

REPORT OF THE SPECIAL ADVISORY COMMISSION ON
MANDATED HEALTH INSURANCE BENEFITS

**MANDATED COVERAGE FOR AUTISM
SPECTRUM DISORDER
HOUSE BILL 83**

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

COMMONWEALTH OF VIRGINIA
RICHMOND
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To: The Honorable Timothy M. Kaine
Governor of Virginia
and
The General Assembly of Virginia

The report contained herein has been prepared pursuant to § 2.2-2504 and § 2.2-2505 of the Code of Virginia.

This report documents a study conducted by the Special Advisory Commission on Mandated Health Insurance Benefits to assess the social and financial impact and the medical efficacy of House Bill 83 regarding coverage for Autism Spectrum Disorder.

Respectfully submitted,

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INTRODUCTION

During the 2008 Session of the General Assembly, the House Committee on Commerce and Labor adopted an amendment in the nature of a substitute to mandate coverage for the diagnosis and treatment of Autism Spectrum Disorder (ASD) in individuals under age 21. The House Committee on Commerce and Labor referred House Bill 83 to the Special Advisory Commission on Mandated Health Insurance Benefits (Advisory Commission). The patron of House Bill 83 was Delegate Robert G. Marshall.

The Advisory Commission held a public hearing on September 29, 2008 in Richmond to receive public comments on House Bill 83. In addition to patron Delegate Marshall and Delegate David Poisson, thirty individuals spoke in favor of the proposal. Representatives from Autism Speaks, the Kennedy-Krieger Institute, The Loudoun Project, The Spiritos School, The Allergy and Nutrition Clinic (northern Virginia), and several medical doctors, therapists, and other professionals involved with individuals on the autism spectrum addressed the Commission. Representatives from the Virginia Association of Health Plans (VAHP), the National Federation of Independent Business (NFIB), and the Virginia Chamber of Commerce (VCC) spoke in opposition of the bill.

In addition, written comments were received from Autism Speaks, the Virginia Nutritionists Association, and the Association for Science in Autism Treatment, and the Relationship Development Intervention (RDI) parent group. Seventy-three written letters and electronic letters were submitted from private citizens in support of the proposed legislation. Also, signatures from 265 residents from the Tidewater and Northern Virginia areas of the Commonwealth were submitted supporting House Bill 83. The VAHP, the NFIB, and the VCC submitted comments in opposition to the bill.

The Joint Legislative Audit and Review Commission (JLARC) staff prepared an "Evaluation of the Proposed Mandated Health Insurance Benefits: House Bill 83, Mandated Coverage of Autism Spectrum Disorder" pursuant to §§ 2.2-2503 and 30-58.1 of the Code of Virginia. A copy of the evaluation is available on the JLARC website at <http://jlarc.state.va.us>.

SUMMARY OF THE PROPOSED LEGISLATION

House Bill 83 adds §38.2-3418.15 to the mandated benefits article and amends § 38.2-4319 to make it applicable to health maintenance organizations (HMOs). The bill applies to insurers that issue group accident and sickness policies providing hospital, medical and surgical or major medical coverage on an expense-incurred basis; corporations providing group accident or sickness subscription contracts and HMOs providing a health care plan.

The bill defines the following terms:

“Applied behavior analysis (ABA)” as 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 (ASD)” is defined as any of the pervasive developmental disorders known as (i) autistic disorder, (ii) Asperger’s Syndrome, or (iii) Pervasive Developmental Disorder - Not Otherwise Specified, as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association.

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

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

“Pharmacy care” in House Bill 83 is defined as medications prescribed by a licensed physician and any health-related services deemed medically necessary to determine the need or effectiveness of the medications.

“Psychiatric care” means direct or consultative services provided by a psychiatrist licensed in the state in which the psychiatrist practices.

“Psychological care” means direct or consultative services provided by a psychologist licensed in the state in which the psychologist practices.

“Therapeutic care” means services provided by licensed or certified speech therapists, occupational therapists, or physical therapists.

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

The bill states that, except for inpatient services, an insurer will have the right to request a review of treatment of an individual receiving service for an ASD once every 12 months unless the insurer, corporation or HMO and the individual’s licensed physician or licensed psychologist agrees that a more frequent review is necessary.

The cost of obtaining a review shall be covered under the policy, contract or plan, and does not apply to inpatient services.

Proposed coverage for ASD shall neither be different or separate from coverage applicable to any other illness, condition, or disorder for purposes of determining deductibles, benefit year, or lifetime durational limits, benefit dollar limits, lifetime episodes or treatment limits, co-payment and coinsurance factors, and benefit year maximum for deductibles and co-payment and coinsurance factors.

The bill does not apply to (i) short-term travel, accident only, limited or specified disease policies, (ii) short-term non-renewable policies of not more than six months' duration, (iii) policies, contracts, or plans issued in the individual market or small group markets to employers with 25 or fewer employees, (iv) policies or contracts designed for issuance to persons eligible for coverage under Title XVIII of the Social Security Act, known as Medicare, or any other similar coverage under state or federal governmental plans. The bill applies to insurance policies, contracts and health care plans delivered, issued for delivery, reissued or extended on and after January 9, 2009.

Delegate Marshall sent revised language to the Advisory Commission prior to the September 29, 2008 meeting and requested that the language be considered by the Advisory Commission. The language was referred to as House Bill 83-Amended in the review process. Delegate Marshall filed the bill for the 2009 session of the General Assembly and the bill was drafted as House Bill 1588.

In addition to providing coverage for the diagnosis and treatment of autism spectrum disorder under the age of 21, House Bill 83-Amended adds that the insurer cannot terminate or otherwise alter coverage solely because an individual is diagnosed with autism (ASD) or has been treated for ASD. House Bill 83-Amended adds two additional disorders to the list of conditions in the ASD definition (Rett syndrome and childhood disintegrative disorder). Also House Bill 83-Amended adds 1) a limit to the coverage, capping the annual maximum benefit at \$36,000; 2) a COLA for inflation beginning 1/1/2011 based on CPI-U; and 3) a requirement that provisions of the bill are in addition to the provisions in the early intervention mandate, § 38.2-3418.5.

RELATED LEGISLATION

The early intervention mandate, § 38.2-3418.5, applies to children from birth to age three and requires that benefits for the early intervention services be limited to \$5,000 per insured per year (subsection A). The provisions are applicable to policies, plans and contracts delivered, issued for delivery or renewed on and after July 1, 1998.

Coverage for early intervention services requires health insurers, HMOs and corporations providing accident and sickness subscription contracts to provide coverage for medically necessary early intervention services. "Early intervention services" means medically necessary speech and language therapy, occupational therapy, physical therapy, and assistive technology services and devices for dependents from birth to age

three who are certified by the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMSAS) as eligible for services under Part H of the Individuals with Disabilities Education Act (20 U.S.C. § 1471 et seq.). "Medically necessary early intervention services for the population certified by the DMHMRSAS" means those services designed to help an individual attain or retain the capability to function age appropriately within his environment and includes services which enhance functional ability without effecting a cure. This coverage is limited to a benefit of \$5,000 per insured or member per policy or calendar year.

The early intervention mandate also requires that the cost of these medically necessary early intervention services not be applied to any contractual provision limiting the total amount of coverage paid by the insurer to or on behalf of the insured during the insured's lifetime. Additionally, copayments, coinsurance or deductibles resulting from receiving early intervention services may be paid by federal, state, or local funds. The provisions are not applicable to short-term travel, accident only, limited or specified disease policies, policies or contracts designed for issuance to persons eligible for coverage under Medicare, or to short-term nonrenewable policies of not more than six months' duration.

Section 38.2-3412.1:01, coverage for biologically based mental illness, includes "autism" in the definition of "biologically based" illnesses. The law requires insurers to provide coverage for biologically-based mental illnesses. The bill applies to insurers proposing to issue group accident and sickness insurance policies providing hospital, medical and surgical or major medical coverage on an expense-incurred basis; corporations providing group subscription contracts; and health maintenance organization (HMOs) providing health care plans to provide coverage for biologically based mental illnesses.

A "biologically based mental illnesses" is defined as "any mental or nervous condition caused by a biological disorder of the brain that results in a clinically significant syndrome that substantially limits the person's functioning." Specifically, the following diagnoses are defined as biologically based mental illnesses, as they apply to adults and children: schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, panic disorder, obsessive compulsive disorder, attention deficit hyperactivity disorder, autism, and drug and alcohol addiction.

In 2006, the Joint Commission on Health Care (JCHC) Behavioral Health Care (BHC) Subcommittee included a review of issues related to autism in its 2006 workplan. House Joint Resolution No. 96 and Senate Joint Resolution No. 125 addressed the Education of Individuals with Autism Spectrum Disorders. The subcommittee encouraged the Department of Education (DOE) and the DMHMRSAS and other relevant entities to take certain actions to improve the education and treatment of individuals with autism spectrum disorders.

The BHC Subcommittee of the Joint Commission on Health Care (JCHC) began its review of issues related to autism spectrum disorders in 2005. Legislation and

budget amendments, introduced on behalf of JCHC, sought to address some of the most pressing needs. HJR 96 and SJR 125 (2006) were identical resolutions which asked: (1) the Department of Education to continue to implement initiatives to strengthen teacher qualifications related to the needs of children with ASDs; and (2) the Department of Mental Health, Mental Retardation and Substance Abuse Services to assist in expanding “training opportunities that include approaches specifically addressing the needs of children with autism spectrum disorders....” HJR 96 and SJR 125 were adopted unanimously by the 2000 General Assembly. During the 2007 General Assembly, a budget amendment was approved to support a variety of training and technical assistance activities relating to working with individuals with ASD.¹

During the 2007 Session, the BHC Subcommittee voted to convene a work group to develop a consensus regarding which state agency should be established or designated as the lead agency for ASD services. During the 2008 Session, JCHC introduced a budget amendment requesting that the Secretary of Health and Human Resources develop a report on an Implementation Plan to determine the State agency that should be responsible for serving individuals with autism spectrum disorders. Although the suggested language was not included in the approved budget, a letter was sent by the Chairman of JCHC asking the Secretary of Health and Human Resources to develop and report on an Implementation Plan.²

The Office of the Secretary of Health and Human Resources reconvened an advisory committee (task force) to include the JCHC, other state agencies involved with assisting individuals affected by different developmental disabilities and, self-advocating groups that represent different types of developmental disabilities. The task force recommended merging services to all individuals with developmental disabilities, including ASD, under one state agency. The umbrella approach would facilitate a more coordinated and integrated delivery system in Virginia. The Department of Mental Health, Mental Retardation and Substance Abuse will be the lead agency for ASD and developmental disabilities.³

PREVIOUS LEGISLATION REVIEWED BY THE ADVISORY COMMISSION

Senate Bill 165, which required coverage for therapies for biologically-based mental illnesses, was referred to the Special Advisory Commission in the 2000 session of the General Assembly. The original bill language provided that the mandate of coverage for “biologically-based mental illness” must include coverage for speech and language therapy, occupational therapy, physical therapy and related therapies relevant to the treatment of the illness, and that coverage must be provided whether or not the therapy effects a cure. Under the provisions of Senate Bill 165, insureds would have been subject to the same deductibles, benefit year or lifetime durational limits, benefit year maximums for deductibles and coinsurance factors as for any other illness covered by the policy.

The amended bill that was reviewed by the Advisory Commission required the expansion of coverage under the early intervention services mandate, § 38.2-3418.5 of

the Code of Virginia, to include coverage for children ages three through twelve with diagnosed developmental disabilities. The definition of “medically necessary early intervention services for children ages three through twelve with diagnosed developmental disabilities” in the amended bill read as follows:

... those services designed to help an individual attain or retain the capability to function age-appropriately within his environment, and shall include services that enhance functional ability without affecting a cure.

The amended bill did not define developmental disabilities.

On December 14, 2000, the Advisory Commission voted unanimously (7-0) to recommend that Senate Bill 165 not be enacted. There were concerns related to yet-to-be determined costs associated with the recent expansion of coverage under the early intervention services mandate.

Senate Bill 1049, proposed in the 2005 Session of the General Assembly by Senator Frank Wagner, would have added § 38.2-3418.15 to the Accident and Sickness Insurance Provisions Chapter and amended § 38.2-4319 in the HMO Chapter of the Code of Virginia. The bill provided that coverage shall be offered and made available for the treatment of developmental delay for children from birth to age five. The bill applied to policies, contracts and plans delivered, issued for delivery or renewed on and after July 1, 2005. Coverage for the treatment of development delay shall not include services that would be covered as medically necessary early intervention services pursuant to § 38.2-3418.5.

The bill defined “developmental delay” as a material delay in a child’s achievement for one or more developmental milestones, including speech and language, fine and gross motor skills, and personal and social skills, as diagnosed by a physician through the administration of a formal screening test, such as the Denver II Developmental Screening Test, and includes developmental delay resulting from pervasive developmental disorders including autistic disorder or autism, Asperger’s disorder, Rett’s disorder, and childhood disintegrative disorder.

Treatments for developmental delay covered by this section would include diagnostic evaluation, education, behavioral therapy, medication, music therapy, physical therapy, and speech therapy. Coverage for treatment of developmental delay would not include services that are covered as medically necessary early intervention services for children from birth to age three pursuant to § 38.2-3418.5. The bill further states that an insurer, corporation or HMO may assess a separate or additional charge or premium for the coverage.

