REPORT OF THE
SPECIAL ADVISORY COMMISSION ON MANDATED
HEALTH INSURANCE BENEFITS

# MANDATED COVERAGE FOR HABILITATIVE SERVICES FOR CHILDREN WITH DEVELOPMENTAL DELAYS
## House Bill 657

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

COMMONWEALTH OF VIRGINIA
RICHMOND
2007

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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 657 regarding coverage for habilitative services for children under age 19 with developmental delays.

Respectfully submitted,

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## INTRODUCTION

During the 2006 Session of the General Assembly, the House Committee on Commerce and Labor referred House Bill 657 to the Special Advisory Commission on Mandated Health Insurance Benefits (Advisory Commission). House Bill 657 was introduced by Delegate Kenneth R. Plum.

The Advisory Commission held a hearing on October 17, 2006 in Richmond to receive public comments on House Bill 657. Delegate Plum spoke in support of the bill. Written comments supporting House Bill 657 were received prior to the public hearing from concerned citizens, parents of children with developmental disorders, professionals who provide habilitative services to children, and representatives from groups, such as the Virginia Autism Resource Center, provided background reports. Representatives from the Virginia Association of Health Plans (VAHP) spoke in opposition to the bill.

The Joint Legislative Audit and Review Commission (JLARC) staff of the Virginia General Assembly prepared a "Review of House Bill 657, Mandated Coverage for Habilitative Services for Children under Age Nineteen with Developmental Delays" 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 PROPOSED LEGISLATION

House Bill 657 would amend and reenact § 38.2-4319 of the Code of Virginia and add § 38.2-3418.15, which would mandate coverage for habilitative services for children under age 19 with developmental delays.

The bill applies to insurers proposing to issue individual or group accident and sickness insurance policies providing hospital, medical or surgical, or major medical coverage on an expense-incurred basis; corporations providing individual or group accident and sickness subscription contracts; and health maintenance organizations (HMOs) providing a health care plan for health care services and requires that they shall provide coverage under any such policy, contract, or plan delivered, issued for delivery or renewed in the Commonwealth on and after July 1, 2005 for medically necessary habilitative services for persons younger than 19 years.

The bill defines "habilitative services" as "health and social services directed toward increasing and maintaining the physical, intellectual, emotional, and social functioning of developmentally delayed individuals, in the areas of self-care, sensory and motor development, interpersonal skills, communication, and socialization; and reduction or elimination of maladaptive behavior." "Habilitative services" does not include services for which coverage is provided or required to be provided pursuant to § 38.2-3418-5.

"Medically necessary habilitative services" is defined as habilitative services that are certified by the Department of Mental Health, Mental Retardation and Substance Abuse Services (MHMRSAS) as designed to help an individual attain or retain the capability to function age appropriately within the individual's environment and shall include habilitative services that enhance functional ability without effecting a cure.

The bill states that an insurer, corporation, or HMOs subject to this section shall not be required to provide coverage for medically necessary habilitative services to the extent that such services are provided through the individual's school; however, this exclusion from coverage shall not alter or diminish the obligation of an insurer, corporation, or HMO to provide coverage for medically necessary habilitative services that are not provided through the individual's school.

The bill requires each insurer, corporation, or HMO subject to its provision to provide notice annually to its insureds, and enrollees about the coverage required.

The bill does not apply to short-term travel, accident only, limited or specified disease policies, or individual conversion policies or contracts, nor to policies designed for issuance to persons eligible for Medicare or similar coverage under state or federal governmental plans.

## TECHNICAL CONCERNS

- Subsection B of HB 657 (line 29 through 33) defines "Medically necessary habilitative services" as

  > "habilitative services that are certified by the DMHMRSAS as designed to help an individual attain or retain the capability to function age appropriately within the individual's environment and shall include habilitative services that enhance functional ability without effecting a cure."

  The DMHMRSAS has no legal mandate to certify or license habilitative services such as occupation therapy, physical therapy, speech therapy or other habilitative services. The DMHMRSAS is responsible for licensing those programs which provide services to persons with mental health, mental retardation and substance abuse disabilities.

