existing Virginia health insurance mandates. However, this estimate appears somewhat high compared to the premium impacts estimated for similar mandates in other states. Concerns with the mandate include the potential increased use of investigational or untested treatments and the desire to ensure that only reputable providers are covered by the mandate. A further concern voiced by medical experts and others is the lack of coordination of services for individuals with ASDs.

## **BALANCING MEDICAL, SOCIAL, AND FINANCIAL CONSIDERATIONS**

There appears to be a need for health insurance coverage of ASD-related services, and coverage of these services appears consistent with the role of health insurance as evidenced by several insurers providing this coverage, autism mandates in other states, and coverage of these services by the U.S. Military health plan. It may be desirable to require that treatments covered by HB 83 be provided by certified or licensed providers and that only evidence-based treatments are covered to ensure that children are receiving safe and effective treatments. Also, capping the annual coverage amounts, as other states have done, would help reduce the potential impact on premiums of the mandate. It may be premature to consider adopting an insurance mandate for ASD-related services prior to the results of a separate JLARC study that is assessing the availability and delivery of services to individuals with ASDs in Virginia, including the coordination of these services.



# JLARC Evaluation of House Bill 83: Mandated Coverage of Autism Spectrum Disorders

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House Bill 83 (HB 83) of the 2008 General Assembly Session would mandate coverage for the diagnosis and treatment of autism spectrum disorders (ASDs) in individuals under the age of 21. Treatment for ASDs is defined as medically necessary habilitative, rehabilitative, pharmacy, psychiatric, psychological, and therapeutic care that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist for an individual diagnosed with an ASD. Intensive behavioral interventions are among the therapies that would be covered by HB 83. The proposed mandate notes that, except for inpatient services, an insurer will have the right to request a review of treatment being provided to an individual receiving treatment for an ASD not more than once every 12 months unless the insurer and the individual's licensed physician or psychologist agree that a more frequent review is necessary.

## **BACKGROUND**

There is a wide range in the level of impairment for individuals diagnosed with ASDs, and each of these individuals has unique abilities and needs. Consequently, there is a wide range of treatments for addressing ASDs, and the type and intensity of treatment required for each person will similarly vary. Examples of therapies used to treat individuals with ASDs include speech therapy, occupational therapy, physical therapy, and behavioral therapy.

### **a. Description of Medical Condition and Proposed Treatment**

The proposed mandate covers treatment for individuals under the age of 21 with an ASD. Children are diagnosed as having an ASD if there is a developmental disability, usually present before the age of three, which affects social interactions, communication, and behavior. There are three main components that define autism spectrum disorder. First, children with ASDs have difficulty interacting socially with peers, teachers, and parents, which can result in difficulty with social relationships, inappropriate social responses, and social isolation. Second, children with ASDs may be delayed in speech and language development, and have difficulty

interpreting social gestures and non-verbal communication such as facial expressions. Third, children with ASDs often have trouble with typical child play and may fixate on one behavior or object rather than exhibit more common play behaviors. It is important to note, however, that the manifestations of ASDs vary greatly depending not only on where the individual falls in the autism disorder spectrum, but also on the developmental level and chronological age of the individual.

ASDs include autistic disorder, Asperger syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS), as defined by the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV). The specific cause of ASDs is unknown, but it is generally accepted that ASDs are caused by abnormalities in brain structure or function. A number of theories are being investigated, such as a link to genetics, medical problems, and environmental influences. Although the disorders within the autism spectrum have similar symptoms, differences in severity and onset of symptoms determine each affected individual's diagnoses. The Center for Disease Control's (CDC's) Autism and Developmental Disabilities Monitoring (ADDM) Network found in a 2007 report that about 1 in 150 (or almost 7 in 1,000) children have an autism spectrum disorder (defined as autistic disorder, Asperger syndrome, and PDD-NOS). However, medical experts indicate that new data is showing that this estimate may be somewhat high.

Two rare disorders included under the broad diagnosis category of pervasive developmental disorder are Rett syndrome and childhood disintegrative disorder (CDD). Symptoms are similar to autism, but are typically much more severe and debilitating, and can be accompanied by additional medical problems. Because of their relative similarity to ASDs, some believe that Rett syndrome and CDD should not be excluded from treatment coverage in HB 83. However, other states that have implemented mandates for the coverage of autism services have adhered to the DSM-IV definition of ASD and have not included these two rare disorders in their coverage. Therefore, for the purposes of this report, the term autism spectrum disorders will refer only to autistic disorder, Asperger syndrome, and PDD-NOS, as specified in HB 83. These conditions are further described in Exhibit 1.

Similar to the wide range of conditions which may result in the diagnosis of an ASD, there is a wide range of treatments for addressing these conditions. Evidence indicates that early intervention and treatment may result in substantially better outcomes for autistic children. As a result, according to the American Academy of Pediatrics (AAP), there is a growing consensus that entry of a child

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## Exhibit 1: Descriptions of Select Medical Conditions Associated With Autism Spectrum Disorders

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**Autistic Disorder.** Characterized by impaired social interaction and communication and restricted repetitive and stereotyped patterns of behavior, interests, and activities. Examples include lack of eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction; lack of social or emotional reciprocity; lack of language skills or stereotyped and repetitive use of language or idiosyncratic language; persistent preoccupation with parts of object; and apparently inflexible adherence to specific, nonfunctional routines or rituals.

**Asperger Syndrome.** Characterized by impaired social interaction and restricted repetitive and stereotyped patterns of behavior, interests, and activities, similar to Autistic Disorder. In contrast to Autistic Disorder, there are no clinically significant delays in language, cognitive development, or age-appropriate self-help skills, adaptive behavior, and curiosity about the environment in childhood.

**Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).** Characteristics for this disorder are identical to those that define Autistic Disorder and are severe and pervasive. Even though the characteristics of PDD-NOS are similar to those that define Autistic Disorder, an individual would be classified as PDD-NOS if the characteristics were not present before age three or because of atypical or sub-threshold symptomatology.

Source: Autism Society of America.

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into intervention as soon as an ASD diagnosis is seriously considered is preferred rather than deferring until a definitive diagnosis is made. Interviews with medical experts and staff in State agencies indicated that creating an individualized therapy plan that best matches an individual's strengths and needs is a critical first step to implementing treatment and improving the individual's behavioral functions and cognitive skills. In addition, the AAP indicates that pediatricians and other primary health care professionals should be involved in the ongoing care and management of ASDs, and should help guide families to empirically supported interventions.

Specific intervention therapies that may be recommended for children with ASDs frequently include speech, occupational, physical, and behavioral therapies. These treatments help people with autism improve their general ability to communicate and interact with others effectively, execute daily tasks such as personal care, build motor control, and improve posture and balance. The Na-

tional Institute of Mental Health states that psychosocial and behavioral interventions are also key parts of comprehensive treatment programs for children with ASDs. One of the most frequently studied types of behavioral interventions is based on Applied Behavior Analysis (ABA). Techniques based on ABA break down skills into small components and apply positive reinforcement following a desired behavior to give autistic individuals repeated opportunities to learn and practice skills to motivate meaningful and positive behavioral change. The technique of using prompts to create a desirable response and subsequently rewarding the child to motivate additional correct responses is known in the clinical field as discrete trial training (DTT) and serves as the foundation for many ABA techniques.

One of the most well-known evaluations of ABA-based treatment was conducted by O. Ivar Lovaas, who reported on the effectiveness of ABA-based treatment for children with ASDs in a 1987 report. Lovaas' use of ABA was a fairly strict application of DTT which involved a formal teaching and reward process to build communication, play, social, academic, self-care, work, and community living skills and to reduce problem behaviors in individuals with autism. This technique has been criticized for creating "robotic" children because of the formalized way in which the child is taught to respond to certain situations. Since Lovaas' study, ABA-based therapy has evolved, and many specialists in the field and ABA providers have expanded ABA-based techniques to help children generalize their reactions and apply them in many different environments and scenarios using multiple techniques in tandem. This approach seeks to maximize the development of cognitive, behavioral, and social skills of children with ASDs. Therefore, although formalized DTT is one method of providing ABA therapy, more varied and flexible techniques using play and other natural activities in a variety of structured social situations as well as semi-structured teaching in social routines are used today to help individuals with ASDs translate appropriate behavior in different scenarios. Exhibit 2 provides two current examples of ABA-based therapy used by a Virginia ABA provider.

As will be discussed further in the Medical Efficacy and Effectiveness section of this report, ABA-based therapies are considered by many, including both clinicians and families, to be the most effective interventions currently available for individuals with ASDs. However, a wide array of other methods are available to help improve these individuals' cognitive, behavioral, and social skills. Some of these methods are described further in Table 1.

It is important to note that some treatment interventions, particularly many of the complementary and alternative medicine thera-



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## **Exhibit 2: Two Current Examples of Therapies Based on Applied Behavior Analysis**

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### **Example A: Increasing Language Repertoire**

Issue: The child uses rote phrases during play, repeats the same phrases when he uses the same materials during play, and does not deviate from these phrases.

Goal: Increase language repertoire during play activities.

Method: The therapist sets up a Thomas the train track with a tunnel. The child typically says, "Thomas is in the tunnel" as he pushes the train through the tunnel. The therapist is looking to increase the repertoire of language for that play item.

As the child pushes the train through the tunnel, the therapist models appropriate phrases such as "Thomas is hiding in the tunnel," "It is dark in the tunnel," etc.

The therapist repeats these phrases as the child pushes the train through the tunnel for the first two or three times through.

During the next three trials, the therapist starts to fade part of the sentence allowing the child to fill in the blank. For example, "It is dark in the \_\_\_\_\_," Thomas is \_\_\_\_\_ in the tunnel."

When the child fills in the blank, the therapist models back the sentence and reinforcement is provided.

The therapist continues to fade back on the verbal model until the child is independently saying each phrase randomly.

### **Example B: Teaching Appropriate Behavior to Get Needs Met**

Issue: The child yells and screams when he cannot open something.

Goal: Teach the child to use appropriate phrases to get his needs met.

Method: The therapist uses a series of trials with a box to reinforce the appropriate way to ask for help.

#### *Trial 1:*

The therapist puts a reinforcing item in a box that the child cannot open independently.

Therapist: says the appropriate phrase "open" and then opens the box.

Therapist: closes the box then puts it in front of the child.

Therapist: says "open" verbally prompting the child.

Child: tries to open the box on his own and starts to scream.

Therapist: (modeling is provided as feedback) says "open" and opens the box but does not allow access to the item inside.

#### *Trial 2:*

Therapist: closes the box and places it in front of the child.

Child: says "ohhh."

Therapist: Models the appropriate phrase "good, open" then opens the box giving the child access to reinforcement.

#### *Trial 3:*

Therapist: closes the box and places it in front of the child.

Child: says "open."

Therapist: Models back "open" then opens the box giving the child access to reinforcement.

Once the child is consistently using the desired phrase to open the box, it will then be generalized and applied to other materials and situations.

Source: Virginia provider of applied behavior analysis (ABA) therapy.