The provisions of the bill did not apply to short-term travel, accident only, limited or specified disease policies, or contracts designed for issuance to persons eligible for

Medicare, or other similar coverage under state or government plans, or short-term nonrenewable policies of not more than six months' duration.

The Advisory Commission voted on Senate Bill 1049 on August 18, 2005. In a vote of nine to one, the Advisory Commission recommended against mandating an offer of coverage for the treatment of developmental delay, but instead, recommended to the General Assembly establishing a committee to further analyze the impact of mandating an offer of coverage for developmental delay.

House Bill 657, mandating an offer of coverage for the treatment of developmental delay, was introduced by Delegate Kenneth Plum in 2006 and was referred to the Advisory Commission. Developmental delay includes a wide range of severity, and may affect an individual in one or several areas such as motor, language, social, or cognitive skills. Individuals with developmental delay may have a diagnosis for another condition, including autism.

The Advisory Commission voted on November 20, 2006 to recommend against enacting House Bill 657 (Yes- 12, No-1). The Advisory Commission expressed concern with regard to 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.

AUTISM/AUTISM SPECTRUM DISORDER (ASD)

The CDC defines Autism Spectrum Disorders (ASDs) as a group of developmental disabilities that are caused by an abnormality in the brain. The CDC explains the wide variation in the range of ASDs. Autistic disorder is a severe form of autism. Asperger syndrome is a milder form of autism. If a child has symptoms of either of these disorders, but does not meet the specific criteria for either, the diagnosis is called pervasive developmental disorder not otherwise specified (PDD-NOS). Other disorders that are included in the autism spectrum disorders are Rett syndrome and Childhood Disintegrative Disorder (CDD).⁴ ASD is an umbrella term for a group of disorders characterized by the delayed development of socialization and communication skills. In many cases, a diagnosis of PDD may be equivalent to a diagnosis of ASD.

Autism Speaks defines autism as:

...A part of a group of disorders known as Autism Spectrum Disorders (ASD). "Autism is a complex neurobiological disorder that typically lasts throughout a person's lifetime. The disorder is characterized by varying degrees of impairment in communication skills and social abilities, and also by repetitive behaviors. Symptoms range from mild to severe. One milder form of the disorder is known as Asperger Syndrome. Other developmental disorders that fall under the Autism Spectrum Disorders are Rett Syndrome,

PDD-NOS (Pervasive Developmental Disorder), and Childhood Disintegrative Disorder.”⁵

A diagnosis of ASD can range from mild to severe. Children diagnosed with autism are likely to exhibit similar traits, but, may also exhibit different symptoms. Each child will display communication, social and behavioral patterns that are individual, but fit into the overall diagnosis of an autism spectrum disorder.⁶

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) classifies autism within the category of disorders usually diagnosed in infancy, childhood, or adolescence. DSM-IV specifically differentiates autism from other classified disorders, including learning, motor skills, communication, and attention deficit disorders. Specifically, autism is included in a group of pervasive developmental disorders. ASD also includes Asperger syndrome, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS).⁷

For a child to receive a diagnosis of “autistic disorder,” the child must have at least six of the twelve symptoms, spread among the three categories—social interaction, communication and behavior--in a certain way. The social interaction category, for example, lists four symptoms; a least two symptoms must be present. Under communication, one symptom is necessary. One symptom is necessary for the behavior category. Collectively, the symptom requirement is four of the six symptoms. The other two symptoms can come from any of the three categories—from one category or distributed over two.⁸

The Diagnostic and Statistical Manual of Mental Health Disorders, Fourth Edition, Text Revision (DSM-IV-TR) lists the diagnostic criteria for the five autistic or autism spectrum disorders. Each of the PDD disorders has its own code and symptoms. PDD is not a specific disorder; it only refers to the category that all of the disorders fall under. The DSM IV-TR Diagnostic Criteria for disorders on the autism spectrum are as follows⁹:

Autistic Disorder

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
 - 1. qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
 - b. failure to develop peer relationships appropriate to developmental level;

- c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest);
 - d. lack of social or emotional reciprocity.
 - 2. qualitative impairments in communication as manifested by at least one of the following:
 - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime);
 - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;
 - c. stereotyped and repetitive use of language or idiosyncratic language;
 - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.
 - 3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;
 - b. apparently inflexible adherence to specific, nonfunctional routines or rituals;
 - c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements);
 - d. persistent preoccupation with parts of objects.
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic Criteria for Asperger's Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - 1. marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction;
 - 2. failure to develop peer relationships appropriate to developmental level;
 - 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people);

4. lack of social or emotional reciprocity.
- B. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:
1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus;
 2. apparently inflexible adherence to specific, nonfunctional routines or rituals;
 3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements);
 4. persistent preoccupation with parts of objects.
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Diagnostic Criteria for Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism," presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Diagnostic Criteria for Rett's Disorder

- A. All of the following:
1. apparently normal prenatal and perinatal development;
 2. apparently normal psychomotor development through the first 5 months after birth;
 3. normal head circumference at birth.
- B. Onset of all of the following after the period of normal development:
1. deceleration of head growth between ages 5 and 48 months;

2. loss of previously acquired purposeful hand skills between 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing);
3. loss of social engagement early in the course (although often social interaction develops later);
4. appearance of poorly coordinated gait or trunk movements;
5. severely impaired expressive and receptive language development with severe psychomotor retardation.

Diagnostic Criteria for Childhood Disintegrative Disorder

- A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
- B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
 1. expressive or receptive language;
 2. social skills or adaptive behavior;
 3. bowel or bladder control;
 4. play;
 5. motor skills.
- C. Abnormalities of functioning in at least two of the following areas:
 1. qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity);
 2. qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play);
 3. restricted, repetitive, and stereotyped patterns of behavior, interest, and activities, including motor stereotypes and mannerisms.
- D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

TREATMENTS FOR AUTISM

Applied Behavior Analysis (ABA)

Applied behavior analysis (ABA) is the process of applying interventions that are based on the principles of learning derived from experimental psychology research to systematically change behavior and to demonstrate that the interventions used are responsible for the observable improvement in behavior. ABA methods are used to increase and maintain desirable adaptive behaviors, reduce interfering maladaptive behaviors or narrow the conditions under which they occur, teach new skills, and

generalize behaviors to new environments or situations. ABA focuses on the reliable measurement and objective evaluation of observable behavior within relevant settings, including the home, school and community.¹⁰

According to the Lovaas Institute, the fundamental idea of ABA is that social and behavioral skills could be taught to autistic children, including those diagnosed as profoundly autistic. Transferred skills are based on scientific principles of behavior and, that one's progress is continually measured and intervention adapted. Skills are taught through a variety of behavioral interventions including: discrete trial teaching (e.g., an instructor says, "Mickey Mouse" the child touches a Mickey doll, the instructor reinforces the behavior); incidental teaching (uses the same ideas as discrete trial training, except the goal is to teach behaviors and concepts throughout a child's day-to-day experience); and pivotal response training (ABA techniques target crucial skills that are important (or pivotal) for many other skills. Thus, if the child improves on one of these pivotal skills, improvements are seen in a wide variety of behaviors that were not specifically trained). The idea is that this approach can help the child generalize behaviors from a therapy setting to everyday settings increasing spontaneity. In fluency-based instruction, the practitioner helps the child build up a complex behavior by teaching each element of that behavior until it is automatic or "fluent," using the ABA approach of behavioral observation, reinforcement, and prompting. Then, the more complex behavior can be built from each of these fluent elements, and peer integration (encouraging relationship development through play dates with peers).¹¹

The perceived value of ABA is that it demonstrates the importance of language training in the educational process. It shows that early intervention is beneficial and should be intense and be of sufficient duration for normal functioning to be achieved. It shows that inclusion of children with autism was an achievable goal. Follow-up studies indicate that ABA has increased results when the intensity of treatment is constant.¹²

The following excerpts are from an overview provided by the Autism Society of America as a guideline to address the range of social, language, sensory, and behavioral difficulties for those with autism.¹³

Treatment for the Education of Autistic and Related Communication Handicapped Children (TEACCH)

The first statewide program for treatment and services for people with autism, TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) was developed at the School of Medicine at the University of North Carolina in the 1970s. It is a structured teaching approach based on the idea that the environment should be adapted to the child with autism, not the child to the environment. It uses no one specific technique, but rather is a program based around the child's functioning level. The child's learning abilities are assessed through the Psycho Educational Profile (PEP), and teaching strategies are designed to improve communication, social and coping skills. Rather than

teach a specific skill or behavior, the TEACCH approach aims to provide the child with the skills to understand his or her world and other people's behaviors. For example, some children with autism scream when they are in pain. The TEACCH approach would search for the cause of the screaming and then teach the child how to signal pain through communication skills.

There have been criticisms that the TEACCH approach is too structured, that children with autism, particularly high-functioning individuals, become too focused on the charts, organizational aids, and schedules, and that it discourages mainstreaming. Others believe that, in an environment conducive to learning, the child with autism understands what is expected and how critical it is to respond appropriately.

Picture Exchange Communication Systems (PECS)

One of the main areas affected by autism is the ability to communicate. Some children with autism will develop verbal language, while others may never talk. An augmented communication program, such as Picture Exchange Communication Systems (PECS), is helpful to get language started as well as to provide a way of communicating for those children that do not talk.

PECS was developed at the Delaware Autistic Program to help children and adults with autism to acquire functional communication skills. It uses applied behavior analysis (ABA) based methods to teach children to exchange a picture for something they want, an item or activity.

The advantage to PECS is that it is clear, intentional and initiated by the child. The child hands you a picture, and his or her request is immediately understood. It also makes it easy for the child with autism to communicate with anyone; all they have to do is accept the picture.

Floor Time

An educational model developed by child psychiatrist Stanley Greenspan, Floor Time is much like play therapy in that it builds an increasing larger circle of interaction between a child and an adult in a developmentally-based sequence. Greenspan has described six stages of emotional development that children meet to develop a foundation for more advanced learning. It is described as a developmental ladder that must be climbed one rung at a time. Children with autism may have trouble with this developmental ladder for a number of reasons, such as over-and under-reacting to senses, difficulty processing information, or difficulty in getting their body to do what they want.

Through the use of Floor Time, parents and educators can help the child move up the developmental ladder by following the child's lead and

building on what the child does to encourage more interactions. Floor Time does not treat the child with autism in separate pieces for speech development or motor development, but rather addresses the emotional development, in contrast to other approaches which tend to focus on cognitive development. It is frequently used for a child's daily playtime in conjunction with other methods such as ABA.

Social Stories

Social Stories were developed in 1991 by Carol Gray as a tool for teaching social skills to children with autism. They address "Theory of Mind" deficits, the ability to understand or recognize feelings, points of view or plans of others. Through a story developed about a particular situation or event, the child is provided with as much information as possible to help him or her understand the expected or appropriate response. The stories typically have three sentence types: descriptive sentences addressing the where, who, what and why of the situation; perspective sentences that provide some understanding of the thoughts and emotions of others; and directive sentences that suggest a response. The stories can be written by anyone, are specific to the child's needs, and are written in the first person, present tense. They frequently incorporate the use of pictures, photographs or music.

Before developing and using social stories, it is important to identify how the child interacts socially and to determine what situations are difficult and under what circumstances. Situations that are frightening, produce tantrums or crying, or make a child withdraw or want to escape are all appropriate for social stories. However, it is important to address the child's misunderstanding of the situation. A child who cries when his or her teacher leaves the room may be doing so because he or she is frightened or frustrated. A story about crying will not address the reason for the behavior. A story about what scares the child and how he can deal with those feelings will be more effective.

Sensory Integration

Children with autism frequently have sensory difficulties. They may be hypo- or hyper-reactive or lack the ability to integrate the senses. Sensory integration therapy, usually done by occupational, physical or speech therapists, focuses on desensitizing the child and helping the child to reorganize sensory information. For example, if a child has difficulties with the sense of touch, therapy might include handling a variety of materials with different textures.

Auditory integration therapy reduces over-sensitivity to sound. It may involve having the child listen to a variety of different sound frequencies coordinated to the level of impairment. Temple Grandin, Ph.D., who

herself has autism, developed a "squeeze machine" to help her learn to tolerate touching through regulated deep pressure stimulation.

Before proceeding with any sensory integration therapy, it is important that the therapist observe the child and have a clear understanding of his or her sensitivities.

Facilitated Communication

Facilitated communication (FC) was developed in the 1970s in Australia by an aide who was trying to help a patient with cerebral palsy to communicate. It is based on the idea that the person is unable to communicate because of a movement disorder, not because of a lack of communication skills. FC involves a facilitator who, by supporting an individual's hand or arm, helps the person communicate through the use of a computer or typewriter. It has not been scientifically validated; critics claim that it is actually the ideas or thoughts of the facilitator that are being communicated. FC is very controversial, and organizations, such as the American Association of Mental Retardation, and the American Academy of Child & Adolescent Psychiatry, have adopted formal positions opposing the acceptance of FC.