- The draft language incorporated in HB 657 does not specifically stipulate benefit requirements or limitations that are found in some other mandated benefits provisions. The language does not distinguish or address deductibles, benefit year or lifetime durational limits, benefit year or lifetime dollar limits, lifetime episodes or treatment limits, co-payment and coinsurance factors and benefit year maximums for deductibles and co-payments and coinsurance factors. Nor does the language prohibit the insurer, corporation or HMO from imposing upon any person receiving benefits any co-payments, fees or conditions imposed upon all individuals in the same benefit category.

## PREVIOUS LEGISLATION REVIEWED BY THE ADVISORY COMMISSION

In 2005, Delegate Kenneth Plum introduced legislation similar to that proposed in HB 657 (2005 HB 2077). However, at the patron's request, the Advisory Commission did not review the bill. House Bill 657 expands upon the definitional language that was contained in 2005 House Bill 2077.

Also in 2005, the Advisory Commission considered a similar coverage requirement when it reviewed Senate Bill 1049, which required an offer of coverage for the treatment of developmental delay for children from birth to age five. Coverage for the treatment of development delay did not include services that would be covered as medically necessary early intervention services pursuant to § 38.2-3418.5. The Advisory Commission voted against enactment of Senate Bill 1049 and recommended that the General Assembly establish a task force or committee to construct a more narrowly defined bill.

## CURRENT REQUIREMENTS

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).

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 DMHMRSAS 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 Department of Mental Health, Mental Retardation and Substance Abuse Services" 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 bill 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 bill's provisions are applicable to policies, plans and contracts delivered, issued for delivery or renewed on and after July 1, 1998. The bill is 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.

Senate Bill 430 was passed by the 1999 General Assembly. It was effective on January 1, 2000. 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.

A "biologically based mental illness" 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.

## DEVELOPMENTAL DELAY

According to Title 1 of the federal Children's Health Act of 2000 (P.L. 106-310), approximately 2% of children under the age of 18 have a significant developmental delay, and these delays include intellectual disability, cerebral palsy, hearing loss and vision impairment. Of these significant developmental delays, intellectual disability (in the past referred to as mental retardation) is the most common.[1] Approximately 17% of children have some type of developmental delay, including more mild challenges such as speech and language disorders, learning disabilities, and Attention Deficit Hyperactivity Disorder (ADHD), which appear to be more common than Autism Spectrum Disorder (ASD). Current information indicates that Down syndrome occurs in 1 out of 800 births and is slightly less common than ASD.

Some service providers prefer to apply the less specific term "developmental delay," when a child's development appears to lag, rather than a more specific disability diagnosis, since symptoms of specific disabilities may be unclear in young children. It is possible that a child with a developmental delay who receives services will not develop a disability; whereas if the same child did not receive services, the delay would become a disability. Because it is based on a comparison of the child's functional level with that of other children of the same age, "developmental delay" can be seen as a statistically defined, socially mediated construct that depends on cultural expectations and the definition of what constitutes a delay.[2, 3]

Some research defines developmental disabilities as a group of related chronic disorders of early onset estimated to affect 5% to 10% of children. Global developmental delay is a subset of developmental disabilities defined as significant delay in all developmental areas, gross/fine motor, speech/language, cognition, social/personal and activities of daily living.[4]

Developmental delay can be restricted to one stream of development (single domain) or to two or more streams of development (global developmental delay). The domains of development can be conceptually categorized into four major areas:

1. Motor development encompasses both gross motor ability (the control of large groups of muscles involved in walking, sitting, or transferring from one position to another) and fine motor abilities (the manipulation of objects with the hands in order to eat, draw, play etc). Children progress through motor milestones in an orderly fashion, attaining these functions in a clear and sequential process. Motor delay is defined as a significant delay in motor abilities without a delay in other developmental categories.[5]

2. Language performance, consisting of articulation, receptive and expressive language skills, and the use of nonverbal symbols, encompasses a major stream of development, arising from the interaction between innate communication abilities and environmental influences. Any significant delay in language or speech skills without a delay in other developmental domains is categorized as a developmental language disorder, developmental dysphasia, or specific language impairment.[6]

3. Adaptive or cognitive development is a measure of the child's ability to problem solve through intuition, perception, and verbal and nonverbal reasoning. Moreover, it encompasses the ability not only to learn and understand but also to retain this information and apply it as needed.[7]

4. Personal or social development encompasses the child's interactions, as shown by the formation and maintenance of relationships and responsiveness to the presence of others. Psychosocial delay presents itself over time as behavioral abnormalities that differ from normal behavioral responses by their quantity, severity, nature, and duration. Personal development involves the formation of self-help skills in various activities of daily living, such as feeding, dressing, and toileting.[8]

Some developmental delays may result in a diagnosis such as Down Syndrome or Fragile X, both of which are a result of chromosomal abnormalities. Others may include hearing or vision impairments, fetal alcohol syndrome, Erb's or Klumple's palsy, autism, Asperger's disorder, Rhett's Syndrome, and pervasive developmental disorder. Cerebral palsy, mental retardation, learning disabilities, etc. could also be categorized as developmental disabilities.