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pies, have not been evaluated as extensively as ABA-based therapies. While some individuals may benefit from the techniques, the overall effectiveness has not been demonstrated. One provider of ABA services noted that the application of ABA-based therapy, no matter how strictly applied, almost always improves the functioning of individuals with ASDs to some degree, and has never been

**Table 1: Selected Treatment Methods for Individuals With Autism Spectrum Disorders**

<b>Treatment Method</b>	<b>Description of Method</b>
Applied Behavior Analysis (ABA)-based therapy	A teaching method that uses positive reinforcement and other principles to build communication, play, social, academic, self-care, work, and community living skills and to reduce problem behaviors in individuals with autism.
Verbal behavior intervention (VBI)	Similar in principle to ABA, but also attempts to capture a child's motivation to develop a connection between the value of a word and the word itself.
Sensory Integration Therapy (SIT)	Facilitates the development of the nervous system's ability to process sensory input in a more typical way. Through integration the brain pulls together sensory messages and forms coherent information upon which to act. SIT uses neurosensory and neuromotor exercises to improve the brain's ability to repair itself. When successful, it can improve attention, concentration, listening, comprehension, balance, coordination and impulsivity control in some children.
Picture Exchange Communication System (PECS)	PECS is a type of augmentative and alternative communication technique where individuals with little or no verbal ability learn to communicate using picture cards. Children use these pictures to "vocalize" a desire, observation, or feeling. In later phases, children are given more than one image so that they must decide which to use when requesting an item, and throughout the process the number of cards grows and thus the child's 'vocabulary' also increases.
Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)	A special education ABA-based program that uses visual cues to enhance the physical, social and communicating environment for autistic children to build receptiveness, understanding, organization and independence. TEACCH does not specifically focus on social and communication skills as fully as other therapies and is therefore used along with such therapies to enhance effectiveness.
Relationship development intervention (RDI)	A parent-based treatment that focuses on the core problems of gaining friendships, feeling empathy, expressing love, and being able to share experiences with others.
Developmental, individual differences, relationship-based approach (DIR)	Also known as "Floortime," this treatment method is based on the premise that the child can increase and build a larger circle of interaction with an adult who meets the child at his current developmental level and who builds on the child's particular strengths. The autistic child is challenged in moving naturally through these milestones as a result of sensory over- or under-reactions, processing difficulties, and poor control of physical responses. Floortime does not separate and focus on speech, motor, or cognitive skills but rather addresses these areas through a synthesized emphasis on emotional development.
Complementary and alternative medicine therapies	Includes techniques such as homeopathy, biologically-based therapies, energy therapies, etc.

Source: Centers for Disease Control and Prevention and Autism Speaks.

shown to cause regression in individuals' behavioral or emotional state. However, other intervention techniques have not always been shown to produce progress, and in some cases, have caused individuals to regress in their treatment.

In addition to the wide range of treatments available, the amount of treatment required for addressing children's developmental delays varies widely. For example, a health care professional might recommend that a child with high-functioning autism disorder receive fewer hours of treatment per week to help develop language, social, and motor skills compared to individuals with more severe disabilities related to their autistic disorders who need more extensive and comprehensive treatment to develop these skills.

## **b. History of Proposed Mandate**

A number of mandates previously proposed in Virginia have covered autism and other developmental delays. In 2006, HB 657 was proposed to cover medically necessary habilitative services for children with developmental delays under the age of 19. The determination as to which services would be considered medically necessary would have been made by the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS). The mandate also would not have obligated insurers to pay for services provided through schools. The Special Advisory Commission on Mandated Health Insurance Benefits voted to recommend against the enactment of HB 657 and expressed concern over defining the scope of the benefit, namely, the conditions to be remediated, current service delivery through mechanisms already in place, and the creation of a prudent and appropriate policy. The mandate also was not adopted by the General Assembly.

In 2005, SB 1049 was proposed and would have mandated health insurance coverage for treatment of developmental delays for children from birth to age five. The Advisory Commission concluded that further analysis was required of the burden that would be placed on the health care system, and the mandate was not adopted by the General Assembly.

In 2000, SB 165, as amended, would have expanded the population of children covered by the existing early intervention mandate. The early intervention mandate (Section 38.2-3418.5 of the *Code of Virginia*) requires that insurers provide coverage for medically necessary early intervention services up to \$5,000 per calendar year for children under age three. Early intervention services include those that are medically necessary, such as speech and language therapy, occupational therapy, physical therapy, and assistive technology services and devices. SB 165 would have expanded the population covered for medically necessary early intervention

services from children under age three to children under age 13 with diagnosed developmental disabilities. The Advisory Commission did not recommend the mandate based on concerns that costs associated with the existing early intervention mandate were unknown.

In 1999, the General Assembly enacted a health insurance mandate requiring parity with regard to mental illness that specifically includes autism. Section 38.2-3412.1:01 of the *Code of Virginia* requires that coverage for biologically based mental illnesses not be different from coverage for any other illness, condition, or disorder in determining deductibles, benefit year or lifetime durational limits, co-payment factors, and coinsurance factors.

At least 21 other states have adopted insurance mandates that cover autism. Many of these states include autism in their mental health parity mandates, as Virginia has included autism in its biologically based mental illness mandate. Mental health parity mandates require that coverage for mental illnesses not be different from coverage provided for other illnesses. However, according to insurance company representatives and advocacy groups for children with autism, such mandates often do not result in greater coverage of treatments for autism because many services, in particular behavioral treatments, may still be excluded. Also, many of the therapies normally covered through these mandates serve as restorative therapies for adults suffering illness or injury requiring rehabilitation. Historically, these services have been covered by insurance on a limited basis on the belief that they could be used more extensively than necessary to regain function. Thus, children often face more limited service coverage because the coverage was largely designed to cover adult needs.

A number of states have adopted more comprehensive autism mandates that require coverage of behavioral treatments for autism, such as ABA-based therapy. Behavioral treatments are the most controversial services in terms of obtaining health insurance coverage and are frequently excluded by insurance companies on the grounds that they are experimental or not medically necessary. Table 2 shows seven states—Arizona, Florida, Indiana, Louisiana, Pennsylvania, South Carolina, and Texas—that have passed mandates that specifically require private insurance companies to cover ABA-based treatments or other structured behavioral treatments. Pennsylvania is the most recent state to adopt a mandate in July 2008. More than half of the states in Table 2 require providers of behavioral treatments to be licensed or certified. In addition, most states have an annual maximum coverage limit ranging from \$25,000 to \$50,000.

**Table 2: States with Autism Spectrum Disorder Mandates Including Coverage for Applied Behavior Analysis-Based Treatment**

State	Year Enacted	Eligibility	Provider Requirements	Coverage Limits
Arizona	2008	Birth to 16 years.	Behavioral therapy services shall be provided or supervised by a licensed or certified provider	Annual: \$50,000 up to age 9 \$25,000 if between ages 9 & 16. Lifetime: None
Florida	2008	Under 18 years, or 18 years & older if in high school & have a developmental disability diagnosis at age 8 or younger.	ABA services shall be provided by an individual certified or licensed pursuant to Florida statute.	Annual: \$36,000 Lifetime: \$200,000
Indiana	2001	Not specified.	No licensing requirement.	Not specified.
Louisiana	2008	Under 17 years.	ABA providers must be certified by the Behavior Analyst Certification Board or provide comparable credentials.	Annual: \$36,000 Lifetime: \$144,000
Pennsylvania	2008	Under 21 years.	Behavior specialists must be licensed or certified by the State Board of Medicine according to statutory guidelines or be enrolled in Pennsylvania's medical assistance program.	Annual: \$36,000 Lifetime: None
South Carolina	2007	Under 16 years & diagnosed with an ASD at age 8 or younger.	Not specified.	Annual: \$50,000 Lifetime: None
Texas	2007	Older than 2 years & younger than 6 years.	Practitioners must hold a state or national license, certification, or registration or be certified under the TRICARE military health system.	Not specified

Source: Information on Arizona, Florida, Indiana, South Carolina, and Texas provided by Autism Speaks, PA HB 1150.

In addition to those states requiring coverage for autism services, the federal government has also begun covering treatments for autism for dependents of military personnel through TRICARE, the federal government's health insurance plan for military personnel and their dependents. TRICARE covers habilitative services, including ABA-based treatment, for individuals with ASDs. This coverage is available under TRICARE's Extended Care Health Op-

tion (ECHO). The TRICARE maximum allowable charge for ECHO services, including ABA-based treatment, is \$2,500 per month as long as a certified provider administers the service. As of March 2008, TRICARE initiated an Enhanced Access to Autism Services Demonstration which will offer more options for autistic children. While the maximum allowable charges for services remains the same, the demonstration seeks to expand the availability of ABA-based services by expanding the definition of who can be an authorized ABA provider.

### **c. Proponents and Opponents of Proposed Mandate**

Proponents and opponents of HB 83 will have the opportunity to officially express their views at a public hearing held on September 29, 2008, by the Special Advisory Commission on Mandated Health Insurance Benefits. The main proponents for the proposed mandate appear to be advocacy groups for children with autism, ABA-based therapy providers, and parents of children with ASDs. The main opponents to the proposed mandate appear to come from the health insurance industry.

Proponents of the proposed mandate indicate that the therapeutic needs of children with ASDs are not adequately addressed through the public school system, and in some cases, cannot be adequately addressed by the school system. They further advocate that health insurance should assist families in helping to ensure that children with autism receive recommended levels of therapeutic services as early as possible. Proponents point out that there is a window of opportunity for helping these children while they are young, and missing this window, due to lack of finances or protracted appeals processes with insurance companies, prevents children from reaching their maximum potential in terms of learning and functioning in society.

Opposition to the proposed mandate appears to come primarily from the health insurance industry. Reasons include the view that it is inappropriate for health insurance companies to cover habilitative services even though some companies already provide limited coverage of these services. Insurers also argue that many treatments for autism are experimental or investigational. Another cause for opposition is concern that any mandate leads to higher health insurance premiums, which in turn may increase the number of uninsured.

### **MEDICAL EFFICACY AND EFFECTIVENESS**

Speech, physical, and occupation therapy are generally accepted by the medical and educational communities as being effective treatments for individuals with ASDs. Therefore, the medical efficacy

and effectiveness of these treatments will not be discussed in this section. In addition to these therapies, many other treatment methods are used to address conditions associated with ASDs, in particular behavior disorders. Among those treatments designed to address behavioral disorders are those based on Applied Behavior Analysis (ABA). According to medical experts and the American Academy of Pediatrics (AAP), the effectiveness of ABA-based therapy has been well documented over many decades. However, the extent to which other behavioral treatments have been researched and their effectiveness documented varies. In general, the AAP indicates that any treatments used should be based on sound theoretical constructs, rigorous methodologies, and empirical studies of efficacy.

#### **Medical Efficacy**

Assessments of medical efficacy are typically based on clinical research, particularly randomized clinical trials, demonstrating the efficacy of a particular treatment compared to alternative treatments or no treatment.

#### **Medical Effectiveness**

Medical effectiveness refers to the effectiveness of a particular treatment in a normal clinical setting as opposed to ideal or laboratory conditions.

### **a. Medical Efficacy of Benefit**

No randomized clinical trials on treatment interventions for individuals with ASDs were found. However, many researchers have conducted a large number of studies based on small sample size populations. In aggregate, these studies appear to establish a pattern that certain treatment approaches do improve the outcomes of individuals with ASDs, with behavioral interventions such as ABA-based therapy being especially effective for improving social, cognitive, and behavioral skills of individuals with ASDs.