OTHER TREATMENT OPTIONS FOR AUTISM

Comprehensive Treatment Programs range from specific methods of learning, to applied behavior analysis, to reaching certain developmental goals. In general, the National Institutes of Health state that children need to be in this type of program for 15-40 hours a week, for two years or more, to change their behaviors and prevent problems. Positive Behavioral Interventions and Support (PBS) looks at the interactions between people with autism, their environment, their behavior, and their learning processes to develop the best lifestyle for them. It is an approach that tries to increase positive behaviors, decrease problem behavior, and improve the individual's lifestyle. Individualized Education Programs (IEPs) involve a variety of interventions and are designed to help a child or adult with autism to overcome his or her specific problems.¹⁴

Relationship Development Intervention (RDI)

RDI is a parent-based, cognitive-developmental approach, in which primary caregivers are trained to provide daily opportunities for successful functioning in increasingly challenging dynamic systems. Dr. Steven Gutstein, creator of the RDI, bases treatment on the presumption that autistic individuals have six shared deficits (emotional referencing, social coordination, declarative language, flexible thinking, relational information processing, and foresight and hindsight), with one common element. These shared deficits rely on "dynamic intelligence" rather than "static intelligence." The purpose of RDI is to build or remediate dynamic intelligence.¹⁵

A second study in a series reviewed the progress of 16 children who participated in RDI between 2000 and 2005. Changes in the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview—Revised (ADI—R), flexibility, and school placement were compared prior to treatment and at a minimum 30 month follow-up period. While all children met ADOS/ADI—R criteria for autism prior to treatment, no child met criteria at follow-up. Similar positive results were found in relation to flexibility and educational placement. It is difficult to generalize current findings which are limited by the lack of a control or comparison group, constraints on age and IQ of treated children, parent self-selection, and parent education conducted through a single clinic setting.¹⁶

EARLY INTERVENTION IN VIRGINIA

In Virginia, early intervention services are provided through the Infant and Toddler Connection. The Infant and Toddler Connection is a responsibility of the Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS). Currently, Part C services and supports for all early childhood programs are being shifted to the Office of Early Childhood Development.¹⁷

For ease of comprehension, the information in this analysis discusses early intervention services in its current operation (without consideration to the transition of services to the Office of Early Childhood Development). Early Intervention services are designed for infants and toddlers (from birth through age three) who are not developing as expected or who have a condition that can delay normal development. Early Intervention services focus on increasing a child's ability to participate in family and community life. Typically, an "Early Intervention specialist" works with the child and family to identify treatment needs, gather resources and information, and coordinate therapy and other intervention services. Further support for the child and family is provided by a multidisciplinary team that may include occupational, physical, and speech/language therapists as well as other appropriate service providers. Parents and other caregivers are taught to use everyday "learning" activities to help the child progress in his or her physical and cognitive development.

Part C of the federal Individuals with Disabilities Education Improvement Act, P.L. 108-446 (IDEA) provides authorization for Early Intervention services (also known as Part C). Part C services are guided by state statute through the Code of Virginia, §§ 2.2-5300–5308. Eight state agencies share responsibility for providing Part C services through the Virginia Interagency Coordinating Council: the Departments for the Blind and Vision Impaired, Deaf and Hard of Hearing, Education, Health, Social Services, Medical Assistance Services, and Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) as well as the Virginia Office for Protection and Advocacy. The Code of Virginia (§ 2.2-5300) provides that children from birth to age three and their families are eligible for Part C services when a determination has been made that the child has:

- a developmental delay of at least 25 percent in one of the developmental domains of cognition, communication, motor, adaptive, or social/emotional; and
- atypical development; and/or
- a diagnosed physical or mental disability that has a high probability of resulting in developmental delay (e.g., significant central nervous system anomaly, congenital or acquired hearing loss, chromosomal abnormalities, and inborn errors of the metabolism).

To be eligible for Part C services, an infant or toddler must meet the criteria above after having been evaluated by at least two professionals whose backgrounds are in different areas of child development. Eligibility is determined by the local lead agency. Part C services are available to all eligible children regardless of their families' ability to pay.¹⁸

In its administration of the system, DMHMRSAS contracts with 40 local lead agencies (local Infant and Toddler Connection entities), which are designated by the local city or county government. Currently, 33 Community Services Boards (CSBs) serve as local lead agencies for Part C services. Lead agencies for the remaining localities include two public schools, two universities, two local social services departments, and one local health department. The local lead agency is required to designate a single point of entry for the local system, which is usually, but not always, itself.¹⁹

The local lead agencies are also responsible for local service delivery. They determine eligibility and provide service coordinators (case managers) who guide families through the Early Intervention process and who facilitate the development and implementation of a required document called an Individualized Family Services Plan (IFSP). Each IFSP is the result of collaboration between direct service providers, who include representatives from the Departments of Health, Department of Social Services (DSS), and Department of Education (DOE); Community Services Boards; and networks of private providers. The IFSP lists the outcomes that the family and Part C team would like to see for the child and identifies the services and supports needed to meet those outcomes.²⁰

The DMHMRSAS *Infant & Toddler Connection Annual Performance Report for FFY 2004* indicates that from 2001 to 2004, referrals for Part C came from the following sources: 57% from physicians, 11% from hospitals, 11% from friends and relatives, and 3–4% from social workers and preschool or day-care sources. The more recent *System of Payments Summary Report* by Solutions Consulting Group, in comparing referral data over time, found that in FY 2006, physician referrals decreased to 39% of all referrals; hospital referrals increased slightly to 12%; referrals from parents and guardians more than doubled to 23%; and referrals from friends, neighbors, and relatives decreased to approximately 3%.²¹

Data on the unduplicated number of infants and toddlers receiving services under Part C is calculated annually in two ways: as a count at a point-in-time (December 1st), referred to as the “December Child Count;” and as a total number served during the year, referred to as the “Annualized Count” (previously known as the Aggregate Count). It is important to know that the December Child Count does not reflect all children served throughout the year. Each December 1st, DMHMRSAS tallies the number of individuals served by Part C services on that day.

The Department of Medical Assistance (DMAS) provides Early and Periodic Screening, Diagnosis and Treatment (EPSDT), a program of preventive health care and well child examinations with appropriate tests and immunizations for children and teens from birth to age 21. Medically necessary services, which are required to correct or ameliorate defects and physical or mental illnesses that are discovered during a screening examination, may be covered as a part of EPSDT program even if they are not covered under the State’s Medicaid benefit plan.²² Data from DMAS was not readily formatted to address the provisions of House Bill 83.

EARLY CHILDHOOD SPECIAL EDUCATION IN VIRGINIA

The Individuals with Disabilities Act (IDEA) of 1975 was intended to ensure equal educational opportunities for children with disabilities. Virginia defines autism as a developmental disability that severely affects communications and social interactions, generally evident before the age of three (34 CFR §300.7(c)(1)). Children with autism are guaranteed a free and appropriate public education in the least restrictive environment available. To evaluate placement for a student with autism, the levels of functioning and areas of educational need are determined. An Individualized Education Program (IEP) is developed to determine the best way to meet an individual’s needs.²³

When IDEA was initially implemented, cases of autism in the U.S. schools were minimal. According to the U. S. Department of Education Annual Reports to Congress, the number of children aged 6 to 21 with autism in U.S. schools increased from 5,415 in the 1991-92 school year to 118,602 in the 2001-02 school year.²⁴

In Virginia, each school district must provide an appropriate program of special instruction for exceptional students. As of December 1, 2007, school divisions and State Operated Programs in Virginia served 7,509 children and youth with ASDs between birth and age 21. As of December 1, 2006, school divisions and State Operated Programs in Virginia served 6,452 children and youth with ASDs between ages birth to 22. As of December 1, 2005, school divisions and State Operated Programs in Virginia served over 5,674 children and youth with autism spectrum disorders between ages birth to 22. And, as of December 1, 2004, school divisions and State Operated Programs in Virginia served over 4,751 children and youth with autism spectrum disorders between ages birth to 22.²⁵

For some parents, school services will meet the needs of their child’s prescribed treatments. For others, the services provided in schools cannot meet the medical needs

prescribed for their child. The responsibility of the educational system is different from medical services. Schools provide speech therapy and other related services to enable a child with a disability to receive a free appropriate public education.²⁶

Written comments from parents of children with autism indicate that services for children with ASD exist. However, parents noted there are barriers which reduce access to those services. Barriers highlighted in a Pennsylvania analysis proposing mandated benefits for autism include fragmented services, an inability to cover all of those in need, and inadequate payment schedules for some providers and/or specific services. Some studies highlight the belief that parents are consistently excluded from coverage of some treatments for autism, particularly those that involve behavioral treatments such as speech therapy and ABA. The reason for the exclusion or limiting the number of treatment sessions is thought by some to be that insurers are of the opinion that such therapies do not have a reasonable expectation of achieving sustainable, measurable improvement in a reasonable and predictable period of time. Also, studies referenced in the Pennsylvania analysis note that some group insurers have blanket exclusions for autism.²⁷

SOCIAL IMPACT

According to the Centers for Disease Control (CDC), as many as 1 in 150 children are autistic. Approximately 1.5 million people in the United States are on the autism spectrum. Government statistics suggest the rate of autism is increasing 10 to 17% annually. Also, according to the CDC, of the approximately 4 million babies born every year, 24,000 of them will eventually be identified as autistic. Recent studies suggest boys are more susceptible than girls to developing autism. In the United States, 1 out of 94 boys are suspected of being on the spectrum. Girls appear to manifest a more severe form of the disorder than their male counterparts.²⁸

The CDC funded the Autism and Developmental Disabilities Monitoring (ADDM) Network to determine the prevalence of ASDs in six states in 2000 and 2002. The importance of the study was that it provided some baseline data about ASDs and answered questions specific to how common ASDs are to place and time. It also allowed some insight into understanding the impact of autism on a particular community.²⁹

The definition and diagnostic criteria for ASD has been refined since autism was first described in 1943. Although the criteria for ASD in the DSM-IV in 1994 are most restrictive, some research studies show a steady rise in the number of affected individuals. Some research concludes that the growth indicates a true increase, since the criteria has remained uniform and since the probability that the diagnosis in each case has been accepted by the same medical, educational and developmental teams.³⁰

The prevalence of autism and ASDs is closely linked to a history of changing criteria and diagnostic categories. Several studies indicate the rate of pervasive developmental disorders is higher than reported 15 years ago. The growth rate in one

study is comparable to that in previous birth cohorts from the same area and surveyed with the same methods, suggesting a stable incidence.³¹

The two most prevalent trends confirmed by research are that the incidence of autism has increased remarkably and a shift in the time of onset of autistic symptoms. Research supports a trend that children with ASD are most detected when entering first grade rather than at earlier ages. If this trend continues, there will be a greater increase in the number of younger children needing services, more programs being organized to handle the influx, and an increased number of trained therapists.³²

There is not a full population count of all individuals with an ASD in the United States. However, using the most current prevalence data, the CDC estimates that if 4 million children are born in the United States every year and assuming the prevalence rate has been constant over the past two decades, up to 560,000 individuals between the ages of 0 to 21 have an ASD. Many of these individuals may not be classified as having an ASD until school-age or later. Since behaviors related to the ASDs are usually present before the age of 3 years, but not diagnosed until later, the CDC and other public health professionals use prevalence measures to track ASDs. Prevalence is the number of existing disease cases in a defined group of people during a specific time period as opposed to “incidence” measures. Incidence is the number of new cases of disease in a defined group of people over a specific time. Incidence is very difficult to establish because the exact time a person develops an ASD is not known.³³

Statistics from the CDC concur that more children are being classified as having ASDs. The CDC has not definitively determined if the increase is due to changes in how ASDs are identified and classified in people or if the increase is due to a true increase in prevalence. By current standards, ASDs are the second most common serious developmental disability after mental retardation/intellectual impairment, 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).³⁴

In 2002 in several areas of the United States, data suggested the average ASD prevalence was 6.7 per 1,000 for 8-year-olds. In 2000, average ASD prevalence was 6.6 per 1,000 for 8-year-olds. The prevalence equates to approximately 1 in 150 children in these communities. Most ADDM Network sites found 5.2 to 7.6 per 1,000 eight-year-old children with ASDs in 2002. The prevalence was much lower (3.3 per 1,000) in Alabama and higher (10.6 per 1,000) in New Jersey in 2002. Prevalence stayed the same from 2000 to 2002 in four of the six sites with data for both years. It rose slightly in Georgia and significantly in West Virginia, indicating the need for tracking prevalence over time.³⁵

The DMHMRSAS reported that the Commonwealth is currently serving 185 infants and toddlers who have the potential for ASD, which is defined as them having impairment in social interaction and communication skills along with restricted and repetitive behaviors. Generally, children from birth to age 3 have not been specifically

diagnosed with autism. Local systems show that during calendar year 2007, there were 68 children with this as an eligibility category who were referred out of Part C and into Part B (early childhood special education).³⁶

The Infant & Toddler Connection of Virginia reported to the Office of Special Education Programs the following Part C statistics for the Commonwealth of Virginia as of December 1, 2007:

Total Number of infants and toddlers served	6,023
Gender of Infants and Toddlers, ages birth through 2, receiving early intervention services	3,837 (male) 2,186 (female)
Setting of Infants and Toddlers, ages birth through 2, receiving early intervention services	4,745 (home) 0,276 (community-based) 1,002 (other)

This dataset includes 975 infants and toddlers receiving services through the public school systems.³⁷

Supporters of HB 83 believe that families, public agencies, and private insurance jointly bear responsibility of paying for costly services involved in educating and treating symptoms associated with ASDs. Supporters also believe more accurate reporting standards related to ASD prevalence can help people plan for the resources that may be needed, which include therapies, trained teachers, diagnosticians, health care providers, and related service professionals.³⁸

There is a distinct difference in recommended therapy received through the public schools and private therapies. Typically, families would have to choose between treatments which either focus on services or individual needs. Parents of children with ASD seek ways of determining if the treatment their child(ren) is receiving is what has been empirically validated by competent professionals, whether the approach to treatment is based on a medical model or an educational model.