According to the CDC, ASD prevalence is estimated to fall within a range of two to six per thousand (equivalent to 1 in 500 to 1 in 166). ASDs are considered the most common of severe disorders of development, with an estimated prevalence of 6 out of 1,000. Although there have been medical and technological advancements in treating and understanding the disorder, autism-related disabilities are largely inexplicable.[9]

The CDC defines ASDs as a group of developmental disabilities that are caused by an abnormality in the brain.[10] Autism is not a specific disease but rather a disorder of brain development with a strong genetic basis. Because of qualitative and quantitative variations in symptoms, autism is referred to as one of a spectrum of disorders on a continuum. This term encompasses the classic autistic disorder and other pervasive developmental disorders.[11]

Children with autism demonstrate behaviors and skills that span a broad continuum extending from very mild peculiarities to severe developmental challenges. Autism is known to be a very heterogeneous disorder, with milder forms being more common than the classic form. Although clinical patterns vary depending on severity, all children with autism demonstrate some degree of qualitative impairment in reciprocal social interaction, qualitative impairment of communication, and restricted, repetitive, and stereotypic patterns of behaviors, interests, and activities.[12] ASD-specific early intervention services are dependent upon early detection and formal diagnosis. Positive outcomes are based on young children being screened for ASD, identified as being at risk, and referred for comprehensive evaluation and assessment in an efficient and timely manner.[13]

The significant overlap that exists between the behavioral and developmental aspects of developmental delay is what makes it complex. As children mature, their language skills and cognitive experience will vary, and behavioral issues can mask the underlying problem or mimic characteristics of other associated disorders. Developmental trajectories in key areas will become prominent indicators. The possibilities for differential diagnosis will become greater with increased variability in symptom expression, language ability and social demands. Studies indicate that 70% to 80% of children in need of services are not identified by their primary care provider. As a result, children are misdiagnosed or miss opportunities for assistance during the most critical time of brain development in early life.[14]

Another consideration for clinicians is cultural diversity and the role of linguistic backgrounds. Labeling a child "developmentally delayed" can impact academic success and social acceptance, especially for children from birth to age nine. A professional's thorough review and monitoring efforts are important in avoiding errors in diagnosis borne from differences acceptable in various cultures about what constitutes a disability or delay.[15]

## HABILITATIVE SERVICES

Habilitative services refer to services prescribed to children who are born with mental or physical disabilities, who, beyond the age of 3 require services to enhance and improve the individual level of functioning. Habilitative treatment enables a child to reach age appropriate developmental milestones and to perform important tasks of daily living typical of same age peers.[16]

Habilitative services can include intensive behavioral intervention. Some therapies require 20 to 40 hours per week up to 12 months a year. Behavioral intervention can be delivered by a trained paraprofessional or special educator as long as it is supervised by a qualified and experienced program developer. Some specific names of 'treatments' include Positive Behavior Support, Verbal Behavior Therapy, Pivotal Response Training, Inclusion Coaching, Shadowing, Applied Behavior Analysis, Relationship Development Intervention. Also, many children with ASD have nutritional deficiencies due to odd eating habits which impact their food intake and subsequently their growth and development.[17]

For example, most school districts do not offer feeding programs because these habits do not usually impact the child's education. Insurers do not usually cover these services because the children are not usually at risk of death or illness and they cannot be cured of their autism, yet many children eat only a very narrow selection of food -- like mashed potatoes, or saltine crackers. There are feeding clinics that can help, but other than military insurance, or private funding, there are no other funding streams.[18]

As defined in the bill, habilitative services does not include services for which coverage is provided or required to be provided pursuant to § 38.2-3418.5. The early intervention mandate (§ 38.2-3418.5) provides medically necessary services for children birth to age 3. Under the current mandate, the Part C system conducts evaluations and assessments to determine eligibility for habilitative services. The Individualized Family Services Plan (IFSP) serves as the plan of care document to meet requirements that these children's services are medically necessary. The Early Intervention mandate is a private insurance mandate for coverage for habilitative services under Part C of the Individuals with Disabilities Education Act (IDEA).