### **b. Medical Effectiveness of Benefit**

Although randomized clinical trials are not available, research has shown the effectiveness of certain treatment models for ASDs, in particular ABA-based therapy. Studies dating back to the 1960s have documented the success of applied behavioral intervention methods, and the AAP indicated in a 2007 clinical report that “the effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research.” The AAP further stated that children who receive early intensive behavioral treatment have been shown to make substantial gains in IQ, language, and social behavior. In addition, a review conducted by the U.S. Surgeon General in 1999 stated that applied behavioral treatment methods are useful in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior for individuals with ASD. Medical experts in autism at two Virginia medical schools also indicated that evidence supports the use of ABA-based therapy in children with autism.

As mentioned previously, the benchmark study showing the effectiveness of ABA-based therapy on children with ASDs was conducted by O. Ivar Lovaas in 1987. This study examined the effectiveness of intensive behavioral therapy for two years and

compared it with two control groups. First-grade follow-up revealed that nearly half the experimental group was able to participate in regular school compared to very few of the matched control group.

A 1993 follow-up to Lovaas' 1987 study assessed the same 19 subjects at a mean age of 11.5. The results of the 1993 study showed that the experimental group preserved its gains over the control group. The nine experimental subjects who had achieved the best outcomes at age seven received particularly extensive evaluations indicating that eight of them were indistinguishable from average children on tests of intelligence and adaptive behavior.

In addition to Lovaas' research, more recent studies have continued to document the effectiveness of early intensive behavioral treatment. In particular, several studies published between 2002 and 2006 compared the effectiveness of intensive behavioral treatment, defined as one-on-one behavioral treatment for 25-40 hours per week, to more "eclectic" intervention methods that employ a variety of treatment techniques. The findings of these studies are consistent with previous research showing the effectiveness of intensive behavioral treatment over other therapy types. The children receiving early intensive behavioral treatment in these studies were found to have larger improvements in their IQs, perform better on other cognitive tests, and were more likely to be placed in regular education classrooms than children in the control groups receiving other treatment techniques.

A recent Fairfax County public school program provides further evidence demonstrating the effectiveness of ABA-based therapy. Fairfax County schools implemented an Applied Behavior Analysis Enhanced Services program in 2002 which incorporates ABA techniques into the classroom setting for children with ASDs. The children placed in these classrooms tend to be on the moderate or severe end of the ASD spectrum. Teachers are trained in a core set of principles, including reinforcement, prompting, and task analysis, and use different methods such as verbal behavior intervention and shaping to enhance the learning experience. A 2006 review of the program found improved outcomes for aberrant behavior and communication, daily living, socialization, and motor skills. In addition, between 56 and 71 percent of surveyed parents indicated that they strongly agreed or agreed that their autistic child had progressed in their academic, behavioral, communication, motor, self help, and social skills.

While the effectiveness of ABA-based therapy has been well documented, the AAP indicates in its clinical report that the evidence is more limited for other types of therapies, such as structured teaching (TEACCH), floortime, and sensory integration therapy. (These



therapies are described in Table 1.) Many families with children who have ASDs also explore complementary and alternative medicine (CAM) treatment, such as music therapy, chelation, or gluten/casein-free diets. The AAP indicates that there is not enough scientific evidence yet to either support or refute the use of CAM interventions as treatment for ASDs. Further, some CAM treatments can be dangerous and, therefore, cannot be endorsed outside of appropriately monitored clinical trials. In general, the AAP recommends that all treatments, including educational interventions, should be based on sound theoretical constructs, rigorous methodologies, and empirical studies of efficacy.

## **SOCIAL IMPACT**

The CDC estimates that one in 150 children have an ASD, though more recent data indicates that this estimate may be somewhat high. Data provided by the Department of Education (DOE) indicates that there are approximately 7,500 public school children in Virginia with an ASD aged 20 or younger. Services to treat ASDs are provided through the Early Intervention System and the public schools. However, families, medical experts, and providers of ASD services indicate that some children require services in addition to those provided through the schools, and it appears that the majority of families seek treatment for their child's ASD outside of the schools. One third of health insurance plans indicate that they cover ASD-related treatment, but far fewer cover treatment for ABA-based therapy. For those families that do not have insurance coverage for ASD services, the cost of obtaining services may result in a considerable financial hardship depending on the severity of their child's condition. In some cases, the cost of intensive behavioral therapies could range from nearly ten percent of median household income in Virginia to greater than median household income.

### **a. Utilization of Treatment**

House Bill 83 would affect those services that children with ASDs receive outside of the public schools. A 2002 DOE report indicated that most families appear to access services outside of the public schools for their children. In a survey of parents, 72 percent reported incurring out-of-pocket expenses for services related to their child's disability during the past three years. Experts and advocates indicate that the number of families wishing to obtain services is probably higher, but some families are prohibited from obtaining additional services due to an inability to pay for such services.

The specific services a child with an ASD receives depend greatly on the severity of the disabilities associated with the ASD and the child’s level of functioning. The DOE report and Medicaid provide insight into the types of services children are receiving outside of the school setting. Table 3 provides information from the DOE report on the percent of parents who paid for services out of pocket during the three years preceding the report. Medical treatment and speech therapy were the services parents reported paying for most frequently, followed by occupational therapy, behavior therapy, and counseling.

**Table 3: Percent of Parents Who Paid for Services Out of Pocket According to 2002 Department of Education Study**

Type of Service	Percent of Parents Who Paid for Service
Medical Treatment	34%
Speech Therapy	27
Occupational Therapy	16
Behavior Therapy	16
Counseling	13
Respite Services	12
Tutoring	7
Sensory Integration	5
Physical Therapy	2

Note: Percentages sum to more than 100 because some parents paid for more than one service.

Source: Services Available for Individuals with Autism and Pervasive Developmental Disorders; Virginia Department of Education, 2002.

Because Medicaid covers treatment for ASDs, Medicaid data also reveal the types of services children receive outside of the school setting. Table 4 shows that case management was the most frequently provided service through Medicaid to children with ASDs. Evaluative services were the next most frequently provided service, followed by pharmacological management, respite care and skills training, individual psychotherapy and behavior modification therapy, and mental health and behavioral health services provided in group homes.

Several differences appear to exist between the services reported by parents to DOE and those provided through Medicaid. First, while speech and occupational therapy were among the services most frequently reported by parents, comparatively fewer children on Medicaid received these services outside of school. The two most frequently provided services for children on Medicaid were case management (60 percent) and evaluative services (49 percent). There is currently not a designated case management system to coordinate care for children outside of the Medicaid system. With regard to evaluative services, children reflected in the DOE report

already had an educational identification of autism so families had already participated in an evaluation process in the education setting. Another possible explanation for the differences in the services provided shown in the two tables is that the services in Table 3 likely were obtained by parents on the advice and under the direction of physicians and therapists, but in some cases, perhaps on their own initiative. In many cases, the services provided to children on Medicaid would have been coordinated through a case manager.

**Table 4: Percent of Children With ASDs on Medicaid Who Received Services Outside of a School Setting, July 2005 - June 2007**

<b>Category of Service</b>	<b>Percent of Children Receiving Service</b>
Case Management	60%
Evaluative Services	49
Pharmacological Management	34
Respite Care and Skills Training	28
Individual Psychotherapy and Behavior Modification Therapy	25
Mental Health and Behavioral Health at Group Homes	20
Speech Therapy	14
Other Psychotherapy (including group & family)	14
Occupational Therapy	9
Physical Therapy	5

Source: JLARC staff analysis of data provided by the Department of Medical Assistance Services.

With regard to medical, pharmacological, mental health, and psychotherapy services, medical experts indicate that many children with autism have co-occurring conditions such as depression, anxiety, or obsessive compulsive disorders. Therefore, it is difficult to discern whether services are provided to treat a child's autism versus another condition.

ABA-based therapy was not separately identified as a category of service in the DOE report, and Medicaid does not have a service category dedicated to ABA-based therapy. If ABA-based therapy were provided through Medicaid, it would be included in the individual psychotherapy and behavior modification therapy category. Staff at the Department of Medical Assistance Services (DMAS) were not aware of any recent requests to obtain Medicaid coverage for ABA-based therapy, but Medicaid may be reimbursing these types of services as individual specific therapies under the category of individual psychotherapy and behavior modification therapy.

As discussed above, while case management for children with autism is often provided through Medicaid, such coordination of services is not provided for children covered by other third party health care financing programs. Medical experts and service providers indicate that coordination of services between schools, home, and the community is crucial to ensure continuity of services provided to children with ASDs and to ensure the success of treatments. However, currently this is often done to only a limited extent. Coordination of services is also important to ensure consistency of services, a key aspect for children with ASDs, who often depend on structure and routine. Presently, most experts agree that services are generally not well coordinated for children with ASDs, and it is often left up to the parents to find and coordinate services for their child.

### **b. Availability of Coverage**

Based on a Bureau of Insurance (BOI) survey of the top 50 health insurance providers in Virginia, 14 of the 42 companies responding to the survey indicated that they provide coverage of ASD-related services. However, several providers indicated that services are limited based on a member's policy limits, medical necessity review, the plan's medical policy, and covered provider types. Less than one third of companies indicating they provide coverage for ASD-related services appear to cover ABA-based therapy. Of those companies providing coverage of ASD services, only four indicated that they cover ABA-based therapies. One company indicated that ABA-based therapy is covered if rendered by a covered medical professional, and that there is a limit of 20 visits per year with a \$1,000 per year annual cap and a \$10,000 lifetime limit for certain of its plans. Two other plans appear to only cover this type of therapy as part of a separate behavioral health benefit.

Twenty companies responding to the survey indicated that they do not provide coverage for ASD services as required by HB 83. Several of these respondents indicated that coverage for ASDs is already provided under the State's biologically based mental illness mandate, which requires that coverage for mental illnesses not be different from coverage provided for other illnesses. However, as mentioned previously, the biologically based mental illness mandate does not prevent insurers from excluding certain services such as behavioral therapy. (An additional eight plans indicated that Virginia health insurance mandates do not apply to their policies.)

Health insurance companies indicate a number of reasons why they do not provide coverage for certain types of ASD-related services. One reason is that many treatments for ASDs are considered experimental, investigational, or unproven. ABA-based therapy is

frequently included in this category, even though medical experts and the AAP have indicated that sufficient evidence exists to establish its effectiveness. In addition, insurance companies often make a distinction between therapies which are rehabilitative and those which are habilitative, or not restorative, in nature. These definitions often reflect considerations for adults injured or recovering from illness rather than the growth and developmental issues associated with children. Insurance is more likely to cover rehabilitative therapies that restore a level of function. Further, while treatment for medical conditions frequently associated with ASDs, such as digestive problems, are covered under health insurance, other treatments, such as ABA-based techniques, are viewed by health insurers as educational or behavioral and therefore not medically necessary. Medical experts indicate that even though there is often an attempt to classify ASD treatments as either educational or medical, many treatments can be considered both educational and medical so such a distinction is not warranted.