Some proponents of House Bill 83 believe that insurance carriers exclude or limit services for treatment of individuals diagnosed with autism which causes financial burdens for their families. Proponents believe House Bill 83 would ensure that insurance companies provide coverage for medically-necessary, evidence-based treatments for autism, which would include behavioral therapies, namely, ABA.

MEDICAL EFFICACY

Scientists are not certain what causes autism, but it is likely that both genetics and environment play a role. Researchers have identified a number of genes associated with the disorder. Studies of autistic people have found irregularities in several regions

of the brain. Other studies suggest that people with autism have abnormal levels of serotonin or other neurotransmitters in the brain. These abnormalities suggest that autism could result from the disruption of normal brain development early in fetal development caused by defects in genes that control brain growth and that regulate how neurons communicate with each other. These findings are preliminary and require further study.³⁹

Most professionals agree there is no best treatment for all children with ASD. Most professionals also agree that early intervention is important, and that most individuals with ASD respond well to highly structured and specialized programs.

Proponents assert ABA is neither new nor investigational citing a 2007 clinical report conducted by the APA on the medical management of children with autism spectrum disorders noted its record of pediatric efficacy.⁴⁰

The effectiveness of ABA-based intervention in ASDs [autism spectrum disorders] has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.

The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles, calling for an intensive, one-on-one child-teacher interaction for 40 hours per week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential. The Lovaas Model of ABA is the most rigorously controlled early intervention research published to date. The research has the longest follow-up tracking of children with autism who have received intensive early intervention (McEachin, 1993) and replication research (Sallows, 2005 and Cohen, 2006).⁴¹

The Lovaas Model of ABA asserts that children must receive 35 to 40 hours of intense intervention per week. The benefit of approximately 40 hours of intense therapy provides a child with structured intervention throughout the day. The intervention allows the environment to be systematically manipulated to help a child remain successful while also teaching new skills quickly. The intensity of the therapy empowers parents and encourages a continuation of learned skills throughout the child's waking hours. The purpose of an intensive program is to allow a child with autism to learn how to learn in the natural environment and ultimately catch up to his or her typically developing peers.⁴²

The validity of the Lovaas method has been challenged due to lack of double-blind studies comparing the Lovaas approach against a control group not receiving ABA. Sallows and Graupner's 2005 study, which compared groups treated by professionals vs. those treated at home by their parents, replicated the results of Lovaas, but found little difference in outcome between the groups. This study represents the most comprehensive and rigorous replication to date, and their findings nearly mirror Lovaas'.⁴³

In a report evaluating ASD for HB 1150 in Pennsylvania (2008), in addition to behavioral therapy, it was determined that many children with ASD are prescribed medications. In a study conducted by Mandel et al, it was determined that 56% of children with ASD used at least one prescription medication, and among those who used medication, 20% used three medications simultaneously. The study also found that older children (older than five years) were more likely to have used medication. Sixty-one percent of children with Asperger disorder used psychotropic medications, while 53% of children with autistic disorders used medications. This study used 2001 Medicaid data on children from all 50 states plus the District of Columbia to investigate psychotropic medication use.⁴⁴

The Surgeon General of the United States recognizes the efficacy of ABA, as well as the Departments of Health in New York, California and Maine. Other research studies support its positive outcomes. The demonstrated efficacy of applied behavioral methods is that it reduces inappropriate behavior and increases communication, learning, and appropriate social behavior."⁴⁵ In the report, *Mental Health: A Report of the Surgeon General* states, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."⁴⁶

Some research studies conclude that ABA and other structured behavioral therapies are the most effective forms of treatment and have the best outcomes when a child is diagnosed with ASD at an early age and interventions begin. Although there is no cure for ASD, the studies indicate behavioral therapies seem to be the most effective at maximizing appropriate behaviors and minimizing maladaptive behaviors. The affects are manifested in both human costs and in long-term economic benefits. Advocates point out that on a national level, few private insurance companies or other employee benefit plans cover ABA and other behavioral therapies. They cite as evidence those insurance companies which designate autism as a diagnostic exclusion, which means that for most insureds, no autism-specific services are covered, including those services that would be used to treat other conditions.⁴⁷

The American Academy of Pediatrics (AAP) reports that ASD is challenging to pediatricians and other clinicians in the context of primary care visits, because there is no pathognomonic sign or laboratory test to detect it. Therefore, the physician is left to make the diagnosis on the basis of the presence or absence of a collection of symptoms. ASD is a phenomenologic rather than an etiologic disorder (eg, trisomy 21 in Down syndrome), making the diagnosis more difficult.⁴⁸

The AAP clinical report, "Identification and Evaluation of Children with Autism Spectrum Disorders" points out that many primary care pediatricians (PCPs) actually care for a number of children with ASDs. Another survey indicated that although 44% of PCPs care for a minimum of 10 children with ASD in their practice, only 8% stated that they routinely screened for ASD. Another survey indicated that although PCPs were aware of current DSM-IV-TR diagnostic criteria, they sometimes were hesitant to make a definitive diagnosis, which would allow for early interventions. The clinical report also stresses to medical professionals that patients will use nonstandard therapies or complementary and alternative medicine therapies in addition to educational strategies and associated therapies. The report emphasizes that families require guidance in evaluating scientific evidence and recognizing unsubstantiated treatments.⁴⁹

FINANCIAL IMPACT

In a 2006 study, children with autism had a higher annual number of total clinic, pediatric, and psychiatric outpatient visits compared with children without autism. The study concluded that treatment for autism is expensive. The same study found that the mean annual total cost per member in one large health care plan was more than three times higher for children with autism (\$2,757 versus \$892).⁵⁰

A 2007 study found that individuals with an autism spectrum disorder had average medical expenditures that exceeded those without an autism spectrum disorder by \$4,110-\$6,200 per individual.⁵¹ In another study, researchers found that average annual health care expenditures for individuals with an autism spectrum disorder increased 20.4% from 2000 to 2004, even after adjustment for inflation.⁵² Researchers estimated in the April 2008 issue of *Pediatrics* that households with a child with autism have a loss of income of 14% or \$6,200.⁵³

Proponents state the out-of-pocket cost of ABA will vary with the funding source for the intervention, the amount of financial assistance afforded, the service provider, and the number of hours of service delivered. According to survey data from the Interactive Autism Project (IAN), an online autism research project, seventy-seven percent of families nationwide pay the full cost of ABA out-of-pocket. Of the families surveyed, five percent nationwide pay over \$2,500 per month for ABA (\$30,000 annually). This study also concluded that twenty percent of the families that use ABA with their children spend over \$500 per month for the intervention. Thirty-five percent of families reported quitting a job or significantly reducing hours at work to either take a child to treatment or to conduct treatment at home.⁵⁴

In its review of coverage for autism, evidence submitted to the Pennsylvania Health Care Cost Containment Commission reported:⁵⁵

"...a finding of marginal premium increase costs of approximately \$1 PM/PM attributable to the ASD benefit. These cost increases are modest relative to: ongoing insurance cost increases; estimated

cost offsets for families and the Commonwealth; and better results for children and youth with ASD. The clinical and cost effectiveness research studies provided indicate that improvements in clinical and role functioning and quality of life can be anticipated for those children and youth with ASD who use evidence based behavioral therapies, including Applied Behavioral Analysis.”

Autism Speaks provides the following cost data: ⁵⁶

Estimates of the cost of providing comprehensive insurance coverage to children with autism often miss this critical point. For example, the Pennsylvania Insurance Department in its submission to PH4C projected commercial insurer annual medical cost for fiscal year 2008-2009 of \$118 per child. This projection was based on an estimated projected commercial insurer cost for fiscal year 2008-2009 per child with autism of \$17,700 and an assumed prevalence rate of 1 in 150 children ($\$17,700/150 = \118). But the assumption that Pennsylvania commercial insurers will provide \$17,700 in new, autism-related services to 1 in 150 children is belied by the difference in the number of children with autism served by the Department of Public Welfare (DPW) and the estimated number of children with autism in the state (as derived by dividing 3,200,000, the total state population of children between the ages of 2 and 20, by 150). DPW reports serving 13,800 of the estimated 21,300 Pennsylvania children with autism. Thus, DPW does not provide autism services to 1 in 150 Pennsylvania children; rather, DPW provides autism services to approximately 1 in 233 Pennsylvania children ($13,800/3,200,000$). Dividing the commercial insurer cost of \$17,700 projected by the Pennsylvania Insurance Department by 233 yields an annual medical cost of approximately \$76 per child, rather than the \$118 per child estimated by the department.

The Pennsylvania Insurance Department assumes in a mid-range estimate that 33% of insureds are children and that family rates are 3 times the single rate. The annual medical costs per family thus should be \$75 annually ($\76 (cost per child) X % of insured children (33%) X family factor (3.0)). Assuming that these costs represent only 85% of total cost to insurers, monthly premium costs should be \$7.35 per family ($\$75/12/.85$), and family premiums, which average nationally about \$1,009 monthly according to the Kaiser Family Foundation, should increase by 0.7% ($\$7.35/\$1,009$).

Even with an adjustment to correct for the overstatement of treatment prevalence, the Pennsylvania Insurance Department

estimate is high relative to cost projections in South Carolina and Louisiana. Governor Mark Sanford of South Carolina estimated that S. 20, R-85, would add \$48 annually to insurance policies. The Louisiana Legislative Fiscal Office estimated a premium policy increase for Louisiana's autism insurance measure, House Bill 958, ranging from 0.13% to 0.46%, or \$1.12 per policy per month to \$3.87 per policy per month.

From the estimates available in Pennsylvania, South Carolina, and Louisiana, we can project that Virginia HB 83 will have a likely rate impact of no more than 0.7%. There is good reason to believe that the actual rate impact will be significantly less. The treated prevalence of autism in Pennsylvania may be unusually high. Pennsylvania provides behavioral health rehabilitation services that wraparound other services. These services are available through medical assistance to children with autism and other severe disabilities regardless of parental income. This well-established "loophole" enables and encourages families to apply for medical assistance and to seek services. Moreover, the per capita cost of treating children with autism may be less than that projected by the Pennsylvania Insurance Department. The department in fact acknowledges that its estimate, which is 20% higher than the per child cost of the Department of Public Welfare, may be too high: "We use \$17,700 rather than the DPW number of \$14,900 to allow for an increased cost for commercial insurers vs. the MA [medical assistance] program]. If insurers are able to manage costs better than DPW, the \$17,700 could be a high estimate."

A better estimate of Virginia costs might be gleaned from the Virginia state statistics of the Interactive Autism Network (IAN) convenience sample. According to IAN, the average annual overall out-of-pocket treatment cost per child is \$6,154 in the United States and \$7,661 in Virginia – far less than what Pennsylvania's DPW projected as the commercial insurer cost of HB 1150. The DPW estimate may reflect costs that commercial insurers currently cover for children with autism. For example, if a child with autism also carries a diagnosis of dyspraxia, the child's speech therapy may be covered and the child's family may not be out-of-pocket. Using the same methodology as the Pennsylvania Insurance Department used in its midrange estimate and assuming that 1 in 233 Virginia children will receive \$8,000 (rather than \$17,700) in additional services related to their autism, the projected increase in monthly family premiums in Virginia would be 0.3% -- a scant \$3.23 on a monthly family premium [$\$8,000/233$ (1 out of 233 children) = \$33 (annual medical cost); $\$33 \times .33$ (percentage of insured who are

children) X 3.0 (family factor) = \$33 (annual medical cost for family);
\$33/12/.85 = \$3.23 (additional monthly premium)].

Written comments indicate that many families cannot afford the care they desire for their children. Without adequate health insurance, these families believe they are at a disadvantage accessing care and paying for services. As a result, the outcome is the possibility of postponing care or doing without necessary care to save money. In the case of a child with autism, doing without care or diluting care could mean the loss of critical opportunities to lessen the effects of the condition.

The financial impact of the amended version of House Bill 83 (House Bill 1588) will be impacted by the annual maximum limit of \$36,000.

INSURANCE COVERAGE

The State Corporation Commission Bureau of Insurance (BOI) recently surveyed 50 of the top writers of accident and sickness insurance in Virginia regarding each of the bills to be reviewed by the Advisory Commission this year. Forty-two companies responded by August 27, 2008. Seven indicated that they have little or no applicable health insurance business in force in Virginia and, therefore could not provide the information requested. Of the 35 respondents that completed the survey, 14 indicated that they currently provide the coverage required under House Bill 83 in their standard benefit package. Twenty-one indicated they did not provide coverage under their standard benefit package. Of the 21 companies indicating no ASD coverage under their standard benefit package, nine indicated mandated coverage provisions under §38.2-3412.01:1 or § 38.2-3418.5, the early intervention legislation.