## EARLY INTERVENTION SERVICES IN VIRGINIA

In Virginia, Part C early intervention program (EI) is administered by DMHMRSAS. The Part B program, Early Childhood Special Education (ECSE), which serves children with disabilities aged 2 to 5, is managed by the Virginia Department of Education (VDOE).

The EI system incorporates shared responsibility for development and implementation of the system among various agencies at both the state and local levels to help the state meet federal regulations and guidelines based on a collaborative model of service provision. Full implementation of the Part C Program includes the assurance that a statewide system of EI services is in effect.

Part C requires that payment for early intervention services be coordinated from federal, state, local, and private sources (including public and private insurance coverage) prior to the use of PART C funds (34 CFR 303.522 (a)(1) and 34 CFR 303.527). The Department of Medical Assistance Services (DMAS) requires that Medicaid providers provide “medically necessary” services approved in the State Plan for Medical Assistance to Part C children. Specifically, Medicaid providers must ensure that all Part C eligible children and their families will receive each medically necessary covered service to treat all conditions whether congenital in nature or as a result of illness or trauma, and whether the services is required to prevent deterioration or maintain and improve ability and function.[19]

In Virginia, children age 0-3 are eligible for Part C early intervention services provided they have developmental delay; or atypical development; and/or a diagnosed physical or mental handicapping condition that has a high probability of resulting in delay (i.e., significant central nervous system anomaly, congenital or acquired hearing loss, chromosomal abnormalities, and inborn errors of the metabolism).[20]

The same eligibility procedures and definition of developmental delay are used throughout the Commonwealth to determine potential eligibility for all children referred to the Part C system. Any child diagnosed as physically or mentally disabled or who otherwise meets the eligibility requirements can be referred to Virginia's Part C system. The child must be diagnosed by a physician or other qualified medical professional.

All families referred to the Part C system are eligible to receive:

- Multidisciplinary evaluation and assessment,
- An Individualized Family Services Plan (ISFP), and
- Service Coordination.

Specific services and the level of services deemed necessary and appropriate are made on an individual basis by negotiation among all team members and are included on the IFSP. Services identified on the IFSP are available to all eligible children and families. Not all early intervention services provided by the program are free of charge, although Part C is an entitlement program. Necessary services identified on the IFSP require that fees are to be charged according to state law. Federal law requires that all sources of public and private funds (including Medicaid, CHAMPUS, private insurance, donation, etc.), as well as fees based on family ability-to-pay mechanisms, must be used prior to utilizing Part C Early Intervention funds. Part C services are generally provided on a sliding fee scale.[21]

## EARLY CHILDHOOD SPECIAL EDUCATION IN VIRGINIA (ECSE)

According to research studies, educational interventions are designed to help children with developmental delay, particularly ASD, and provide structure, direction, and organization for the child. Educational interventions should be individualized to the child and take into account his or her overall developmental status and specific strengths and deficits. Methods that improve the child's functional communication in all environments are important and will usually include speech therapy with an emphasis on the use of visual cues.[22]

The DOE reports that as of December 1, 2005, a total of 175,730 students with disabilities were being served through all school divisions and state operated programs, with the majority, 175,176, being assisted in school divisions. The disability categories with the largest number of cases are Specific Learning Disability (65,686); Speech or Language Impairment (32,239); Other Health impairment (25,600); Developmental Delay (14,945); Emotional Disturbance (12,425), and Mental Retardation (11,823).

According to the Virginia Department of Education, in 2003, local school divisions provided special education and related services to 172,848 students, of which 12,623 aged 3 to 22, were categorized as developmental delay.[23]

**NOTE**: The following explanation of ECSE in Virginia is taken from the Virginia Board for People with Disabilities website unless otherwise indicated.[24]

In Virginia, children, adolescents, and young adults with disabilities who have not yet reached their 22nd birthday may be eligible to receive special education and related services provided by local educational agencies (LEAs) and overseen by the Virginia Department of Education (VDOE). These include preschool services for children ages two through five. Part B of the federal Individuals with Disabilities Education Improvement Act (IDEIA) mandates that such services be available starting at age three, but Virginia parents have the option of their child participating in either Part B preschool services or Part C early intervention services between the ages of 24 and 36 months. A separate eligibility determination is required for Part B services from that required for Part C services, and children already receiving early intervention services may or may not qualify for special education services.