### **c. Availability of Treatment / Benefit**

The availability of ASD services may be problematic in certain areas of the state. A 2005 study by Pricewaterhouse Coopers noted that there may be shortages of physical, occupational, and speech therapists in Northern Virginia. This conclusion was based on a survey conducted of providers in 2004 regarding unfilled staff positions. DOE's 2002 report on services for individuals with autism and pervasive developmental disorders also found that there may be a shortage of providers in a few areas of the State, although no specific regions were identified. However, 11 percent of parents who were asked why their children with ASDs were not receiving needed treatments indicated that services were not available in their area.

### **d. Availability of Treatment Without Coverage**

Children with ASDs have access to treatment even without insurance coverage for their conditions through Early Intervention Services (EIS) and the public schools. EIS is a joint federal and local program that was established by Part C of the federal Individuals with Disabilities Education Improvement Act (IDEA). EIS provides many services for children age three and younger with developmental delays or at risk for developmental delays. For children that qualify for the EIS program, some services are provided free of charge. For other services, there is a sliding scale for payment, based on ability to pay.

For children older than age two with disabilities, Part B of IDEA obligates public schools to provide the services and support neces-

sary for their education. In particular, schools are to provide a free and appropriate public education (FAPE) for children who are identified with a disability that requires special education and related services. To provide children with FAPE, children requiring special education and related services receive an Individualized Education Program (IEP). The IEP is the cornerstone of their education and must be individualized for each child. The IEP includes information such as the child's current performance; annual goals for the child (which can include academic, social, behavioral, and other goals), special education services to be provided, and the extent to which the child will participate with non-disabled children.

Although children's IEPs must specify the services they are to receive, this data is not captured at the State level. Therefore, statewide data on the services received by children with ASDs in Virginia's public schools is not available. However, services most frequently provided (in addition to educational services by a teacher) likely include those provided by speech therapists, occupational therapists, school psychologists, social workers, school nurses, or aides.

Even though services for children with ASDs are provided through EIS and the public schools, many families, medical experts, and providers of ASD services indicate that there may be situations in which children are unable to receive adequate services through the schools to address their needs. (These may also be services that schools deem to be outside the scope of IDEA's entitlement to FAPE.) This was also reflected in the 2002 DOE report that found almost 30 percent of parents and 25 percent of special education teachers surveyed disagreed that children with ASDs receive the types of services that they need. While the survey did not specify where services are provided, given that the majority of services are currently provided through schools, the survey responses support the assertion that adequate services may not always be available in the schools.

Part of the disconnect between the services some children may need and what they receive from the public schools may stem from the fact that schools are required to provide what is needed for students to learn and function in an educational environment. However, the services provided by schools may not fully meet the needs of children to function at home or in settings outside of school. Further, some schools may not be equipped to provide the highly intensive one-on-one behavioral therapy that is needed by some children. Some children who do not receive this intensive behavioral therapy may not develop the basic attention skills needed to benefit from the programs a school has to offer.

If children require additional services outside of school, costs can be significant, and depending on the impact of the child's disability on functioning, those costs can pose a significant barrier for families seeking these services. As described in the 2002 DOE report, among parents whose children were not receiving needed services, the two most frequently cited reasons were inability to afford needed services (33 percent) and insurance refusing to cover the cost of services (28 percent).

#### **e. Financial Hardship**

For families without health insurance coverage for treatment related to their child's ASD, the level of financial hardship depends on the severity of the disability associated with the child's ASD. A high-functioning child may require very little, if any, treatment outside of the school system. However, a child with more severe disabilities related to autism may need much more intensive treatment. In addition, costs may vary depending on a child's age. The costs for intensive behavioral therapies are typically much higher when a child is young (for example, from ages three to six) and diminish as a child ages. For these reasons, it is very difficult to generalize about the potential level of financial hardship for a family with a child that has an ASD.

One medical center in Virginia provided illustrative cost estimates for various therapies a child with an ASD could receive (Table 5). Hourly cost estimates would vary by the provider and the menu of services a child would receive would depend on his particular level of disability. However, the annual cost estimates on Table 5 range from \$5,928 for receiving physical or occupational therapy once a week to nearly \$75,000 for highly intensive ABA-based therapy.

While \$75,000 may be on the high end of what families may face, these estimates are in the range reported by other sources. A 2003 study estimated the annual cost of intensive behavioral therapies to be \$41,295 for preschool-aged children and to range from \$4,140 to \$5,914 for older children. A 2007 study estimated the cost of early intensive behavioral interventions to be approximately \$22,500 annually.

A Virginia provider of ABA services also estimated annual costs in this range for behavioral therapy. This provider indicated that services for in-home ABA-based treatment are approximately \$50 an hour, and the provider recommends that individuals receive no less than 12 hours per week in order to maintain the efficacy of the service. The provider indicated that children typically receive 15 hours of in-home therapy per week, which results in approximately \$3,000 per month or \$36,000 per year in therapy costs.

**Table 5: Illustrative Costs for Therapies a Child With Autism May Receive**

<b>Treatment</b>	<b>Cost per Hour</b>	<b>Frequency</b>	<b>Estimated Annual Cost</b>
Speech therapy	\$114	3 times weekly	\$17,784
Physical & occupational therapy, cognitive skills development	\$114	1-2 times weekly	\$5,928-\$11,856
Physical & occupational therapy, sensory integration	\$114	2 times weekly	\$11,856
Physical & occupational therapy, activities of daily living	\$114	1-2 times weekly	\$5,928-\$11,856
Physical & occupational therapy, manual therapy	\$114	1-2 times weekly	\$5,928-\$11,856
Applied Behavior Analysis (ABA)-based therapy	\$40	4-6 hours daily for 6 days per week	\$49,920-\$74,880
Other therapies, such as aquatics, exercise or dance	\$15	1-2 times weekly	\$780-\$1,560

Source: Virginia medical center.

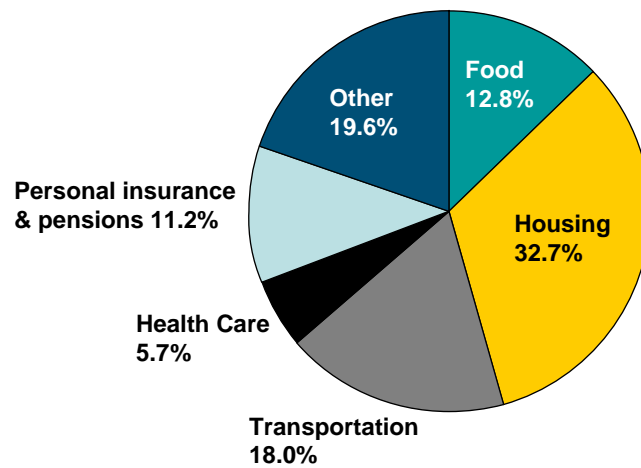
Depending on the level of services children may need, the cost of providing treatment for their ASDs could result in a considerable financial hardship for families. Based on data from the U.S. Census Bureau that has been adjusted for inflation, the median household income in Virginia for 2008 is \$58,607. Therefore, the costs of speech, physical, or occupational therapies could range from 10 to 30 percent of median household income. The costs of intensive behavior therapies could be even higher, ranging from 38 percent to well over median household income. As shown in Figure 1, this is significantly more than the amount households typically allocate to health care costs. According to the Bureau of Labor Statistics Annual Consumer Expenditure Survey for 2005, U.S. households typically allocated 5.7 percent of their annual expenditures on health care costs.

Many children with ASDs would not require the levels of therapy discussed above; therefore, the costs to their families would not be as great. However, several other issues may exacerbate the financial hardship faced by families with children who have ASDs. Some children require multiple therapies listed on Table 5, which would increase costs. Also, some families have multiple children with ASDs, which can greatly drive up the cost of services for these



families. Further, studies have found that children with ASDs often have higher medical costs, in addition to those costs related to their ASD therapies. One 2004 study found that children with ASDs utilized medical services more frequently, and the total annual cost to address the medical needs of a child with an ASD is more than three times higher than the medical expense for children without an ASD (\$2,757 versus \$892). For those families with children requiring multiple and intensive therapies, some families report accumulating substantial debt in order to provide what they can for their children.

**Figure 1: Distribution of Total Annual Household Expenditures by Major Category, 2005**



Source: Bureau of Labor Statistics, Consumer Expenditure Survey

#### **f. Prevalence/ Incidence of Condition**

The CDC reports that about one in 150 children have an ASD. This is based on a 2007 report by the CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network which found that about one in 150 (or about 6.66 in 1,000) eight-year-old children in multiple areas of the United States had an ASD. Based on this prevalence rate and Virginia’s population, approximately 13,810 Virginians aged birth to 19 are estimated to have an ASD. However, medical experts indicate that recent data shows that actual prevalence rates may be lower than the CDC’s estimate of one in 150. Therefore, the estimated prevalence in Virginia of 13,810 individuals is likely on the high end.

Data from DOE indicates that, as of December 2007, 7,509 children aged 20 or younger were identified with an ASD and received special education and related services within the public school sys-

**Prevalence**

Prevalence is defined as the total number of cases of the condition in the population at a specific time.

tem. This number is well below the number of children with ASDs estimated using the CDC's prevalence rate, but may provide a somewhat conservative estimate for several reasons. First, DOE does not have data on the number of children under age two that have been diagnosed with an ASD. Also, some children with ASDs may not meet the eligibility requirements to receive services through the school system and therefore may not have been identified as having an ASD for educational purposes. Further, some children with ASDs are enrolled in private schools, or are not enrolled in school at all, as may be the case of the individuals in the older age range specified by the bill.

A 2005 study estimated the prevalence of separate ASDs within the autism spectrum. This study was based on preschool children living in England and found a prevalence of 1.9 in 1,000 children for autistic disorder; 0.95 in 1,000 for Asperger syndrome; and 3.1 in 1,000 children for Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

According to the CDC, more children than ever before are being classified as having an ASD. Also, boys are three times more likely to be diagnosed with an ASD than girls. However, it is unclear how much of the increase in prevalence is due to changes in how ASDs are identified and classified and how much is due to a true increase in prevalence. By current standards, ASDs are the second most common serious developmental disability after mental retardation/intellectual disability, but they are still less common than other conditions that affect children's development, such as speech and language impairments, learning disabilities, and attention deficit/hyperactivity disorder (ADHD).

### **g. Demand for Proposed Coverage**

Several sources indicate that there is demand for the coverage in HB 83. The 2002 DOE report on autism services indicated that the inability to afford services and lack of insurance coverage prevented children with autism from receiving autism-related services. When parents were surveyed about the reasons their children had not received needed services, the most frequently cited reasons were inability to afford services (33 percent) and insurance refusing to cover the cost of services (28 percent). Also, previously proposed legislation in Virginia that would have covered children with developmental delays, including autism, appears to demonstrate a persistent demand for coverage of these services. As indicated previously, while a third of insurance companies responding to a BOI survey indicated that they provide coverage of ASD services, far fewer of those provide coverage for ABA-based therapy, the type of therapy most frequently discussed as needing coverage by some medical experts and advocates of HB 83. The DOE survey

results, combined with the lack of coverage for ASD services reported by health plans, suggests that many parents of children with ASDs desire greater insurance coverage for treating their children's condition.

However, not all children with ASDs would benefit from HB 83. According to the best available estimates, there are 7,509 children with ASDs in Virginia (based on the number of children identified with ASDs and receiving special education and related services within the public school system in 2007). Based on estimates that about one third of Virginia's population are in health plans that are affected by mandates, approximately one third of these children (about 2,500 children) could benefit from the proposed mandate if they do not have coverage already and if they require additional services outside of school.