When asked about specific coverage for ABA, 4 companies reported specific coverage for ABA. Two of the three companies indicated that the coverage fell under the member's medical or behavioral benefit, and that rendered services may not be considered experimental or investigational.

Twenty-one companies provided premium cost estimates relating to House Bill 83. Respondents estimated cost figures between \$.14 and \$6.67 per member per month for standard individual policy. One company estimated the monthly cost at \$313.50 for individual major medical coverage. The BOI has not received a response to our request from one company which reported a cost of \$657 for individual optional coverage. Twenty companies estimated cost figures between \$.04 and \$6.15 for standard group coverage. Sixteen companies estimated monthly premium costs ranging from \$.08 to \$14.00 per group certificate for optional coverage. The amended bill language contained a maximum of \$36,000 that would likely effect premium cost estimates.

In general, treatment for autism and ASDs are covered, including coverage for co-morbid conditions. Services or treatments are not specifically limited because of the diagnosis of ASD. However, certain treatments (i.e. ABA) are not covered because

insurers deem them as experimental or investigational. Most services that would be limited are due to applied limitations based on a member's policy limits, medical necessity review, medical policies, or covered provider types.

Autism Speaks notes that few health insurance plans in Virginia or elsewhere cover ABA. Although ABA is often considered investigational or experimental, Autism Speaks notes scientific evidence of its efficacy and its endorsement by the nation's leading health authorities. Interventions other than ABA may be available only if autism is not listed as a child's primary diagnosis. Autism Speaks highlighted a study of diagnostic exclusions in private behavioral health care plans, where researchers examined a total of forty-six commercial, employment-based behavioral health plans covering a total of 496,911 lives. The researchers found that autism was a diagnostic exclusion in all of the plans. Even where a diagnosis of autism is not an absolute bar to treatment, the nature of the care may result in a denial of service. Children with autism often require habilitative care – that is, they require care that imparts a new ability, rather than care that restores one that has been lost. This distinction can result in a denial of service.⁵⁷

LEGISLATION IN OTHER STATES

Staff reviewed an on-line search of insurance laws indicating that 23 states have enacted laws relating to autism coverage. Connecticut, Georgia, Indiana, Kentucky, Maryland, New York and Tennessee have laws that specifically address insurance coverage for autism-related services. Ten other states -- California, Illinois, Iowa, Kansas, Louisiana, Maine, Montana, New Hampshire, New Jersey and Virginia – mandate coverage for autism-related services as part of legislation addressing autism as a biologically-based mental illness requiring insurers to cover autism as they do other mental illnesses.⁵⁸

The states of Arizona, Florida, Louisiana, Pennsylvania, South Carolina and Texas have most recently enacted laws relating to ASDs, and generally require coverage for ABA services, establish benefit maximums, and do not apply to individual health insurance policies or policies issued to small employers (50 or fewer employees).

REVIEW CRITERIA

SOCIAL IMPACT

- a. *The extent to which the treatment or service is generally utilized by a significant portion of the population.*

There is not a full population count of all individuals with an ASD in the United States. However, using the most current prevalence data, the CDC estimates that if 4 million children are born in the United States every year and assuming the prevalence rate has been constant over the past two decades, up to 560,000 individuals between the ages of 0 to 21 have an ASD. Many of these individuals may not be classified as

having an ASD until school-age or later. Since behaviors related to the ASDs are usually present before the age of 3 years, but not diagnosed until later, the CDC and other public health professionals use prevalence measures to track ASDs. Prevalence is the number of existing disease cases in a defined group of people during a specific time period as opposed to “incidence” measures. Incidence is the number of new cases of disease in a defined group of people over a specific time. Incidence is very difficult to establish because the exact time a person develops an ASD is not known.⁵⁹

According to the Centers for Disease Control (CDC), as many as 1 in 150 children are autistic. Approximately 1.5 million people in the United States are on the autism spectrum. Government statistics suggest the rate of autism is increasing 10 to 17% annually. Also, according to the CDC, of the approximately 4 million babies born every year, 24,000 of them will eventually be identified as autistic. Recent studies suggest boys are more susceptible than girls to developing autism. In the United States, 1 out of 94 boys are suspected of being on the spectrum. Girls appear to manifest a more severe form of the disorder than their male counterparts.⁶⁰

The DMHMRSAS reported that the Commonwealth is currently serving 185 infants and toddlers who have the potential for ASD, which is defined as them having impairment in social interaction and communication skills along with restricted and repetitive behaviors. Generally, children from birth to age 3 have not been specifically diagnosed with autism. Local systems show that during calendar year 2007, there were 68 children with this as an eligibility category who were referred out of Part C and into Part B (early childhood special education).⁶¹

The Infant & Toddler Connection of Virginia reported to the Office of Special Education Programs the following Part C statistics for the Commonwealth of Virginia as of December 1, 2007:

Total Number of infants and toddlers served	6,023
Gender of Infants and Toddlers, ages birth through 2, receiving early intervention services	3,837 (male) 2,186 (female)
Setting of Infants and Toddlers, ages birth through 2, receiving early intervention services	4,745 (home) 0,276 (community-based) 1,002 (other)

This dataset includes 975 infants and toddlers receiving services through the public school systems.⁶²

In Virginia, each school district must provide an appropriate program of special instruction for exceptional students. As of December 1, 2007, school divisions and State Operated Programs in Virginia served 7,509 children and youth with ASDs between birth and age 21. As of December 1, 2006, school divisions and State Operated Programs in Virginia served 6,452 children and youth with ASDs between

ages birth to 22. As of December 1, 2005, school divisions and State Operated Programs in Virginia served over 5,674 children and youth with autism spectrum disorders between ages birth to 22. And, as of December 1, 2004, school divisions and State Operated Programs in Virginia served over 4,751 children and youth with autism spectrum disorders between ages birth to 22.⁶³

For some parents, school services will meet the needs of their child's prescribed treatments. For others, the services provided in schools cannot meet the medical needs prescribed for their child. The responsibility of the educational system is different from medical services. Schools provide speech therapy and other related services to enable a child with a disability to receive a free appropriate public education.⁶⁴

- b. *The extent to which insurance coverage for the treatment or service is already available.*

The State Corporation Commission Bureau of Insurance (BOI) surveyed 50 of the top writers of accident and sickness insurance in Virginia regarding each of the bills to be reviewed by the Advisory Commission this year. Forty-two companies responded by August 27, 2008. Seven indicated that they have little or no applicable health insurance business in force in Virginia and, therefore, could not provide the information requested. Of the 35 respondents that completed the survey, 14 indicated that they currently provide the coverage required under House Bill 83 in their standard benefit package. Twenty-one indicated they did not provide coverage under their standard benefit package. Of the 21 companies indicating no ASD coverage under their standard benefit package, nine indicated mandated coverage provisions under §38.2-3412.01:1 or § 38.2-3418.5, the early intervention legislation.

When asked about specific coverage for ABA, four companies reported specific coverage for ABA. Two companies indicated that the coverage fell under the member's medical or behavioral benefit, and that rendered services may not be considered experimental or investigational.

In general, treatment for autism and ASDs are covered, including coverage for co-morbid conditions. Services or treatments are not specifically limited because of the diagnosis of ASD. However, certain treatments (i.e. ABA) are not covered because insurers deem them as experimental or investigational. Most services that would be limited are due to applied limitations based on a member's policy limits, medical necessity review, medical policies, or covered provider types.

Autism Speaks notes that few health insurance plans in Virginia or elsewhere cover ABA. Although ABA is often considered investigational or experimental, Autism Speaks notes scientific evidence of its efficacy and its endorsement by the nation's leading health authorities. Interventions other than ABA may be available only if autism is not listed as a child's primary diagnosis. Autism Speaks highlighted a study of diagnostic exclusions in private behavioral health care plans, where researchers

examined a total of forty-six commercial, employment-based behavioral health plans covering a total of 496,911 lives. The researchers found that autism was a diagnostic exclusion in all of the plans. Even where a diagnosis of autism is not an absolute bar to treatment, the nature of the care may result in a denial of service. Children with autism often require habilitative care, care that imparts a new ability, rather than care that restores one that has been lost. This distinction can result in a denial of service.⁶⁵

The VAHP stated in its presentation to the Advisory Commission that private health insurance (medical services), Individuals with Disabilities Education Act Parts B and C (Education services), and Medicaid (Medical, long-term care, educational, and support services) were three current major funding streams for autism treatment or services.

- c. *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.*

Proponents believe House Bill 83 would prevent insurers from restricting coverage to an individual solely because that individual was diagnosed with an ASD. Simultaneously, House Bill 83 would allow insurers to continue evidence-based policy decisions. Several speakers reiterated accounts of children being diagnosed with ASD, and being advised to receive weekly behavioral therapy that would cost approximately \$3,000 to \$3,200 per month. However, they stated, it is difficult to develop a work plan to facilitate a child's progress when therapy is prohibitive due to its expense or unavailability (shortage) of board-certified behavioral therapists. The child with ASD would not adequately progress when therapies are delayed as behavioral therapies are most effective when children are between the ages of 2 and 5, and the mind is open and pliable. Also, because different disabilities on the spectrum affect individuals differently, it is sometimes difficult for parents to determine if services provided in the educational system have the same goals and results as those services provided or prescribed in a medical environment.

Many families cannot afford the care that they desire for their children. Without adequate health insurance, these families are at substantial disadvantage when it comes to paying for services, and may postpone or do without necessary care to save money. In the case of a child with autism, doing without care or diluting care could mean the loss of critical opportunities to ameliorate the harmful effects of the condition.⁶⁶

Testimony presented at the public hearing emphasized that few health insurance plans cover behavioral treatment for ASD citing in many cases that "Medical and mental health services for the treatment of pervasive developmental disorders are considered not medically necessary, as no medical or mental health treatments have been proven effective for the primary diagnosis of pervasive developmental disorders."⁶⁷

Some research studies conclude that ABA and other structured behavioral therapies are the most effective forms of treatment and have the best outcomes when a

child is diagnosed with ASD at an early age and interventions begin. Although there is no cure for ASD, the studies indicate behavioral therapies seem to be the most effective at maximizing appropriate behaviors and minimizing maladaptive behaviors. The affects are manifested in both human costs and in long-term economic benefits. Advocates point out that on a national level, few private insurance companies or other employee benefit plans cover ABA and other behavioral therapies. They cite as evidence those insurance companies which designate autism as a diagnostic exclusion, which means that for most insureds, no autism-specific services are covered, including those services that would be used to treat other conditions.⁶⁸

- d. *If the coverage is not generally available, the extent to which the lack of coverage results in unreasonable financial hardship on those persons needing treatment.*

Autism is an expensive disorder. In a 2006 study, children with autism had a higher annual number of total clinic, pediatric, and psychiatric outpatient visits compared with children without autism. This same study found that the mean annual total cost per member in one large health care plan was more than three times higher for children with autism (\$2,757 versus \$892). A 2007 study found that individuals with an autism spectrum disorder had average medical expenditures that exceeded those without an autism spectrum disorder by \$4,110-\$6,200 per individual. In yet another study, researchers found that average annual health care expenditures for individuals with an autism spectrum disorder increased 20.4% from 2000 to 2004, even after adjustment for inflation.⁶⁹

Costs associated with autism include long-term intensive behavioral therapy. The JLARC evaluation stated that the cost of providing treatment for ASDs could result in a considerable financial hardship for families, depending on the level of services children may need. Also, several other issues may exacerbate the financial hardship, such as, some children requiring more than one type of therapy or some families having multiple children with ASDs.⁷⁰

Autism Speaks referenced a recommendation from the Commission on Behavioral and Social Sciences and Education, a division of the National Academy of Sciences that “services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of behavioral therapy 25 hours per week, 12 months per year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives.” Some models the Commission studied recommended as many as 45 hours per week of behavioral therapy for children with autism.⁷¹

According to survey data from the Interactive Autism Project (IAN), an online autism research project, 77% of families nationwide pay the full cost of ABA out-of-pocket. Of the families surveyed, 5% nationwide pay over \$2,500 per month for ABA (\$30,000 annually). This study also concluded that 20% of the families that use ABA with their children spend over \$500 per month for the intervention. Thirty-five percent of

families reported quitting a job or significantly reducing hours at work to either take a child to treatment or to conduct treatment at home.⁷²

At the public hearing, a parent from northern Virginia told the Advisory Commission that in May of 2007, her son at age two was diagnosed with autism. He rapidly regressed to “sitting in a corner, chewing his shirt and playing with shadows.” He had lost eye contact, his play skills and imitation skills, and would not respond to any stimulation. The recommendation was that he receive 40 hours per week of ABA. She and her husband went into debt to afford 20 hours of ABA for this child. In September, the family had an issue with plumbing and had to decide to cut off water to their upstairs or cut the ABA sessions. By December, the family was “maxed out” financially. In January 2008, a 17-month old son was diagnosed with autism. His regression was similar to the older sibling, and he lost his ability to chew. The younger son would be eligible for 8 hours of ABA through Child Find (IDEA Part C), although he was recommended to receive 40 hours of ABA treatment also.