The Virginia DOE, Division of Special Education and Student Services, is responsible for administration and oversight of special education instruction regarding students with disabilities enrolled in kindergarten through 12th grade. The division is responsible for seeking out and locating children at risk for developmental disabilities and attempting to facilitate accurate intervention programs and document the need for additional EI.

DOE collaborates with other state agencies, including the Virginia Department of Rehabilitative Services, the Virginia Department of Health, the Virginia Department for the Blind and Vision Impaired, the Virginia Department for the Deaf and Hard of Hearing, and other agencies as prescribed in the Individuals with Disabilities Education Act (IDEA) and other federal and state legislation to accomplish its goals in special education. IDEA pertains to all children with various disabilities in grades K-12, and provides transportation needs to children and young adults to age 22 (age 21, inclusive). The Preschool Grant Program serves children with disabilities aged two to five. Head Start programs, operated by the Virginia Department of Social Services, provide children with disabilities aged 2-5, who are eligible for services to low-income families, with early intervention, day care, and educational services. Transition services are required to be provided to students with disabilities and their families as students progress through middle and high school beginning at age 14 and ending at age 22 (to age 21 inclusive).

If the child is found to have a disability as defined by IDEA, he or she becomes eligible for special education and related services, and within 30 calendar days an Individualized Education Program (IEP) team is convened. The IEP is a written statement developed for a child with a disability by an interdisciplinary team which specifies the individual education needs of the child and what special education and related services are necessry to meet the needs. Re-evaluation and revision the IEP is a requirement to determine if the child continues to qualify for services, and to adjust the child's IEP as indicated.

Under IDEIA and companion federal and state regulations, Preschool through Secondary School (K-12) Special Education schools receiving federal funds must provide eligible students with disabilities with a FAPE. Further, students who receive special education services are entitled to have those services delivered in the LRE. The significance of LRE is that students with disabilities have the right to be educated with their peers who do not have disabilities, and that students with disabilities cannot be moved to special classes, placed in separate schools, or otherwise removed from the general education environment unless it is demonstrated that, due to the nature and severity of their disabilities, they cannot be educated in a regular education class through the use of supplemental aids and services.

"Mainstreaming," now more commonly identified as "inclusion" is considered to be a best practice, although, neither is a legal precept. LRE is the legal requirement, and may or may not result in placement in a regular education classroom depending on each individual's unique needs. Regardless of placement, students with disabilities are required to have access to the general educational curriculum to the maximum extent appropriate. In Virginia, this would be the Standards of Learning (SOL) curriculum.

In Virginia, "Special Education" means specially designed instruction, at no cost to the parent or parents, to meet the unique need of a child with a disability including instruction conducted in a classroom, in the home, in hospitals, in institutions and in other settings and instructions in physical education. The term includes speech-language pathology services, vocational education and travel training. (COV § 22.1-213:34 CFR § 300.26). The specially designed instruction includes adapting to the content, methodology or delivery of instruction needs of the child as a result of the disability and it ensures the child's access to the general curriculum, so that the child can meet the educational standards that apply to all children within the jurisdiction of the local educational agency. (34 CFR § 300.26 (b) (3).[25]

In Virginia, "Related Services" encompasses developmental, corrective, and other supportive services required to assist a child with a disability so that the child benefits from special education. Supportive services may include artistic and cultural programs, and art, music and dance therapy, as well as other programs that may benefit a child by participating in special education. COV § 22.1-213; 34 CFR § 300.24 (a).[26]

Special education students may be found eligible for Early Childhood Special Education (ECSE) services under one or more of 14 disability categories, which are defined in the federal and state regulations:

1. autism
2. deaf-blindness
3. emotional disturbance

8. orthopedic impairment
9. other health impairment
10. severe disabilities

4. hearing impairment/deaf
5. learning disabilities
6. mental retardation
7. multiple disabilities
11. speech or language impairment
12. traumatic brain injury
13. visual impairment/blind
14. developmental delay