#### **h. Labor Union Coverage**

Unions do not appear to have advocated specifically for the inclusion of services to treat children's ASDs in their health benefit packages. Typically, unions advocate for broader benefits, rather than benefits as specific as coverage for habilitative services for children with ASDs.

#### **i. State Agency Findings**

In 2002, DOE reported to the General Assembly on the services available for individuals with autism and pervasive developmental disorders. The findings of this report are referenced as relevant under the various criteria for this report.

In 2005, DMHMRSAS reported to the General Assembly on the cost and feasibility of alternatives to the State's five mental retardation training centers. The report recommended that the current Medicaid waiver for persons with mental retardation allow reimbursement for therapeutic behavioral consultation. Although many children with ASDs receive services from the Individual and Family Developmental Disabilities Supports (DD) waiver or the Early Periodic Screening, Diagnosis and Treatment (EPDST) program, this report noted that allowing reimbursement for therapeutic behavioral consultation services would enable more people to receive services such as positive behavior support or other types of ABA therapy. This change acknowledged the importance of ABA-based therapy as part of the treatment plan for developmentally disabled individuals.

In 2005, the Special Advisory Commission on Mandated Health Insurance Benefits studied SB 1049, which would have mandated health insurance coverage for treatment of developmental delays

for children from birth to age five. The report documenting the Advisory Commission's study indicates that the Commission voted against enacting SB 1049.

In 2006, the Advisory Commission studied HB 657, which would have covered medically necessary habilitative services for children with developmental delays under the age of 19. The report documenting the Advisory Commission's study indicates that the Commission voted against enacting HB 657.

In 2006, the Joint Legislative Audit and Review Commission (JLARC) also evaluated HB 657. The JLARC evaluation found that the proposed mandate was consistent with the role of insurance and that there appears to be a need for habilitative services for children with developmental delays. However, the report found that the costs of the proposed mandated were unclear, making it difficult to determine whether the benefits would justify the costs. The report suggested that clarifying language in the mandate and gathering additional data for further evaluation would be useful.

#### **j. Public Payer Coverage**

Medicaid provides greater coverage for developmental delays, including autism, than many private insurance policies. The State Medicaid plan provides coverage for physical, occupational, and speech therapy for children with developmental delays which is medically necessary. In the context of treating children with developmental delays, these therapies are often habilitative because they are frequently used to help children attain functioning which they have never possessed. Although insurers often distinguish between habilitative and rehabilitative services and only cover rehabilitative services, arguing they are services to regain functions lost to illness or injury, Medicaid does not make this distinction. These services are used to assist children in attaining functions considered as part of normal growth and development. The DMAS provider manual describing coverage for rehabilitative services specifically states that "rehabilitation services for speech impairments secondary to developmental delays, autism, and other related communication disorders are also covered services."

In addition to the State Medicaid plan, children with ASDs may receive services through the Medicaid waiver programs. The Mental Retardation (MR) and Elderly or Disabled with Consumer Direction (EDCD) waivers cover children with a developmental delay up to age six. Once a child with an ASD turns six, if there is no accompanying mental retardation diagnosis the child will ideally receive services through the Individual and Family Developmental Disabilities Supports (DD) waiver according to slot allocation and funding. As of June 2008, 594 individuals were receiving services

through the DD waiver and approximately half of those had a diagnosis of an ASD. There were also 597 people on the waiting list for the DD waiver, 274 of whom were diagnosed with an ASD.

While on the wait list for the DD waiver, children will often receive services through the EDCD waiver until a DD waiver slot becomes available. If children who are on the MR waiver turn age six and do not have a diagnosis of mental retardation, they will remain on the MR waiver until a smooth transition to the DD waiver occurs. The services available through the EDCD waiver include Personal Care (agency and consumer directed), Skilled Respite (agency directed), Non-Skilled Respite (agency and consumer directed), Personal Emergency Response System (PERS), Assistive Technology, Environmental Modifications, Transition Coordination, Transition Services, and Adult Day Health Care. Services available under the DD and MR waivers are Personal Care (agency and consumer directed), Respite Care (agency and consumer directed), Companion Care (agency and consumer directed) Assistive Technology, Environmental Modifications, Crisis Stabilization, Skilled Nursing, Transition Services, PERS, Congregate Residential (MR waiver only), Family/Caregiver Training (DD waiver only), Therapeutic Consultation (Psychology, Social work, Speech, Physical Therapy, Occupational Therapy, Therapeutic Recreation, Rehabilitation, Psychiatry, Psychiatric nursing, Positive Behavioral Supports, Behavioral Consultation), In-home residential, Day support, Prevocational Services, and Supported Employment.

Children with an ASD may also be eligible to receive services through a Medicaid program called Early Periodic Screening, Diagnosis and Treatment (EPSDT). This program covers additional therapies considered medically necessary that are not covered by the State's plan and was established specifically to identify and address growth and development needs in children. Although coverage for ABA-based therapy is allowed under EPSDT, DMAS staff indicated that they have not received any EPSDT reimbursement requests specifically for ABA services. However, Medicaid may be reimbursing these services as individual specific therapies. In general, there are very few EPSDT reimbursement requests for ASD-related services, although there was a recent request for intensive in-home therapy for behavioral modification for an autistic adolescent exhibiting violent behavior. DMAS staff indicated that the lack of reimbursement requests for additional ASD-related services could be because parents with autistic children enrolled in Medicaid may not be aware of ABA-based treatment; few ABA providers are enrolled in Medicaid; and Medicaid case managers may request reimbursement by specific therapy rather than indicating it is an ABA-based therapy or may not include this type of therapy in the child's service package or request

### **Public Health**

The role of public health is to protect and improve the health of a community through preventive medicine, health education, and control of communicable diseases.

## **k. Public Health Impact**

The proposed mandate could result in a positive health impact due to improvements in the cognitive, social, and behavioral skills and mental and emotional well-being of children with ASDs. There could also be direct health benefits to children, particularly for those who receive services at a very early age, which in some cases could include a reduced need for medical and other services over their lifetimes. However, it does not appear that, as a result of the proposed mandate, insurance companies could lower premiums due to avoiding future expenditures on children with ASDs. Although the cost of services for some children could be substantially lower by providing early intervention, the types of services children would otherwise need in the future are similar to those currently not covered by many insurance companies. An increase in insurance premiums as a result of the proposed mandate could lead to an increase in the number of uninsured Virginians. However, as will be discussed in a later section, the estimated premium impacts for the proposed mandate is within the range of the premium impacts for other existing mandates, suggesting that any negative public health impact due to higher premium costs would be similar to those observed for existing mandates.

## **FINANCIAL IMPACT**

The median estimated premium impact of HB 83 is \$4.88 per month for standard coverage, which is within the range of existing Virginia health insurance mandates. (Monthly premium estimates for optional coverage are higher.) This premium estimate appears somewhat high compared to the premium impacts estimated for similar autism mandates in other states. Including an annual or lifetime cap on coverage would help control the impact on premiums. Several other concerns exist with the mandate related to the safety and efficacy of treatments, but which could also affect premiums. These include the potential increased use of investigational or untested treatments and how to ensure that only reputable providers are covered by the mandate. These concerns could be addressed by limiting the mandate to evidence-based treatments and requiring certification or licensure of providers. A further concern voiced by medical experts and others is the lack of coordination of services for individuals with ASDs. This will be one of several issues reviewed in a separate JLARC study assessing the current availability and delivery of services to individuals with ASDs in Virginia.

### **a. Effect on Cost of Treatment**

House Bill 83 could have a modest impact on the cost of ASD-related treatments. One provider indicated that providers may in-

crease their charges if insurance were required to cover these services. Also, to the extent that there may be a shortage of providers in some areas, this may also drive up the cost of services as a result of increasing demand. However, as with other services, providers would need to enter into a contractual agreement with insurance companies. This could put pressure on providers to accept lower reimbursement rates in exchange for a higher volume of patients as a result of being included in a health plan's network. Because some parents already pay out of pocket ASD-related services and health insurance mandates affect an estimated one-third of the health insurance market, there may not be a large enough increase in the demand for services to significantly alter the costs of treatment.

### **b. Change in Utilization**

Utilization of services for children with ASDs would probably increase as a result of the proposed mandate. As indicated previously, many families seek treatment for their children with ASDs in addition to what is provided through the schools. In addition, some of the most frequent reasons mentioned by parents for why children do not receive treatment is an inability to pay for services and a lack of insurance coverage. Of the 7,509 children with ASDs reported by DOE, an estimated one third (approximately 2,500 children) would potentially benefit from the mandate. Although the mandate requires that the services provided be ordered or prescribed by a licensed physician or psychologist, there is some concern over the potential for an increase in unproven or untested treatments, and a possible lack of coordination with or decrease of services provided by public schools.

One concern voiced by some medical experts, treatment providers, and the insurance industry is that HB 83 does not require that covered treatments have evidence-based research supporting their effectiveness. Therefore, the language in the proposed mandate could leave the door open for individuals to seek reimbursement for any type of intervention therapy, not just those that have been evaluated and shown to be effective. Some medical experts and treatment providers suggest that this concern could be ameliorated by including language that would only require insurers to cover evidence-based treatment. With regards to whether this would include ABA-based therapies, as mentioned in the Medical Effectiveness section of the report, medical experts and the AAP consider these therapies to be an evidence-based treatment.

Another concern mentioned by the insurance industry and some medical experts is that requiring private insurance to pay for ASD-related services may create an incentive for public schools to discontinue or reduce services for children with ASDs. The extent to

which this would occur may be mitigated by the fact that mandates would only affect an estimated one third of children with autism. Further, DOE indicates that it does not anticipate that the proposed mandate would impact school services for students with ASDs. A reduction in school services for children with ASDs is not permitted by IDEA unless determined appropriate by the IEP team, which includes parents. Therefore, according to DOE, school divisions would continue to educate students regardless of outside service coverage.

Part of the concern over the potential impact of the mandate on school services likely stems from the fact that services for children with ASDs are generally not well-coordinated across treatment settings. Currently, there is often not a third party to assess and coordinate services provided by the school and the need for services outside of schools. In the case of Medicaid, DMAS often coordinates the services received by children with ASDs through a system of case management. DMAS staff indicate that case management is very important to the effective management of services for some children, particularly those with more severe disabilities related to their ASDs, because requests for service outside the schools may come from a number of sources including parents, doctors, and therapists. A separate JLARC study required by House Joint Resolution 105 from the 2008 General Assembly directs JLARC to assess the current availability and delivery of autism services in the Commonwealth and recommend ways to improve the delivery of autism services. Among other things, the JLARC report, which will be completed in 2009, will assess how services to children with autism are currently coordinated and how this process could be improved.

Related to the issue of coordination of services, there is frequently an effort by insurance companies and others to categorize services as either educational or medical, in part to determine the responsibility for paying for services. Medical experts indicate that trying to make this distinction is often not helpful or legitimate. Many treatments, including ABA-based treatments, are both educational and medical. According to one medical expert, “There is no answer to whether ASD therapies are medical or educational – they are both.” A public health expert further indicated that much of this distinction makes little sense considering that the primary role of children in our society is to learn to become functioning adults and productive members of society.