The unreasonable financial hardship led the family to ask the community for assistance. A church conducted a yard sale. Another group conducted a bake sale, and a fitness organization held an exercise-a-thon to raise money. Two six-year-old neighborhood boys asked their birthday party guests to donate monies to this family rather than give them birthday gifts. The testimony concluded with the parent saying that her sons need more one-on-one therapy; children with autism deserve treatment that will help them; parents should not have to decide if providing half of the treatment for each child is adequate; if caring for the child who needs treatment the most is acceptable; or if helping the son that may excel the furthest, letting the other son go without is sufficient.

e. *The level of public demand for the treatment or service.*

The definition and diagnostic criteria for ASD has been refined since autism was first described in 1943. Although the criteria for ASD in the DSM-IV in 1994 are most restrictive, some research studies show a steady rise in the number of affected individuals. Some research concludes that the growth indicates a true increase, since the criteria has remained uniform and since the probability that the diagnosis in each case has been accepted by the same medical, educational and developmental teams.⁷³

Other research concludes the prevalence of autism and ASDs is closely linked to a history of changing criteria and diagnostic categories. Several studies indicate the rate of pervasive developmental disorders is higher than reported 15 years ago. The growth rate in one study is comparable to that in previous birth cohorts from the same area and surveyed with the same methods, suggesting a stable incidence.⁷⁴

The two most prevalent trends confirmed by research are that the incidence of autism has increased remarkably, and there has been a shift in the time of onset of autistic symptoms. Research supports a trend that children with ASD are most often

detected when entering first grade rather than at earlier ages. If this trend continues, there will be a greater increase in the number of younger children needing services, more programs being organized to handle the influx, and an increased number of trained therapists.⁷⁵

As of December 1, 2007, school divisions and State Operated Programs in Virginia served 7,509 children and youth with ASDs between birth and age 21.⁷⁶ The DMHMRSAS reported that the Commonwealth is currently serving 185 infants and toddlers who have the potential for ASD, which is defined as having impairment in social interaction and communication skills along with restricted and repetitive behaviors. Generally, children from birth to age 3 have not been specifically diagnosed with autism. Local systems show that during calendar year 2007, there were 68 children with autism as an eligibility category who were referred out of Part C and into Part B (early childhood special education).⁷⁷ The Infant & Toddler Connection of Virginia reported serving a total of 6,028 infants and toddlers in Part C (IDEA) as of December 1, 2007. This dataset includes 975 infants and toddlers receiving services through the public school systems.⁷⁸

The JLARC evaluation addressed the level of public demand in this manner:

The 2002 Department of Education (DOE) report on autism services indicated that the inability to afford services and lack of insurance coverage prevented children with ASD 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%) and insurance refusing to cover the cost of services (28%). 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.⁷⁹

Autism Speaks emphasizes the public demand for autism services by pointing out the fact that eight states [Indiana (2001), Minnesota (2001, insurance settlement), South Carolina (2007), Texas (2007), Arizona (2008), Florida (2008), Louisiana (2008), and Pennsylvania (2008)] provide comprehensive coverage to children with autism.

f. The level of public demand and the level of demand from providers for individual and group insurance coverage of the treatment or service.

The Advisory Commission held a public hearing on September 29, 2008 in Richmond to receive public comments on House Bill 83. In addition to patron Delegate Marshall and Delegate David Poisson thirty individuals spoke in favor of the proposal. Representatives from Autism Speaks, the Kennedy-Krieger Institute, The Loudoun Project, The Spiritos School, The Allergy and Nutrition Clinic (northern Virginia), and several medical doctors, therapists, and other professionals involved with individuals on the autism spectrum addressed the Commission.

In addition, written comments were received from Autism Speaks, the Virginia Nutritionists Association, and the Association for Science in Autism Treatment, and the Relationship Development Intervention (RDI) parent group. Seventy-three written letters and electronic letters were submitted from private citizens in support of the proposed legislation. Also, signatures from 265 residents from the Tidewater and Northern Virginia areas of the Commonwealth were submitted supporting House Bill 83.

Written comments addressing House Bill 83 from parents of children with autism indicate that services for children with ASD exist. However, parents noted there are barriers which reduce access to those services. A review of an analysis proposing mandated coverage for autism in Pennsylvania highlighted very similar barriers. Those barriers included fragmented services, an inability to cover all of those in need, and inadequate payment schedules for some providers and/or specific services. Some studies highlight the belief that parents are consistently excluded from coverage of some treatments for autism, particularly those that involve behavioral treatments such as speech therapy and ABA. The reason for the exclusion or limiting the number of treatment sessions is thought by some to be that insurers are of the opinion that such therapies do not have a reasonable expectation of achieving sustainable, measurable improvement in a reasonable and predicable period of time. Also, studies referenced in the Pennsylvania analysis note that some group insurers have blanket exclusions for autism.⁸⁰

g. The level of interest of collective bargaining organizations in negotiating privately for inclusion of this coverage in group contracts.

No information was received from collective bargaining organizations addressing potential interest in negotiating privately for inclusion of this coverage in group contracts.

h. Any relevant findings of the state health planning agency or the appropriate health system agency relating to the social impact of the mandated benefit.

Senate Bill 165, which required coverage for therapies for biologically-based mental illnesses, was referred to the Special Advisory Commission in the 2000 session of the General Assembly. On December 14, 2000, the Advisory Commission voted unanimously (7-0) to recommend that Senate Bill 165 not be enacted. There were concerns related to the yet-to-be determined costs associated with the recent expansion of coverage under the early intervention services mandate.

Senate Bill 1049, proposed in the 2005 Session of the General Assembly by Senator Frank Wagner, would have added § 38.2-3418.15 to the Accident and Sickness Insurance Provisions Chapter and amended § 38.2-4319 in the HMO Chapter of the Code of Virginia. The Advisory Commission voted on Senate Bill 1049 on August 18, 2005. In a vote of nine to one, the Advisory Commission recommended against mandating an offer of coverage for the treatment of developmental delay, but instead

recommended to the General Assembly establishing a committee to further analyze the impact of mandating an offer of coverage for developmental delay.

House Bill 657, mandating an offer of coverage for the treatment of developmental delay, was introduced by Delegate Kenneth Plum in 2006 and was referred to the Advisory Commission. The Advisory Commission voted on November 20, 2006 to recommend against enacting House Bill 657 (Yes- 12, No-1). The Advisory expressed concern with regard to 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.

FINANCIAL IMPACT

- a. *The extent to which the proposed insurance coverage would increase or decrease the cost of treatment or service over the next five years.*

Autism Speaks emphasizes that demand for autism treatments and services exceed the available supply. They reason that the imbalance is due to distortions in the delivery of services. Families have difficulty accessing treatment through private insurance coverage. This leaves them at a competitive disadvantage in negotiating the price of services. A study of exclusions and limitations in behavioral health coverage concluded that policy restrictions drove prices upwards:

Health insurance generally increases the affordability of children's behavioral health care, but the presence of benefit limits or diagnostic exclusions can mean that some children effectively become uninsured if they require more intensive services than those covered under the plan or if they need treatment for disorders that are excluded under the plan. Although current utilization management strategies employed by managed behavioral health organizations, through which few patients ever reach their benefit limits, render benefit parity almost irrelevant, some children do exceed their benefit limits. The cost of obtaining uncovered services can be very high, because the price of services that are not billable to an insurance plan can be significantly higher than payments for those same services under negotiated agreements between insurers and providers.⁸¹

The JLARC assessment indicates that a shortage of providers in some areas could drive up the cost of services as a result of increasing demand. With regard to other services, providers would need to enter into contractual agreements with insurance companies. The contractual agreements would compel providers to accept lower reimbursements rates in exchange for a higher volume of patients as a result of being included in a health plan's network.⁸²

- b. *The extent to which the proposed insurance coverage might increase the appropriate or inappropriate use of the treatment or service.*

Autism Speaks stated in written comments that House Bill 83 mandates core treatments for autism. Private insurance coverage of these treatments may not only decrease costs, but may increase their appropriate utilization. Insurers can often provide members with the assistance that allows policyholders to select appropriate coverage. Conversely, with inadequate insurance coverage, families of children with ASDs are forced to make difficult decisions unassisted.

Parents of children with ASD testified that in many instances, they seek supplemental or complementary treatment for their children in addition to what is provided through the schools. However, there is concern that few board certified behavioral therapists are available to assist individuals with specialized therapies.

The JLARC evaluation states that the Department of Education does not anticipate the proposed mandate impacting 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.⁸³

- c. *The extent to which the mandated treatment or service might serve as an alternative for more expensive or less expensive treatment or service.*

Alternatives to ASD treatments or services are limited to diluting the treatment, postponing or doing without necessary care to save money, or institutionalization. Several parents testified about their inability to pay for recommended amount of service for their child. In some cases they paid for what they could afford. Parents and medical experts indicate that as a result, children may not reach their full potential, especially when research indicates that the window of opportunity for maximizing skills is limited for children with ASDs.

Proponents believe that most ASD children live to be older citizens, and many develop other costly medical or psychological conditions that could have been avoided if interventions were applied early in life. In some cases, individuals with ASD can be institutionalized when they did not receive appropriate or adequate service. The JLARC evaluation referenced a 2004 study which concluded that the average costs were significantly higher for persons in congregate settings (\$115,830) compared to less restrictive non-congregate settings (\$96,010). While ASD treatments may not prevent all children from being institutionalized, it could impact some individuals, allowing them to live and become a part of the general society.

- d. *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.*

Insurance coverage for ASD treatment may increase the number of trained providers to deliver day-to-day, one-on-one services. Most insurance carriers require monitoring of services by a licensed provider.

It cannot be determined the effect the proposed mandate might have. The effect is dependant on the level of increased demand for services resulting from the proposed mandate. If demand is high, the number of providers could possibly increase to meet the demand. However, other variables to consider are parents' ability to pay for additional services and the small population affected by mandates.

Currently, the Commonwealth does not provide licensing for providers of ABA therapy. However, a national non-profit corporation does provide professional credentialing for those therapists seeking review and validation pursuant to standards established by experts in the field

- e. *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.*

Representatives of the insurance industry indicated that administrative costs for House Bill 83 would be higher than other mandates because most insurance carriers do not typically cover some the services included in the proposed mandate. If enacted, insurers would need to establish provider networks and negotiate reimbursement rates with providers of the newly covered services.

The Bureau of Insurance surveyed 50 of the top writers of accident and sickness insurance in Virginia regarding House Bill 83 prior to the September 2008 changes. Of the 35 respondents that completed the survey, 14 indicated that they currently provide the coverage required under House Bill 83 in their standard benefit package. Twenty-one indicated they did not provide coverage under their standard benefit package. Of the 21 companies indicating no ASD coverage under their standard benefit package, nine indicated mandated coverage provisions under § 38.2-3412.01:1 or § 38.2-3418.5, the early intervention legislation.

When asked about specific coverage for ABA, four companies reported specific coverage for ABA. Two of the three companies indicated that coverage fell under the member's medical or behavioral benefit, and that rendered services may not be considered experimental or investigational.

Twenty-one companies provided premium cost estimates relating to House Bill 83. Respondents estimated cost figures between \$.14 and \$6.67 per member per month for standard individual policy. One company estimated the monthly cost at \$313.50 for individual major medical coverage. The BOI has not received a response to our request from one company who reported a cost of \$657 for individual optional coverage. Twenty companies estimated cost figures between \$.04 and \$6.15 for

standard group coverage. Sixteen companies estimated monthly premium costs ranging from \$.08 to \$14.00 per group certificate for optional coverage.

The maximum of \$36,000 would likely affect the premium cost estimates. In general, treatment for autism and ASDs are covered, including coverage for co-morbid conditions. Services or treatments are not specifically limited because of the diagnosis of ASD. However, certain treatments (i.e. ABA) are not covered because insurers deem them as experimental or investigational. Most services that would be limited are due to applied limitations based on a member's policy limits, medical necessity review, medical policies, or covered provider types.

f. The impact of coverage on the total cost of health care.

According to proponents, the cost of providing children diagnosed with ASD with individualized behavioral therapy requires up to forty hours per week for maximum effectiveness, and can range from \$30,000 to \$60,000 per year, per child. Proponents also cite a social cost if public school districts are not able to provide services causing parents without ample financial means to be left with few options for their children. The majority of parents are not Medicaid eligible.

Estimates of the total annual societal per capita cost of caring for and treating a person with autism is \$3.2 million depending on the extent of therapies, care, and support services figured into the equation. A recent study, conducted by Dr. Michael Ganz, determined the following lifetime costs for an individual with ASD:

Data from medical literature and from national surveys were used to estimate the direct medical and non-medical costs of autism, including prescription medications, adult care, special education and behavioral therapies. Approximate indirect costs, including lost productivity of both individuals with autism and their parents, were calculated by projecting average earnings and benefits at each age, adjusted for the fact that some autistic individuals can work in supported environments. Only costs directly linked to autism, and no medical or non-medical costs that would be incurred by individuals with or without autism, were included.