The VDOE defines "developmental delay" as a disability affecting a child between the age of two through eight who is (1) experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas, physical development, cognitive development, communication development, social or emotional development, or adaptive development; and (2) who, by reason there of, needs special education and related services. (34 CFR § 300.7 (b); § 300.313) Local school divisions determine the criteria for being found eligible for services under the developmental delay category.[27]

## SOCIAL IMPACT

The CDC estimates that 17% of children in the United States under age 18 have a developmental or behavioral disability. In addition, many children have delays in language or other areas, which also impact school readiness. However, less than 50% of these children are identified as having a problem before starting school, by which time significant delays may have already occurred and opportunities for treatment have been missed.[28]

In Virginia, there are approximately 270,000 children under 17 with special needs. This number represents 15.3% of all children and adolescents.[29]

According to the Infant and Toddler online Tracking System (ITOTS), the chart below indicates the number of children served by Part C services and referred to other services by Virginia's Infant and Toddler Connection:

| | Children Served | Children Referred |
|---|---|---|
| **12/1/2001 - 12/2/2002** | 7,415 | 2,449 |
| **12/2/2002 - 12/1-2003** | 9,076 | 2,688 |
| **12/2/2003 - 12/1/2004** | 9,615 | 3,030 |

30 DMHMRSAS projects that almost 9,000 children ages birth to 3 years will be receiving Part C services by 2010.

Of the 98,958 children born each year in Virginia, approximately, 4849 children or 4.9% are infants known to have birth defects or congenital anomalies. Also, characteristics of Virginia communities serving the highest percentage of the birth to age three population include smaller communities, familiarity of physician with the Part C system, reciprocal communication between Part C system and referral sources, longevity of primary contact person with the local Part C system and stable local intervention program.[31]

The Virginia Early Childhood Comprehensive Systems Project (VECCS) conducted an environmental scan in 2004 through 2006 to identify gaps and strengths in the Commonwealth's system of services for young children and families. Data was collected and analyzed from five core component areas (medical home, behavioral health and social-emotional development, early care and education, parent education and family support). Concerns emphasized long waiting lists for behavioral services, in addition to an increase in the number of children under age 5 who are referred for behavioral services. The 2004 Mental Health Parent Satisfaction conducted by DMHMRSAS about CSB clients showed that 0.7% of CSB clients were under the age of three years.[32]

The Title V Maternal and Child Health Needs Assessment reported that only 62% of children with emotional, developmental or behavioral problems requiring treatment and counseling received mental health services in the last year.[33]

The study identified gaps to integrating systems of care. The two primary gaps in integrated systems of care are barriers to accessing services (financial and non-financial) and a lack of knowledge concerning the range of existing services by providers. Specific elements which limit access to services include financial, child care, transportation, geographic and cultural/language barriers. Quantitative data to demonstrate the burden of these barriers are not available, however, there is data to support disparities between different racial, age and socio-economic groups.[34]

The study indicated gaps which limit the ability of families and the public to understand and be directly involved in all levels of the early childhood system. One recommendation to address the problem was to increase awareness and educate families and policy decision-makers about the importance of early childhood health issues. The long term benefits of family involvement in an integrated system of care includes improved parenting skills and parental knowledge of child development, improved access to quality child care, increased parental involvement in child education.[35]

Other survey data focused on early learning and behavior. The National Survey of Children's Health reported 36% of Virginia parents of children under 5 expressing concerns about their child's development, learning, or behavior. This survey also found that 24.5% of Virginia children aged 1-5 are at moderate or high risk for developmental delay.[36]

James S. Reinhard, M.D., Commissioner, DMHMRSAS, agreed with the evidence incorporated in the environmental scan and noted ...

> "The second system that is left to deal with children's behavioral health problems is the public schools system. Frequently problems are first recognized at school, but school systems are ill prepared to deal with children with serious emotional disorders. Few schools have school-based mental health services that enable children with psychiatric disorders to learn in school..."[37]

## MEDICAL EFFICACY

Children diagnosed as developmental delay have the same health care needs as children without disabilities and benefit from the same health promotion and disease prevention activities. Also, children diagnosed as developmental delay may have unique health care needs that relate to etiologic conditions (i.e. Angelman syndrome, fragile X syndrome, tuberous sclerosis) or other conditions (i.e. epilepsy) associated with their specific condition. Managing the etiologic or co-morbid conditions might include administering medications, referral to and consultation with appropriate specialists. There is no cure for developmental delay; however, the overall goal is to minimize core symptoms, prevent harmful behaviors (i.e. aggression and self-injurious behaviors), facilitate access to intervention programs, maximize beneficial effects of nonmedical interventions, and improve the quality of life for the child and his or her family.[38]