### **c. Serves as an Alternative**

The alternatives for children receiving services to treat their ASDs are either going without services or, in some cases, institutionalization. Anecdotally, families indicate that if they are unable to pay



for the recommended amount of services for their child, they will pay for what they are able. For example, rather than receiving a recommended 25 hours of ABA-based therapy each week, their child will only receive 15 hours. Parents and medical experts indicate that as a result, children may not reach their full potential, particularly given that the window of opportunity for maximizing the treatment for children with ASDs is limited.

In other cases, if children do not receive adequate services they may ultimately end up in an institution. Studies have shown institutionalization to be more costly, and often less desirable, than remaining in the community. For example, a 2004 study examined data on 50 people with mental retardation and challenging behavior who were in residences where either most persons had similar challenging conditions (congregate setting) or most persons did not have these conditions (non-congregate setting). The study concluded that the average costs were significantly higher for persons in the congregate setting (\$115,830) compared to the less restrictive non-congregate setting (\$96,010). While ASD treatments may not prevent all children from entering an institution or congregate setting, it could impact some, allowing them to live and participate in the general community.

#### **d. Effect on Providers**

The effect on providers will depend on the level of increased demand for services resulting from the proposed mandate. If there is a strong demand for services, the number of providers would probably increase to meet this demand in most areas. However, two factors may temper any increase in demand for services resulting from the proposed mandate: (1) some parents already pay out of pocket for habilitative services, so the proposed mandate will only change who pays for services, and (2) health insurance mandates affect only an estimated one third of Virginia's population.

One consideration is how to ensure that existing and potentially new providers of ASD services are reputable. While HB 83 requires that psychiatric care, psychological care, and therapeutic care must be provided by licensed or certified providers, there is no such requirement for habilitative and rehabilitative services, including ABA-based treatment. As a result, insurance companies have also indicated that it would be a challenge for them to determine which providers to include in their networks for habilitative and rehabilitative services that they do not currently cover.

Most states with ASD mandates covering behavioral services, such as ABA-based therapy, require that behavioral specialists must be licensed or certified. For example, the recently enacted Pennsylvania mandate requires that behavior specialists be licensed or

certified by the State Board of Medicine. Virginia does not currently provide licensing for ABA providers. However, a therapist can become certified by the Behavior Analyst Certification Board (BACB), a national non-profit corporation established to meet professional credentialing needs identified by behavior analysts, governments, and consumers of behavior analysis services. The BACB certification procedure requires regular review and validation pursuant to standards established by content experts in the field. Providers of ABA services in Virginia have indicated that certification does not necessarily ensure a higher quality service. Rather, they cited autism-specific coursework and training (as opposed to the more general ABA-based instruction provided by BACB certification) and intensive supervision as more effective in helping to ensure a high quality of service. However, requiring some level of certification or State licensure of providers would help to ensure a minimum level of quality for habilitative and rehabilitative services, such as ABA.

#### **e. Administrative and Premium Costs**

The proposed mandate is expected to result in increased administrative costs for insurance companies as a result of having to establish provider networks and negotiate reimbursement rates with providers they currently do not have in their networks. Median premium impacts for standard coverage are estimated to be \$4.88, with estimates for optional coverage being higher. These appear to be in the range of existing Virginia mandates, albeit on the high end. However, the premium estimates for HB 83 appear to be higher than those reported for other states. Including a cap on the annual claims amount would help limit the potential impact of HB 83 on premiums.

#### ***Administrative Expenses of Insurance Companies***

In its survey of insurance providers, BOI does not ask companies to provide estimates of their administrative expenses associated with the proposed mandate. However, representatives of the insurance industry indicate that the administrative expenses related to HB 83 would be higher than other mandates because health insurance does not typically cover some of the services included in the proposed mandate to treat ASDs. Therefore, insurers would need to establish provider networks and negotiate reimbursement rates with providers of the newly covered services. However, many services used to treat ASDs are already covered as rehabilitative services, such as speech therapy, physical therapy, and occupational therapies. Thus, provider networks would not require a totally new set of providers.

#### **Average Individual Insurance Premiums**

In October 2007, the Virginia Bureau of Insurance reported an average annual health insurance premium (with current mandated benefits) for an individual contract, single coverage, of \$2,929.58, or approximately \$244 per month.

### **Impact of Premiums on Employers' Decisions to Offer Health Insurance**

“Elasticity of offer” indicates how sensitive employers are to changes in premiums in their decisions to offer health insurance. The Congressional Budget Office and others have reported an elasticity of offer of approximately -0.25 across all employers meaning that a 10 percent increase in the average premium is predicted to decrease the likelihood of an employer offering health insurance by about 2.5 percent. Small employers are more sensitive to price and have a higher elasticity of offer. In addition to premiums, other factors affect employer decisions to offer health insurance including the availability of public coverage, such as Medicaid, non-group coverage alternatives for employees, the type of industry, and the employer's location.

### **Premium and Administrative Expenses of Policyholders**

BOI annually surveys the top 50 Virginia health insurers (based on premium volume) about the impact of proposed health insurance mandates. While an overall response rate to the survey of 84 percent (42 companies) was achieved, only a subset provided an estimate of the monthly premium cost for HB 83. Nine companies provided an estimate for individual policy holders (Table 6), and 20 companies provided an estimate for group certificate holders. (Eight additional companies responded that they did not conduct any business in Virginia that is impacted by mandates.) Although the mandate seeks to exclude individual policies from its required coverage, individual estimates are included here because there is an estimated annual premium available against which to compare the potential premium impacts of the mandate.

Among those companies providing individual coverage, the median monthly premium estimate for providing the proposed coverage as a standard benefit is \$4.88, with estimates ranging from \$0.14 to \$6.67. The median monthly estimate for providing the proposed coverage as an option is \$340.30, with estimates ranging from \$13.33 to \$657.60. Due to the low number of insurance companies providing estimates for individual optional coverage, and estimates at the top of the range that are grossly out of line with other premium estimates, the reliability of the estimates for individual optional coverage appears questionable. If the estimates of \$657.60 from two insurance companies are not included, the median estimate for individual optional coverage drops to \$18.17.

A premium increase of \$4.88 for individual standard coverage would result in a monthly premium increase of two percent based on the estimated average monthly premium cost for a single coverage, individual contract, as defined in BOI's 2007 report on the financial impact of mandated health insurance benefits. This would be more expensive than most of Virginia's insurance mandates, but within the range of existing mandates. BOI's 2007 report reports that the impact of existing mandates range from .08 percent to 4.01 percent of the overall average premium.

Among those companies providing group coverage, the median monthly premium estimate for providing the proposed coverage as a standard benefit is also \$4.88, with estimates ranging from \$0.04 to \$6.15. The median monthly estimate for providing the proposed coverage as an option is \$9.28, with estimates ranging from \$0.08 to \$822.00. If the high estimates at the top of the range provided by two insurance companies are not included, the median estimate drops to \$6.25. Data is not available on the monthly premium estimate for group plans, so it is not possible to calculate the percent increase in premium costs resulting from the mandate. However, the cost should be less given the larger insurance pool in group

plans that allows for spreading costs among a larger number of plan members.

**Table 6: Estimated Monthly Premium Impact for HB 83**

	<b># of Responses</b>	<b>Median Estimate</b>	<b>Highest Estimate</b>	<b>Lowest Estimate</b>
Individual (Standard)	9	\$4.88	\$6.67	\$0.14
Individual (Optional)*	4 (2)	\$340.30 (\$18.17)	\$657.60 (\$23.00)	\$13.33
Group (Standard)	20	\$4.88	\$6.15	\$0.04
Group (Optional)*	18 (16)	\$9.28 (\$6.25)	\$822.00 (\$14.00)	\$0.08

Note: Estimates from two companies are grossly out of line with other companies for individual and group optional coverage. If the estimates for these companies are not included, the median estimate drops to \$18.17 for individual option coverage and \$6.25 for group optional coverage.

Source: Bureau of Insurance survey of insurance providers, 2008.

The premium impacts of the estimates in Table 6 are somewhat higher than have been reported for autism mandates in other states. In 2008, the Council for Affordable Health Insurance estimated that mandated coverage for autism increases the cost of a policy by less than one percent. However, as mentioned previously, many states cover autism through their mental health parity mandates, which do not necessarily increase the types of services available to individuals with autism. In 2007, Autism Speaks provided an analysis of the Florida autism mandate, which includes ABA-based therapy. Autism Speaks estimated the maximum rate impact of the Florida mandate to be 0.47 percent. The recent comprehensive autism mandate passed in Pennsylvania is projected to increase premiums by approximately \$1 per month. And, the Louisiana Legislative Fiscal Office estimated a premium impact for Louisiana’s recently adopted autism mandate to range from 0.13 percent to 0.46 percent, or \$1.12 to \$3.87 per month.

One consideration impacting the potential premium impact of HB 83 is that the bill does not include an annual or lifetime cap on claims that would be covered by the mandate. Most other states with autism mandates, particularly those that cover behavioral services, include annual or lifetime caps on expenditures. Annual caps range from \$25,000 to \$50,000, and lifetime caps average around \$200,000. An annual or lifetime cap on claims would help limit the potential premium impact of HB 83.

## **f. Total Cost of Health Care**

There is limited research on the impact on overall costs of providing treatments for children with ASDs. The proposed mandate would allow some children access to services they are not currently receiving, which would increase total health care costs in the short term. However, most experts indicate that by assisting children in reaching their full potential through treating their ASDs, long-term costs could be reduced or avoided. One study that examined the savings possible using early intensive behavior intervention to treat children with ASDs estimated savings that ranged from \$187,000 to \$203,000 per child for ages three to 22 years. These estimates reflect a range of assumptions about the percentage of children treated with early intensive behavior intervention that would function in the normal range as a result of the therapy (between 20 and 50 percent).

Another consideration regarding the total cost of health care is that, as mentioned previously, overall health care costs for individuals with ASDs have been found to be higher than for other individuals. A recently published study found that people with autism spend twice as much as the typical American over their lifetime on medical costs. By effectively treating children with ASDs, it may be possible to reduce other health care costs in these individuals over the long term.

Further, as discussed previously, many autism interventions are both educational and medical in nature. Providing adequate, early intervention to treat ASDs may result in reduced needs for special education in the public schools for some children and their greater participation in society as adults.

## **BALANCING MEDICAL, SOCIAL, AND FINANCIAL CONSIDERATIONS**

There appears to be a need for health insurance coverage of ASD-related services, and the coverage of these services appears consistent with the role of health insurance. It may be desirable to require that treatments covered by the mandate be provided by certified or licensed providers and that only evidence-based treatments are covered to ensure that children are receiving safe and effective treatments. Also, capping the annual coverage amounts would help reduce the potential impact on premiums of the mandate. Currently, services to children with ASDs provided both inside schools and outside of the school setting are often not well coordinated. Therefore, it may be premature to consider adopting an insurance mandate for ASD-related services prior to the results of a separate JLARC study that will recommend ways to improve the delivery of services to individuals with ASDs.