Costs were projected across the lifetime of a hypothetical group of individuals born in 2000 and diagnosed with autism in 2003. Costs estimates were broken down into age groups at five-year intervals, with the youngest group age 3 to 7 years and the oldest age 63 to 66 years. The study concluded that "direct medical costs are quite high for the first five years of life (average of around \$35,000), [then] start to decline substantially by age 8 years (around \$6,000) and continue to decline through the end of life to around \$1,000. "Direct non-medical costs vary around \$10,000 to approximately \$16,000 during the first 20 years of life, peak in the 23- to 27-year age range (around \$27,500) and then steadily decline to the end of life to around \$8,000 in the last age group. Indirect

costs also display a similar pattern, decreasing from around \$43,000 in early life, peaking at ages 23 to 27 years (around \$52,000) and declining through the end of life to \$0."

The study determined that over an individual's life, lost productivity and other indirect costs make up 59.3% of total autism-related costs. Direct medical costs comprise 9.7% of total costs; the largest medical cost, behavioral therapy, accounts for 6.5% of total costs. Non-medical direct costs such as child care and home modifications comprise 31% of total lifetime costs.

However, because these costs are incurred by different segments of society at different points in an autistic patient's life, a detailed understanding of these expenses could help planners, policymakers and families make decisions about autism care and treatment."⁸⁴

MEDICAL EFFICACY

- a. *The contribution of the benefit to the quality of patient care and the health status of the population, including the results of any research demonstrating the medical efficacy of the treatment or service compared to alternatives or not providing the treatment or service.*

The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles, calling for an intensive, one-on-one child-teacher interaction for 40 hours per week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential. The Lovaas Model of ABA is the most rigorously controlled early intervention research published to date. The research has the longest follow-up tracking of children with autism who have received intensive early intervention (McEachin, 1993) and replication research (Sallows, 2005 and Cohen, 2006).⁸⁵

The Lovaas Model of ABA asserts that children must receive 35 to 40 hours of intense intervention per week. The benefit of approximately 40 hours of intense therapy provides a child with structured intervention throughout the day. The intervention allows the environment to be systematically manipulated to help a child remain successful while also teaching new skills quickly. The intensity of the therapy empowers parents and encourages a continuation of learned skills throughout the child's waking hours. The purpose of an intensive program is to allow a child with autism to learn how to learn in the natural environment and ultimately catch up to his or her typically developing peers.⁸⁶

The validity of the Lovaas method has been challenged due to lack of double-blind studies comparing the Lovaas approach against a control group not receiving ABA. Sallows and Graupner's 2005 study, which compared groups treated by

professionals vs. those treated at home by their parents, replicated the results of Lovaas, but found little difference in outcome between the groups. This study represents the most comprehensive and rigorous replication to date, and their findings nearly mirror Lovaas'.⁸⁷

In a report evaluating ASD for HB 1150 in Pennsylvania (2008), in addition to behavioral therapy, many children with ASD are prescribed medications. In a study conducted by Mandel et al, it was determined that 56% of children with ASD used at least one prescription medication, and among those who used medication, 20% used 3 medications simultaneously. The study also found that older children (older than 5) were more likely to have used medication. Sixty-one percent of children with Asperger disorder used psychotropic medications, while 53% of children with autistic disorders used medications (e.g. risperidone or Risperdal). This study used 2001 Medicaid data on children from all 50 states plus the District of Columbia to investigate psychotropic medication use.⁸⁸

The Surgeon General of the United States recognizes the efficacy of ABA, as well as the Departments of Health in New York, California and Maine. Other research studies support its positive outcomes. The demonstrated efficacy of applied behavioral methods is that it “reduces inappropriate behavior and increases communication, learning, and appropriate social behavior.”⁸⁹ The report, *Mental Health: A Report of the Surgeon General* states that “thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”⁹⁰

Some research studies conclude that ABA and other structured behavioral therapies are the most effective forms of treatment and have the best outcomes when a child is diagnosed with ASD at an early age and interventions begin. Although there is no cure for ASD, the studies indicate behavioral therapies seem to be the most effective at maximizing appropriate behaviors and minimizing maladaptive behaviors. The affects are manifested in both human costs and in long-term economic benefits.⁹¹

b. If the legislation seeks to mandate coverage of an additional class of practitioners:

1) *The results of any professionally acceptable research demonstrating the medical results achieved by the additional class of practitioners relative to those already covered.*

Not applicable.

2) *The methods of the appropriate professional organization that assure clinical proficiency.*

Not applicable.

EFFECTS OF BALANCING THE SOCIAL, FINANCIAL AND MEDICAL EFFICACY CONSIDERATIONS

- a. *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.*

Proponents believe House Bill 83 would prevent insurers from restricting coverage to an individual solely because that individual was diagnosed with an ASD. Simultaneously, House Bill 83 would allow insurers to continue evidence-based policy decisions. Therefore, the bill strikes a balance between safeguarding the health-care needs of a vulnerable population of reimbursing effective medical care, and is consistent with the role of healthcare.

VAHP stated that mandates have the effect of making health care too costly for individuals and small businesses that are least able to afford health insurance. Another expense cited by VAHP included an increase in the number of mandates increases the costs of insurance premiums, and employers, particularly small employers, are less likely to offer coverage to their employees.⁹²

VAHP opposed recommending the mandate indicating that federal law currently describes ABA as a service provided within the educational system. Mandating coverage for autism would impact the current delivery system. The VAHP stressed that IDEA requires local schools to provide ABA and similar services through an IEP. Because of the diversity in treatments and high volume of students requiring treatments, most school systems are strained to provide the necessary services due to limited resources. As such, VAHP asked whether having private insurance pay for ASD-related services would induce public schools to reduce or discontinue services for children with ASD. The American Academy of Pediatrics describes ABA as an educational intervention and the Federal Education Law contains an affirmative obligation to provide ABA services.⁹³

VAHP cited an example stressing that several Virginia Counties have lost lawsuits over providing ABA services and have been directed to pay tuition of approximately \$50,000 per year on behalf of a child to a local school that specializes in providing ABA services to children with Autism. VAHP also stated that 15 Richmond area school districts and Virginia Commonwealth University have announced a joint effort to train teachers and educators of students with autism.⁹⁴

- b. *The extent to which the need for coverage outweighs the costs of mandating the benefit for all policyholders.*

The JLARC assessment indicates that 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. Costs will vary depending on the type of therapy, the intensity of the therapy, and other variables.

Proponents testified that when ASD children do not receive those necessary services that allow them to maximize development, the probability is high that they will not become productive, contributing citizens to society. Ultimately, the cost to Virginia and its tax-paying citizens would be higher when services are not received.

JLARC further states that the BOI survey of the 50 top writers of insurance in Virginia reported cost estimates higher than those estimated in other states with similar mandates. Including a cap on coverage 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.

The amended language presented by the patron included a cap on coverage of \$36,000 annually. The VAHP asserted that the mandate would impact 25% of children with autism. Using confirmed figures, 7,509 children up to age 20 were identified as having an ASD and receiving special education and related services in the public school system; 13,810 children from birth to age 19 with ASD based upon CDC prevalence rate and Virginia's overall population; then, if approximately one-quarter of the children or 1,875 to 3,500 would be in fully insured policies that would be eligible for the benefit. VAHP estimated that the range from 1,875 to 3,500 would increase over time as families dealing with autism would seek coverage that included ABA.

- c. *The extent to which the need for coverage may be solved by mandating the availability of the coverage as an option for policyholders.*

Based on the BOI survey of the 50 top writers of insurance in Virginia, the premium impact of a mandated offer would likely be more expensive because only those individuals most likely to use the benefit would purchase it.

RECOMMENDATION

On November 19, 2008, the Advisory Commission recommended enacting coverage for autism, House Bill 83, as amended in September 2008 (Yes- 6, No- 4). The vote was contingent on language being added to the bill to recognize the need to make changes to comply with the federal Mental Health Parity and Addiction Equity Act of 2008.

CONCLUSION

The Advisory Commission expressed concern for those Virginia consumers who are in need ASD treatments and services, and would benefit from the provisions of House Bill 83. The Advisory Commission members had questions about evidence-based treatments, alternative treatments, and discussed issues regarding the most effective mechanism of providing assistance to those families affected by autism and autism-related treatments.

After reviewing data from other states with mandates for the treatment of ASDs and reviewing other substantive follow up information, the Advisory Commission voted to recommend House Bill 83—Amended as it was presented by Delegate Marshall at the September 29, 2008 meeting.

NOTE: The Advisory Commission's deliberations and subsequent vote were based on the provisions incorporated in draft language of House Bill 83 - Amended, which parallel the provisions of House Bill 1588 (2009).

¹ Report Document No.47, Lead Agency to Serve individuals with Autism Spectrum Disorders. Joint Commission on Health Care (JCHC), 2008. Retrieved from Legislative Information Services website, <http://leg2.state.va.us/dls/h&sdocs.nsf/682def7a6a969fbf85256ec100529ebd/fce34b5c5293c3ee85257456005d0893?OpenDocument>)

² Ibid.

³ Office of the Secretary for Health and Human Resources. Report on “Home” for Autism Spectrum Disorders and Developmental Disabilities; Presented to JCHC on October 23, 2008.)

⁴ Centers for Disease Control, Nation Center on Birth Defects and Developmental Disabilities, Autism Information Center, Retrieved June 3, 2008 from website, www.cdc.gov/ncbddd/dd/aic/about/default.htm,

⁵ AutismSpeaks, © 2008 Autism Speaks Inc., retrieved June 17, 2008 from website, <http://www.autismspeaks.org/whatisit/faq.php>

⁶ Ibid.

⁷ Autism Information Page: National Institute of Neurological Disorders and Stroke (NINDS); <Electronic Version>Retrieved June 18, 2008 from <http://www.ninds.nih.gov/disorders/autism/autism.htm>

-
- ⁸ The Early Intervention Network. Autism in Plain English: the DSM-IV-TR Explained, retrieved on June 17, 2008 from website, <http://www.actearly.org/dsmIV/>.
- ⁹ American Psychiatric Association (APA). (2000). Pervasive developmental disorders. In Diagnostic and statistical manual of mental disorders (Fourth edition---text revision (DSM-IV-TR). Washington, DC: American Psychiatric Association, pp.69-70.
- ¹⁰ AMERICAN ACADEMY OF PEDIATRICS: Clinical Report. Management of Children with Autism Spectrum Disorders. Myers, S. M. MD, Plauche-Johnson, Chris, ND, M.Ed., The Council on Children with Disabilities. October 29, 2007
- ¹¹ Lovaas Institute © 2005-2008. All rights reserved. Retrieved June 10, 2008 from <http://www.lovaas.com/approach-detailed.php>,
- ¹² BEHAVIOR MODIFICATION. The Contributions of Applied Behavior Analysis to the Education of People with Autism. Rosenwasser, B., Axelrod, S., Vol. 25, No.5 October 2001, 671-677 ©Sage Publications.
- ¹³ National Institutes of Health, National Institute of Child Health and Human Development, Autism Facts, , retrieved 8/14/2008 from <http://www.niche.nih.gov/autism>.
- ¹⁴ National Institutes of Health, National Institute of Child Health and Human Development, Autism Facts, Retrieved 11/14/2005 from <http://www.niche.nih.gov/autism>,
- ¹⁵ Evaluation of the Relationship Development Intervention Program. Gutstein et al. Autism.2007; 11: 397-411.
- ¹⁶ Id.
- ¹⁷ Memo, Marilyn Tavenner, Secretary of Health and Human Services, Commonwealth of Virginia, July 16, 2008.
- ¹⁸ Virginia Board for People with Disabilities. 2008 Biennial Assessment. Early Intervention. Retrieved July 31, 2008 from website, <http://www.vaboard.org/downloads/biennial/2008/IIVBPDBAEarlyInt.doc>
- ¹⁹ Id.
- ²⁰ Id.
- ²¹ Id.
- ²² Virginia Department of Medical Assistance(DMAS). Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Fact Sheet. Retrieved June 19, 2008 from http://www.dmas.virginia.gov/downloads/pdfs/ch-EPSDT_Fact_Sheet.pdf).