Children with ASD are at greater risk of psychopathologic problems than are children without disabilities. Common psychiatric disorders associated with ASD include mood disorder, anxiety disorders, attention-deficit/hyperactivity disorder, and obsessive-compulsive disorder. Sometimes, other symptoms, such as overactivity, sleep disorders, aggression, stereotypes, or self-injury become the focus of medical treatment. These target behaviors may change as the child grows older or progresses developmentally. Treatment is aimed at decreasing these targeted behaviors to facilitate communication, learning, socialization, and integration into community settings. [39]

Research has demonstrated that early detection of developmental disabilities and evidence-based intervention can significantly improve short-term and long-term outcomes and reduce the need for lifelong interventions. Recently developed screening and diagnostic tools have made earlier identification and referral to developmental and educational programs possible. There is a growing body of evidence that early and appropriate intervention can have a positive impact on overall outcome. [40]

The American Academy of Pediatrics (AAP) Policy Statement (2001) recommends all infants and young children should be screened for developmental delays. Screening procedures should be incorporated into the ongoing health care of the child as part of the provision of a medical home, as defined by the Academy.[41]

Habilitative services include intensive behavioral intervention for 20 to 40 hours per week 12 months a year, speech therapy, occupational therapy and physical therapy. Intensive behavioral intervention can be delivered by a trained paraprofessional or special educator; however, it is required that it is supervised by a qualified and experienced program developer. [42] Other therapies include parent training, medical management, community support and alternative therapies. Some specific names of 'treatments' include Positive Behavior Support, Verbal Behavior Therapy, Pivotal Response Training, Inclusion Coaching, Shadowing, Applied Behavior Analysis, Relationship Development Intervention.[43] Often, several strategies are used simultaneously in treating the same child.

Habilitative therapies include Speech, Occupational, and Physical Therapy. Most children diagnosed as developmental delay display a deficit in functional communication skills as one of the core problems. Techniques to improve language skills are proven to be beneficial. Speech therapy emphasizes language assessment needs, including all areas of communication, particularly semantics and pragmatics, and should lead directly into intervention. [44]

One study specifically evaluated language therapy and found that children retained their gains for at least 3 months after the intervention. Occupational therapy using sensory integration techniques to address sensory processing problems is commonly used in children with ASD. Although many believe occupational therapy is subjectively effective in educational and clinical settings, research data to support its effectiveness is scant. Occupational and physical therapy may be helpful in addressing coordination and motor planning deficits occurring in some children with ASD. All three types of therapy should be interwoven throughout all aspects of a child's program, not just as a "pullout" technique. [45]

Behavioral training and management protocols at home and at school prevent undesirable behavior from developing. Behavioral training, including teaching appropriate communication behaviors, has been shown to be effective in decreasing behavior problems and improving adaptation. The basis of including children with autism in child care centers and regular classrooms with other children as role models can also be effective in decreasing the frequency of undesirable behaviors. The overall goal of the approach is to reinforce desirable behaviors and decrease undesirable behaviors using behavioral psychologic theory. [46]

Comprehensive treatment plans may include behavioral modification and applied behavioral analysis. Overall, it is accepted that positive reinforcement should be primarily used and that methods such as extinction and punishment to decrease behaviors should be limited to very specific situations. Behavioral therapies are most effective when started early and used consistently. Social skills training to promote social competence are an important component of the habilitation plan for children with ASD because it uses a behavioral or developmental approach that emphasizes generalization of skills to all settings.[47]

Various augmentative and alternative strategies also exist. Examples include Daily Life Therapy (the Higashi School), and Bright Start curriculum, the Picture Exchange Communication System (PECS), which teaches the child to exchange a picture of a desired item with the teacher who immediately honors the request, [48] and Treatment and Education of Autistic and Communication Handicapped Children (TEACCH), the well-known strategy. TEACCH services include diagnostic clinics, parent training, classroom programs, residential programs, respite care, and various vocational placement options. The program begins with assessment and emphasizes teaching according to the child's strengths. The TEACCH program has been evaluated by empirical studies of program components and parent evaluations and has been found to be successful in its goal. However, these studies have not included control groups. [49]

## FINANCIAL IMPACT

The DMHMRSAS is responsible for licensing those programs which provide services to persons with mental health, mental retardation and substance abuse disabilities. The proposed legislation would require the DMHMRSAS to certify or license habilitative services such as occupation therapy, physical therapy, speech therapy or other habilitative services. The cost assessment of the added responsibility for that agency was not available prior to this analysis. According to the findings of JLARC, the annual cost to the State for DMHMRSAS to certify services as "medically necessary" is estimated to range between $2.7 million and $3.1 million per year.