### **a. Social Need/ Consistent With Role of Insurance**

Based on the premise that the role of health insurance is to promote public health, encourage the use of preventative care, and provide financial protection for excessive financial expenses for unexpected illnesses, the proposed mandate appears consistent with the role of health insurance. Although the insurance industry often claims that treatment for ASDs, such as ABA-based therapy, are educational and their coverage not appropriate for health insurance, medical experts disagree and indicate that many treatments are both medical and educational. The increasing number of states adopting comprehensive autism mandates, Medicaid coverage of ASD-related services, and coverage of these services by the U.S. military health plan provide further evidence that health insurance coverage of ASD-related services is appropriate.

While some ASD-related services are provided in the public schools, medical experts, advocacy groups, and parents indicate that there is a need for additional services outside of the school setting. In addition, medical experts and the American Academy of Pediatrics indicate that there is ample evidence supporting the effectiveness of certain treatments, such as ABA-based therapy. However, experts also agree that services received in school and outside of the school setting are frequently not well coordinated. State officials dealing with Medicaid indicate that case management is key to ensuring that some individuals with ASDs, particularly those with more severe disabilities related to their disorder, receive the appropriate array and amount of services. A separate JLARC study is assessing the availability and delivery of services to individuals with ASDs and will recommend ways to improve the delivery of services. It may be prudent to wait for the results of the JLARC study, which will be reported in 2009, before considering whether to adopt a health insurance mandate covering ASD services. Another consideration is that HB 83 does not require any certification or licensure of providers of ASD services, in particular ABA providers. Requiring services covered by the mandate to be provided by certified or licensed treatment providers would help ensure that children receive services from reputable and well-qualified providers.

### **b. Need Versus Cost**

There appears to be a significant need for ASD services outside of those provided by the schools for some children as indicated by medical experts, parents, and advocacy groups. For some children, the cost of these services may be very little. However, for children requiring intensive therapies, the cost could range from nearly ten percent of median household income in Virginia to greater than median household income. If families do not have insurance cover-

age and are unable to pay out-of-pocket, children may go without the adequate level of services, which could result in missed opportunities to meet their developmental potential. A BOI survey of health insurers indicates that the cost of the mandate would be within the range of existing mandates, although towards the top end of this range. However, the median premium estimates reported in the BOI survey are higher than those estimated in other states with similar mandates. Including a cap on coverage, as some other states have done, would help limit the impact of a mandate on premiums. Also, limiting the mandate to evidence-based treatments, which medical experts indicate should include ABA-based therapy, would not only control costs but would help ensure that children are receiving safe and effective treatments.

#### **Mandated Offer**

A mandated offer requires health insurers to offer for purchase the coverage described in the mandate for an additional fee.

#### **c. Mandated Offer**

A mandated offer would probably not meet the need for health insurance coverage of ASD services. Based on the BOI survey of health insurers, the premium impact of a mandated offer would likely be much higher, probably because only those most likely to use the benefit would purchase it.

#### **ACKNOWLEDGMENTS**

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## Statutory Authority for JLARC Evaluation of Proposed Mandated Health Insurance Benefits

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§ [2.2-2503](#). Special Advisory Commission on Mandated Health Insurance Benefits; membership; terms; meetings; compensation and expenses; staff; chairman's executive summary.

A. The Special Advisory Commission on Mandated Health Insurance Benefits (the Commission) is established as an advisory commission within the meaning of § [2.2-2100](#), in the executive branch of state government. The purpose of the Commission shall be to advise the Governor and the General Assembly on the social and financial impact of current and proposed mandated benefits and providers, in the manner set forth in this article.

B. The Commission shall consist of 18 members that include six legislative members, 10 nonlegislative citizen members, and two ex officio members as follows: one member of the Senate Committee on Education and Health and one member of the Senate Committee on Commerce and Labor appointed by the Senate Committee on Rules; two members of the House Committee on Health, Welfare and Institutions and two members of the House Committee on Commerce and Labor appointed by the Speaker of the House of Delegates in accordance with the principles of proportional representation contained in the Rules of the House of Delegates; 10 nonlegislative citizen members appointed by the Governor that include one physician, one chief executive officer of a general acute care hospital, one allied health professional, one representative of small business, one representative of a major industry, one expert in the field of medical ethics, two representatives of the accident and health insurance industry, and two nonlegislative citizen members; and the State Commissioner of Health and the State Commissioner of Insurance, or their designees, who shall serve as ex officio nonvoting members.

C. All nonlegislative citizen members shall be appointed for terms of four years. Legislative and ex officio members shall serve terms coincident with their terms of office. All members may be reappointed. However, no House member shall serve more than four consecutive two-year terms, no Senate member shall serve more than two consecutive four-year terms, and no nonlegislative citizen member shall serve more than two consecutive four-year terms. Vacancies occurring other than by expiration of a term shall be filled for the unexpired term. Vacancies shall be filled in the manner as the original appointments. The remainder of any term to which a member is appointed to fill a vacancy shall not constitute a term in determining the member's eligibility for reappointment.

D. The Commission shall meet at the request of the chairman, the majority of the voting members or the Governor. The Commission shall elect a chairman and a vice-chairman, as determined by the membership. A majority of the members of the Commission shall constitute a quorum.

E. Legislative members of the Commission shall receive such compensation as provided in § [30-19.12](#), and nonlegislative citizen members shall receive such compensation for the performance of their duties as provided in § [2.2-2813](#). All members shall be reimbursed for all reasonable and

necessary expenses incurred in the performance of their duties as provided in §§ [2.2-2813](#) and [2.2-2825](#). Funding for the compensation and costs of expenses of the members shall be provided by the State Corporation Commission.

F. The Bureau of Insurance, the State Health Department, and the Joint Legislative Audit and Review Commission and such other state agencies as may be considered appropriate by the Commission shall provide staff assistance to the Commission. The Joint Legislative Audit and Review Commission shall conduct assessments, analyses, and evaluations of proposed mandated health insurance benefits and mandated providers as provided in subsection D of § [30-58.1](#), and report its findings with respect to the proposed mandates to the Commission.

G. The chairman of the Commission shall submit to the Governor and the General Assembly an annual executive summary of the interim activity and work of the Commission no later than the first day of each regular session of the General Assembly. The executive summary shall be submitted as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports and shall be posted on the General Assembly's website.

§ [30-58.1](#). Powers and duties of Commission.

The Commission shall have the following powers and duties:

A. Make performance reviews of operations of state agencies to ascertain that sums appropriated have been, or are being expended for the purposes for which such appropriations were made and to evaluate the effectiveness of programs in accomplishing legislative intent;

B. Study on a continuing basis the operations, practices and duties of state agencies, as they relate to efficiency in the utilization of space, personnel, equipment and facilities;

C. Make such special studies and reports of the operations and functions of state agencies as it deems appropriate and as may be requested by the General Assembly;

D. Assess, analyze, and evaluate the social and economic costs and benefits of any proposed mandated health insurance benefit or mandated provider, including, but not limited to, the mandate's predicted effect on health care coverage premiums and related costs, net costs or savings to the health care system, and other relevant issues, and report its findings with respect to the proposed mandate to the Special Advisory Commission on Mandated Health Insurance Benefits; and

E. Make such reports on its findings and recommendations at such time and in such manner as the Commission deems proper submitting same to the agencies concerned, to the Governor and to the General Assembly. Such reports as are submitted shall relate to the following matters:

1. Ways in which the agencies may operate more economically and efficiently;

2. Ways in which agencies can provide better services to the Commonwealth and to the people; and

3. Areas in which functions of state agencies are duplicative, overlapping, or failing to accomplish legislative objectives or for any other reason should be redefined or redistributed.

# B

## House Bill 83: Mandated Coverage of Autism Spectrum Disorders

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Attached is House Bill 83



HOUSE BILL NO. 83

AMENDMENT IN THE NATURE OF A SUBSTITUTE

(Proposed by the House Committee on Commerce and Labor

on \_\_\_\_\_)

(Patron Prior to Substitute--Marshall, R.G.)

A BILL to amend and reenact § 38.2-4319 of the Code of Virginia and to amend the Code of Virginia by adding a section numbered 38.2-3418.15, relating to health insurance coverage for autism spectrum disorder.

**Be it enacted by the General Assembly of Virginia:**

**1. That § 38.2-4319 of the Code of Virginia is amended and reenacted and that the Code of Virginia is amended by adding a section numbered 38.2-3418.15 as follows:**

§ 38.2-3418.15. Coverage for autism spectrum disorder.

A. Notwithstanding the provisions of § 38.2-3419, each insurer proposing to issue group accident and sickness insurance policies providing hospital, medical and surgical, or major medical coverage on an expense-incurred basis; each corporation providing group accident and sickness subscription contracts; and each health maintenance organization providing a health care plan for health care services shall provide coverage for the diagnosis and treatment of autism spectrum disorder in individuals under the age of 21, as provided in this section.

B. For purposes of this section:

"Applied behavior analysis" means the design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relations between environment and behavior.

"Autism spectrum disorder" means any of the pervasive developmental disorders known as (i) autistic disorder, (ii) Asperger's Syndrome, or (iii) Pervasive Developmental Disorder - Not Otherwise

26 Specified, as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental  
27 Disorders of the American Psychiatric Association.

28 "Diagnosis of autism spectrum disorder" means medically necessary assessments, evaluations, or  
29 tests to diagnose whether an individual has an autism spectrum disorder.

30 "Habilitative or rehabilitative care" means professional, counseling, and guidance services and  
31 treatment programs, including applied behavior analysis, that are necessary to develop, maintain, and  
32 restore, to the maximum extent practicable, the functioning of an individual.

33 "Pharmacy care" means medications prescribed by a licensed physician and any health-related  
34 services deemed medically necessary to determine the need or effectiveness of the medications.

35 "Psychiatric care" means direct or consultative services provided by a psychiatrist licensed in the  
36 state in which the psychiatrist practices.

37 "Psychological care" means direct or consultative services provided by a psychologist licensed in  
38 the state in which the psychologist practices.

39 "Therapeutic care" means services provided by licensed or certified speech therapists,  
40 occupational therapists, or physical therapists.

41 "Treatment for autism spectrum disorder" includes the following care prescribed, provided, or  
42 ordered for an individual diagnosed with one of the autism spectrum disorders by a licensed physician or  
43 a licensed psychologist who determines the care to be medically necessary: (i) habilitative or  
44 rehabilitative care; (ii) pharmacy care; (iii) psychiatric care; (iv) psychological care; and (v) therapeutic  
45 care.

46 C. Except for inpatient services, if an individual is receiving treatment for an autism spectrum  
47 disorder, an insurer will have the right to request a review of that treatment not more than once every 12  
48 months unless the insurer, corporation, or health maintenance organization and the individual's licensed  
49 physician or licensed psychologist agree that a more frequent review is necessary. The cost of obtaining  
50 any review shall be covered under the policy, contract, or plan.

51 D. Coverage for autism spectrum disorder shall neither be different nor separate from coverage  
52 for any other illness, condition, or disorder for purposes of determining deductibles, benefit year, or

53 lifetime durational limits, benefit year or lifetime dollar limits, lifetime episodes or treatment limits,  
54 copayment and coinsurance factors, and benefit year maximum for deductibles and copayment and  
55 coinsurance factors.