-
- ²³ Virginia Department of Education (DOE). Disability Specific Program Information. Retrieved on June 19, 2008 from website: <http://www.doe.virginia.gov/VDOE/sped/dis-specific-autism.shtml>
- ²⁴ Journal of American Physicians and Surgeons. Vol. 8, No. 4, Winter, 2003, Autism in the United States: a Perspective. Yazbak, FE.
- ²⁵ Virginia Department of Education, Data & Reports: Virginia Education Statistics, <http://www.doe.virginia.gov/VDOE/sped/dis-specific-autism.shtml>, retrieved July 2, 2008.
- ²⁶ Id.
- ²⁷ Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150. Durham, NC: Abt Associates, Inc., June 18, 2008.
- ²⁸ Centers for Disease Control (CDC). CDC website, FAQ, Retrieved June 18, 2008 from <http://www.cdc.gov/ncbddd/autism/faq.htm>,
- ²⁹ CDC. Media Advisory Fact Sheet. Prevalence of the Autism Spectrum Disorders in Multiple Areas of the United States, Surveillance Years 2000 and 2002. A Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network. February 8, 2007. Information retrieved on July 2, 2008 from website <http://www.cdc.gov/media/pressrel/2007/f070208.htm>).
- ³⁰ Journal of American Physicians and Surgeons. Vol. 8, No. 4, Winter, 2003, Autism in the United States: a Perspective. Yazbak, FE.
- ³¹ Am J Psychiatry 162:1133-1141, Suniti Chakrabarti, M.D., F.R.C.P.C.H., M.R.C.P., and Eric Fombonne, M.D., F.R.C.Psych. June 2005, © 2005 American Psychiatric Association.
- ³² Journal of American Physicians and Surgeons. Vol. 8, No4., Winter, 2003, Autism in the United States: a Perspective. Yazbak, FE.
- ³³ Department of Health and Human Services. Centers for Disease Control (CDC). Autism Information Center. Frequently Asked Questions, retrieved June 18, 2008 <http://www.cdc.gov/ncbddd/autism/faq.htm>,
- ³⁴ Department of Health and Human Services. Centers for Disease Control(CDC). Autism Information Center. Frequently Asked Questions, retrieved June 18, 2008 <http://www.cdc.gov/ncbddd/autism/faq.htm>,
- ³⁵ CDC. Media Advisory Fact Sheet. Prevalence of the Autism Spectrum Disorders in Multiple Areas of the United States, Surveillance Years 2000 and 2002. A Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network. February 8, 2007. Information retrieved on July 2, 2008 from website <http://www.cdc.gov/media/pressrel/2007/f070208.htm>.
- ³⁶ Memo, David Mills, Data Manager/Technical Assistance Consultant, Infant & Toddler Connection of Virginia, DMHMRSAS, August 8, 2008.

-
- ³⁷ UPDATE. Infant & Toddler Connection of Virginia. Office of Child and Family Services. March 2008. pp. 5-6.
- ³⁸ BEHAVIOR MODIFICATION. The Contributions of Applied Behavior Analysis to the Education of People with Autism. Rosenwasser, B., Axelrod, S., Vol. 25, No.5 October 2001, 671-677 ©Sage Publications.
- ³⁹ Autism Information Page: National Institute of Neurological Disorders and Stroke (NINDS); <Electronic Version>Retrieved June 18, 2008 from <http://www.ninds.nih.gov/disorders/autism/autism.htm>.
- ⁴⁰ BEHAVIOR MODIFICATION. The Contributions of Applied Behavior Analysis to the Education of People with Autism. Rosenwasser, B., Axelrod, S., Vol. 25, No.5 October 2001, 671-677 ©Sage Publications.
- ⁴¹ Lovaas Institute © 2005-2008. All rights reserved. Retrieved June 8, 2008 from <http://www.lovaas.com/approach-differentiate.php>.
- ⁴² Journal of American Physicians and Surgeons. Vol. 8, No 4. Winter, 2003, Autism in the United States: a Perspective. Yazbak, FE.
- ⁴³ Autism Therapies. (No date) retrieved June 19, 2008 from <http://www.answers-about-autism.info/autism-therapies.html>
- ⁴⁴ Autism Spectrum Disorders. Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150. Durham, NC: Abt Associates, Inc., June 18, 2008
- ⁴⁵ BEHAVIOR MODIFICATION. The Contributions of Applied Behavior Analysis to the Education of People with Autism. Rosenwasser, B., Axelrod, S., Vol. 25, No.5 October 2001, 671-677 ©Sage Publications).
- ⁴⁶ Department of Health and Human Services. Mental Health: A Report of the Surgeon General. Rockville, MD: Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institute of Mental Health, 1999.
- ⁴⁷ Autism Speaks, Autism Speaks Announces Multi-State Insurance Legislation Campaign. December 27, 2007, retrieved on June 17, 2008 from website, [http://www.autismspeaks.org/press/insurance legislation campaign.php](http://www.autismspeaks.org/press/insurance%20legislation%20campaign.php).
- ⁴⁸ POLICY STATEMENT. AMERICAN ACADEMY OF PEDIATRICS: The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children; Committee on Children with Disabilities, PEDIATRICS Vol. 107 No. 5 May 2001, pp. 1221-1226.
- ⁴⁹ AMERICAN ACADEMY OF PEDIATRICS: Identification and Evaluation of Children with Autistic Spectrum Disorder. Committee on Children with Disabilities, PEDIATRICS Vol. 120 No. 5 November, 2007.

-
- ⁵⁰ Croen, LA., Najjar, DV., Ray, T., Lotspeich, L., Bernal, P, "A Comparison of Health Care Utilization and Costs of Children With and Without Autism Spectrum Disorders in a Large Group-Model Health Plan," 118 *Pediatrics* 1203 (2006).
- ⁵¹ Shimabukuro, T., Grosse, SD., Rice, C., "Medical Expenditures for Children with an Autism Spectrum Disorder in a Privately Insured Population," 38 *J. Autism and Dev. Disord.* 546 (2008).
- ⁵² Leslie, DL., & Martin, A., "Health Care Expenditures Associated with Autism Spectrum Disorders," 161 *Arch. Pediatr. Adolesc. Med.* 350 (2007).
- ⁵³ Montes, G & Halterman, JS. Halterman, "Association of Childhood Autism Spectrum Disorders and Loss of Family Income," 121 *Pediatrics* e821, e824 (April 2008).
- ⁵⁴ Personal Communication from Alison R. Marvin, Research Data Manager, Interactive Autism Network (IAN), to Stuart Spielman, Senior Policy Advisor and Counsel, Autism Speaks (March 10, 2008, 18:04 EST) (on file with Stuart Spielman).
- ⁵⁵ Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150. Durham, NC: Abt Associates, Inc., June 18, 2008.
- ⁵⁶ *Id.*
- ⁵⁷ Elizabeth Emken, Vice-President, AutismSpeaks, written comments addressing the Virginia Special Commission on Mandated Benefits. August 15, 2008.
- ⁵⁸ Private Insurance Coverage for Treatment of Autism. Kaminski Leduc, Janet. July 31, 2008, 2008-R-0427. Connecticut General Assembly website, retrieved August 4, 2008. <http://www.cga.ct.gov/2008/rpt/2008-R-0427.htm>.
- ⁵⁹ Department of Health and Human Services. Centers for Disease Control (CDC). Autism Information Center. Frequently Asked Questions, retrieved June 18, 2008 <http://www.cdc.gov/ncbddd/autism/faq.htm>,
- ⁶⁰ Centers for Disease Control (CDC). CDC website, FAQ, Retrieved June 18, 2008 from <http://www.cdc.gov/ncbddd/autism/faq.htm>,
- ⁶¹ Memo, David Mills, Data Manager/Technical Assistance Consultant, Infant & Toddler Connection of Virginia, DMHMRSAS, August 8, 2008.
- ⁶² UPDATE. Infant & Toddler Connection of Virginia. Office of Child and Family Services. March 2008. pp. 5-6.
- ⁶³ Virginia Department of Education, Data & Reports: Virginia Education Statistics, <http://www.doe.virginia.gov/VDOE/sped/dis-specific-autism.shtml>, retrieved July 2, 2008.

-
- ⁶⁴ Virginia Department of Education, Data & Reports: Virginia Education Statistics, <http://www.doe.virginia.gov/VDOE/sped/dis-specific-autism.shtml>, retrieved July 2, 2008.
- ⁶⁵ Elizabeth Emken, Vice-President, Autism Speaks. written comments addressing the Virginia Special Commission on Mandated Benefits. August 15, 2008.
- ⁶⁶ Stuart Spielberg for Autism Speaks. Public Hearing, Special Advisory Commission, September 29, 2008, Richmond, VA.
- ⁶⁷ Autism Speaks in Support of House Bill No. 83 Substitute. Special Advisory Commission Public Hearing, September 29, 2008, Richmond, VA.
- ⁶⁸ Autism Speaks, Autism Speaks Announces Multi-State Insurance Legislation Campaign. December 27, 2007, retrieved on June 17, 2008 from website, [http://www.autismspeaks.org/press/insurance legislation campaign.php](http://www.autismspeaks.org/press/insurance%20legislation%20campaign.php).
- ⁶⁹ Autism Speaks. Report Under § 624.215(2), Fla. Stat. (2007), Assessing the Social and Financial Impacts of House Bill 1291 and Senate Bill 2654.
- ⁷⁰ JLARC. Evaluation of Proposed Mandated Health Insurance Benefits. Evaluation of House Bill 83: Mandated Coverage of Autism Spectrum Disorders (p. 20-21), September, 2008, retrieved from website on November 19, 2008, URL: <http://jlarc.state.va.us/Reports/Rpt371.pdf>.
- ⁷¹ Autism Speaks. Report Under § 624.215(2), Fla. Stat. (2007), Assessing the Social and Financial Impacts of House Bill 1291 and Senate Bill 2654.
- ⁷² Personal Communication from Alison R. Marvin, Research Data Manager, Interactive Autism Network (IAN), to Stuart Spielman, Senior Policy Advisor and Counsel, Autism Speaks (March 10, 2008, 18:04 EST) (on file with Stuart Spielman).
- ⁷³ Journal of American Physicians and Surgeons. Vol. 8, No. 4, Winter, 2003, Autism in the United States: a Perspective. Yazbak, FE.
- ⁷⁴ Am J Psychiatry 162:1133-1141, Suniti Chakrabarti, M.D., F.R.C.P.C.H., M.R.C.P., and Eric Fombonne, M.D., F.R.C.Psych. June 2005, © 2005 American Psychiatric Association.
- ⁷⁵ Journal of American Physicians and Surgeons. Vol. 8, No4., Winter, 2003, Autism in the United States: a Perspective. Yazbak, FE.
- ⁷⁶ Virginia Department of Education, Data & Reports: Virginia Education Statistics, <http://www.doe.virginia.gov/VDOE/sped/dis-specific-autism.shtml>, retrieved July 2, 2008.
- ⁷⁷ Memo, David Mills, Data Manager/Technical Assistance Consultant, Infant & Toddler Connection of Virginia, DMHMRSAS, August 8, 2008.

-
- ⁷⁸ UPDATE. Infant & Toddler Connection of Virginia. Office of Child and Family Services. March 2008. pp. 5-6.
- ⁷⁹ JLARC. Evaluation of Proposed Mandated Health Insurance Benefits. Evaluation of House Bill 83: Mandated Coverage of Autism Spectrum Disorders (p. 20-21), September, 2008, retrieved from website on November 19, 2008, URL: <http://jlarc.state.va.us/Reports/Rpt371.pdf>.
- ⁸⁰ Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150. Durham, NC: Abt Associates, Inc., June 18, 2008.
- ⁸¹ Pamela B. Peele, Judith R. Lave, Kelly J. Kelleher, "Exclusions and Limitations in Children's Behavioral Health Care Coverage," 53 Psychiatr. Serv. 591 (2002).
- ⁸² JLARC. Evaluation of Proposed Mandated Health Insurance Benefits. Evaluation of House Bill 83: Mandated Coverage of Autism Spectrum Disorders (p. 20-21), September, 2008, retrieved from website on November 19, 2008, URL: <http://jlarc.state.va.us/Reports/Rpt371.pdf>
- ⁸³ JLARC. Evaluation of Proposed Mandated Health Insurance Benefits. Evaluation of House Bill 83: Mandated Coverage of Autism Spectrum Disorders (p. 20-21), September, 2008, retrieved from website on November 19, 2008, URL: <http://jlarc.state.va.us/Reports/Rpt371.pdf>
- ⁸⁴ GANZ, Michael. 2007, April. Study Sheds Light on Significant Costs of Autism. Archives of Pediatrics and Adolescent Medicine. Abt Associates. Retrieved December 2, 2008 from <http://www.abtassociates.com/page.cfm?PageID=40521>.
- ⁸⁵ Lovaas Institute © 2005-2008. All rights reserved. Retrieved June 8, 2008 from <http://www.lovaas.com/approach-differentiate.php>.
- ⁸⁶ Journal of American Physicians and Surgeons. Vol. 8, No 4. Winter, 2003, Autism in the United States: a Perspective. Yazbak, FE.
- ⁸⁷ Autism Therapies. (No date) retrieved June 19, 2008 from <http://www.answers-about-autism.info/autism-therapies.html>
- ⁸⁸ Autism Spectrum Disorders. Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150. Durham, NC: Abt Associates, Inc., June 18, 2008
- ⁸⁹ BEHAVIOR MODIFICATION. The Contributions of Applied Behavior Analysis to the Education of People with Autism. Rosenwasser, B., Axelrod, S., Vol. 25, No.5 October 2001, 671-677 ©Sage Publication.
- ⁹⁰ BEHAVIOR MODIFICATION. The Contributions of Applied Behavior Analysis to the Education of People with Autism. Rosenwasser, B., Axelrod, S., Vol. 25, No.5 October 2001, 671-677 ©Sage Publications).

⁹¹ Autism Speaks, Autism Speaks Announces Multi-State Insurance Legislation Campaign. December 27, 2007, retrieved on June 17, 2008 from website, [http://www.autismspeaks.org/press/insurance legislation campaign.php](http://www.autismspeaks.org/press/insurance%20legislation%20campaign.php).

⁹² VAHP. Public Hearing, Special Advisory Commission, September 29, 2008, Richmond, VA.

⁹³ VAHP. Public Hearing, Special Advisory Commission, September 29, 2008, Richmond, VA.

⁹⁴ VAHP. Public Hearing, Special Advisory Commission, September 29, 2008, Richmond, VA.