56 E. Nothing shall preclude the undertaking of usual and customary procedures to determine the  
57 appropriateness of, and medical necessity for, treatment of autism spectrum disorder under this section,  
58 provided that all such appropriateness and medical necessity determinations are made in the same  
59 manner as those determinations are made for the treatment of any other illness, condition, or disorder  
60 covered by such policy, contract, or plan.

61 F. The provisions of this section shall not apply to (i) short-term travel, accident only, limited, or  
62 specified disease policies, (ii) short-term nonrenewable policies of not more than six months' duration,  
63 (iii) policies, contracts, or plans issued in the individual market or small group markets to employers  
64 with 25 or fewer employees, or (iv) policies or contracts designed for issuance to persons eligible for  
65 coverage under Title XVIII of the Social Security Act, known as Medicare, or any other similar  
66 coverage under state or federal governmental plans.

67 G. The requirements of this section shall apply to all insurance policies, subscription contracts,  
68 and health care plans delivered, issued for delivery, reissued, or extended on or after January 1, 2009,  
69 and to all such policies, contracts, or plans to which a term is changed or any premium adjustment is  
70 made on or after such date.

71 § 38.2-4319. Statutory construction and relationship to other laws.

72 A. No provisions of this title except this chapter and, insofar as they are not inconsistent with this  
73 chapter, §§ 38.2-100, 38.2-136, 38.2-200, 38.2-203, 38.2-209 through 38.2-213, 38.2-216, 38.2-218  
74 through 38.2-225, 38.2-229, 38.2-232, 38.2-305, 38.2-316, 38.2-322, 38.2-400, 38.2-402 through 38.2-  
75 413, 38.2-500 through 38.2-515, 38.2-600 through 38.2-620, Chapter 9 (§ 38.2-900 et seq.), §§ 38.2-  
76 1016.1 through 38.2-1023, 38.2-1057, Article 2 (§ 38.2-1306.2 et seq.), § 38.2-1306.1, § 38.2-1315.1,  
77 Articles 3.1 (§ 38.2-1316.1 et seq.), 4 (§ 38.2-1317 et seq.) and 5 (§ 38.2-1322 et seq.) of Chapter 13,  
78 Articles 1 (§ 38.2-1400 et seq.) and 2 (§ 38.2-1412 et seq.) of Chapter 14, §§ 38.2-1800 through 38.2-  
79 1836, 38.2-3401, 38.2-3405, 38.2-3405.1, 38.2-3407.2 through 38.2-3407.6:1, 38.2-3407.9 through

80 38.2-3407.16, 38.2-3411.2, 38.2-3411.3, 38.2-3411.4, 38.2-3412.1:01, 38.2-3414.1, 38.2-3418.1 through  
 81 38.2-3418.14, [38.2-3418.15](#), 38.2-3419.1, 38.2-3430.1 through 38.2-3437, 38.2-3500, subdivision 13 of  
 82 § 38.2-3503, subdivision 8 of § 38.2-3504, §§ 38.2-3514.1, 38.2-3514.2, 38.2-3522.1 through 38.2-  
 83 3523.4, 38.2-3525, 38.2-3540.1, 38.2-3542, 38.2-3543.2, Article 5 (§ 38.2-3551 et seq.) of Chapter 35,  
 84 Chapter 52 (§ 38.2-5200 et seq.), Chapter 55 (§ 38.2-5500 et seq.), Chapter 58 (§ 38.2-5800 et seq.) and  
 85 § 38.2-5903 of this title shall be applicable to any health maintenance organization granted a license  
 86 under this chapter. This chapter shall not apply to an insurer or health services plan licensed and  
 87 regulated in conformance with the insurance laws or Chapter 42 (§ 38.2-4200 et seq.) of this title except  
 88 with respect to the activities of its health maintenance organization.

89 B. For plans administered by the Department of Medical Assistance Services that provide  
 90 benefits pursuant to Title XIX or Title XXI of the Social Security Act, as amended, no provisions of this  
 91 title except this chapter and, insofar as they are not inconsistent with this chapter, §§ 38.2-100, 38.2-136,  
 92 38.2-200, 38.2-203, 38.2-209 through 38.2-213, 38.2-216, 38.2-218 through 38.2-225, 38.2-229, 38.2-  
 93 232, 38.2-322, 38.2-400, 38.2-402 through 38.2-413, 38.2-500 through 38.2-515, 38.2-600 through 38.2-  
 94 620, Chapter 9 (§ 38.2-900 et seq.), §§ 38.2-1016.1 through 38.2-1023, 38.2-1057, § 38.2-1306.1,  
 95 Article 2 (§ 38.2-1306.2 et seq.), § 38.2-1315.1, Articles 3.1 (§ 38.2-1316.1 et seq.), 4 (§ 38.2-1317 et  
 96 seq.) and 5 (§ 38.2-1322 et seq.) of Chapter 13, Articles 1 (§ 38.2-1400 et seq.) and 2 (§ 38.2-1412 et  
 97 seq.) of Chapter 14, §§ 38.2-3401, 38.2-3405, 38.2-3407.2 through 38.2-3407.5, 38.2-3407.6 and 38.2-  
 98 3407.6:1, 38.2-3407.9, 38.2-3407.9:01, and 38.2-3407.9:02, subdivisions 1, 2, and 3 of subsection F of §  
 99 38.2-3407.10, 38.2-3407.11, 38.2-3407.11:3, 38.2-3407.13, 38.2-3407.13:1, and 38.2-3407.14, 38.2-  
 100 3411.2, 38.2-3418.1, 38.2-3418.2, 38.2-3419.1, 38.2-3430.1 through 38.2-3437, 38.2-3500, subdivision  
 101 13 of § 38.2-3503, subdivision 8 of § 38.2-3504, §§ 38.2-3514.1, 38.2-3514.2, 38.2-3522.1 through  
 102 38.2-3523.4, 38.2-3525, 38.2-3540.1, 38.2-3542, 38.2-3543.2, Chapter 52 (§ 38.2-5200 et seq.), Chapter  
 103 55 (§ 38.2-5500 et seq.), Chapter 58 (§ 38.2-5800 et seq.) and § 38.2-5903 shall be applicable to any  
 104 health maintenance organization granted a license under this chapter. This chapter shall not apply to an  
 105 insurer or health services plan licensed and regulated in conformance with the insurance laws or Chapter



106 42 (§ 38.2-4200 et seq.) of this title except with respect to the activities of its health maintenance  
107 organization.

108 C. Solicitation of enrollees by a licensed health maintenance organization or by its  
109 representatives shall not be construed to violate any provisions of law relating to solicitation or  
110 advertising by health professionals.

111 D. A licensed health maintenance organization shall not be deemed to be engaged in the  
112 unlawful practice of medicine. All health care providers associated with a health maintenance  
113 organization shall be subject to all provisions of law.

114 E. Notwithstanding the definition of an eligible employee as set forth in § 38.2-3431, a health  
115 maintenance organization providing health care plans pursuant to § 38.2-3431 shall not be required to  
116 offer coverage to or accept applications from an employee who does not reside within the health  
117 maintenance organization's service area.

118 F. For purposes of applying this section, "insurer" when used in a section cited in subsections A  
119 and B of this section shall be construed to mean and include "health maintenance organizations" unless  
120 the section cited clearly applies to health maintenance organizations without such construction.

121 #



Appendix **C**

## Evaluation Topic Areas and Criteria for Assessing Proposed Mandated Health Insurance Benefits

Topic Area	Criteria
<b>1. Medical Efficacy</b>	
a. Medical Efficacy of Benefit	The contribution of the benefit to the quality of patient care and the health status of the population, including the results of any clinical research, especially randomized clinical trials, demonstrating the medical efficacy of the treatment or service compared to alternatives or not providing the treatment or service.
b. Medical Effectiveness of Benefit <i>JLARC Criteria*</i>	The contribution of the benefit to patient health based on how well the intervention works under the usual conditions of clinical practice. Medical effectiveness is not based on testing in a rigid, optimal protocol, but rather a more flexible intervention that is often used in broader populations.
c. Medical Efficacy of Provider	<p>If the legislation seeks to mandate coverage of an additional class of practitioners:</p> <p>1) The results of any professionally acceptable research, especially randomized clinical trials, demonstrating the medical results achieved by the additional class of practitioners relative to those already covered.</p> <p>2) The methods of the appropriate professional organization to assure clinical proficiency.</p>
d. Medical Effectiveness of Provider <i>JLARC Criteria*</i>	The contribution of the practitioner to patient health based on how well the practitioner's interventions work under the usual conditions of clinical practice. Medical effectiveness is not based on testing in a rigid, optimal protocol, but rather more flexible interventions that are often used in broader populations.
<b>2. Social Impact</b>	
a. Utilization of Treatment	The extent to which the treatment or service is generally utilized by a significant portion of the population.
b. Availability of Coverage	The extent to which insurance coverage for the treatment or service is already generally available.
c. Availability of Treatment <i>JLARC Criteria*</i>	The extent to which the treatment or service is generally available to residents throughout the state.
d. Availability of Treatment Without Coverage	If coverage is not generally available, the extent to which the lack of coverage results in persons being unable to obtain necessary health care treatments.
e. Financial Hardship	If the coverage is not generally available, the extent to which the lack of coverage result in unreasonable financial hardship on those persons needing treatment.
f. Prevalence/Incidence of Condition	The level of public demand for the treatment or service.
g. Demand for Coverage	The level of public demand and the level of demand from providers for individual or group insurance coverage of the treatment or service.

h. Labor Union Coverage	The level of interest of collective bargaining organizations in negotiating privately for inclusion of this coverage in group contracts.
i. State Agency Findings	Any relevant findings of the state health planning agency or the appropriate health system agency relating to the social impact of the mandated benefit.
j. Public Payer Coverage <i>JLARC Criteria*</i>	The extent to which the benefit is covered by public payers, in particular Medicaid and Medicare.
k. Public Health Impact <i>JLARC Criteria*</i>	Potential public health impacts of mandating the benefit.
<b>3. Financial Impact</b>	
a. Effect on Cost of Treatment	The extent to which the proposed insurance coverage would increase or decrease the cost of treatment of service over the next five years.
b. Change in Utilization	The extent to which the proposed insurance coverage might increase the appropriate or inappropriate use of the treatment or service.
c. Serves as an Alternative	The extent to which the mandated treatment or service might serve as an alternative for more expensive or less expensive treatment or service.
d. Impact on Providers	The extent to which the insurance coverage may affect the number and types of providers of the mandated treatment or service over the next five years.
e. Administrative and Premium Costs	The extent to which insurance coverage might be expected to increase or decrease the administrative expenses of insurance companies and the premium and administrative expenses of policyholders.
f. Total Cost of Health Care	The impact of coverage on the total cost of health care.
<b>4. Effects of Balancing Medical, Social, and Financial Considerations</b>	
a. Social Need/Consistent with Role of Insurance	The extent to which the benefit addresses a medical or a broader social need and whether it is consistent with the role of health insurance.
b. Need Versus Cost	The extent to which the need for coverage outweighs the costs of mandating the benefit for all policyholders.
c. Mandated Option	The extent to which the need for coverage may be solved by mandating the availability of the coverage as an option for policy holders.

\*Denotes additional criteria added by JLARC staff to criteria adopted by the Special Advisory Commission on Mandated Health Insurance Benefits.

Source: Special Advisory Commission on Mandated Health Insurance Benefits and JLARC staff analysis.

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