Written comments related to House Bill 657 from an occupational therapist in Northern Virginia, suggest that costs for therapy vary throughout the state from approximately $85 per treatment session to $120 per treatment session. In the case of a child with severe neurological problems, services could be required twice weekly from each discipline (physical therapy, occupational therapy, speech therapy). It is not uncommon in the case of a severely disabled child to require services five to six times per week. In the case of a moderately involved child, services may be required from each discipline one time per week or every other week, depending on the presenting problems. Based on the information above, the estimated annual cost per child per family could range from approximately $26,520 to more than $37,000.

Proponents of HB 657 view the financial impact of the proposed legislation in terms of short range and long range effects and costs. Early intervention services which include habilitative services can improve outcomes early in life for children with DD such that delays may not develop into disabilities that may require more frequent and more intense therapies or institutionalization.

The 2004 *Virginia Cost Study* produced a per child cost using two different methods. The total cost for the FY 03 Part C system was $33.4 million. The first cost of $8,002 per child (in FY 03) is based on the child count data, which represents an unduplicated count of children with an IFSP on December 1 of each year.[1] The second method of examining enrollment used the aggregate count which reflected an average annual per child cost of $4,158 for FY 03. [50]

The VDOE reported that in the 2000-2001 year, 162,265 students received special education services at a cost of $13,817 per student. The per student cost for children not receiving special education was $6,632.[51]

## INSURANCE COVERAGE

The State Corporation Commission Bureau of Insurance surveyed fifty of the top writers of accident and sickness insurance in Virginia in May 2006, regarding bills to be reviewed by the Advisory Commission this year. Forty-three companies responded to the survey. Eight companies indicated that they have little to no applicable health insurance business in force in Virginia. Of the thirty-five respondents completing the survey, eighteen indicated that they currently provide coverage for developmental delay. However, of the eighteen carriers, nine indicated the company definition for habilitative services was different than the requirements of HB 657, or that the coverage provided did not include all services as required under the bill; one company provided coverage only if the patient had not reached functional capacity through early intervention; and, one company provided coverage for physical therapy only. One company did not pay for the diagnosis of developmental delay, but stated if another diagnosis was provided, physical therapy, occupational therapy or speech/language therapy could be available. The company reserved the right to review each case on an individual basis. Seventeen companies indicated they did not provide coverage.

Respondents to the survey provided cost figures of between $.00 and $2.00 per month per standard individual policy. Cost figures for individual optional coverage ranged from $.78 to $10.00. Cost figures were between $.00 and $2.94 per month per standard group certificate, to provide the coverage required by House Bill 657. Group optional coverage cost estimates ranged from $.00 to $22.53 per month per group certificate. One respondent reported $431.25 for the monthly cost of its total policy premium and did not supply an estimate or cost for each bill.

Research examining the insurance industry as it relates to children with special needs, indicates that in practice, many plans commonly exercise their discretion in authorizing the full amount of coverage and negotiates with providers the extent of intervention needed to achieve an acceptable outcome. Plans typically exercise this discretion for mental health, home health, ancillary therapy and other services needed over an extended period of time. In making determinations, most plans depend on contract language to establish the criteria for coverage, such as language requiring significant improvement within a short period of time or limiting coverage to crisis intervention until a patient is stabilized. Some companies also rely on internally developed guidelines.[52]

## SIMILAR LEGISLATION IN OTHER STATES

Staff reviewed information available from the National Association of Insurance Commissioners (NAIC), National Insurance Law Service (NILS), and various other sources to determine if requirements of House Bill 657 are imposed in other states.

Maryland Insurance Code (§ 15-835) mandates coverage for habilitative services for children under 19 years of age; it applies to HMOs, non-profits, group insurers and individual insurance carriers. The mandate requires carriers to provide coverage of habilitative services for children under the age of 19 years with a congenital or genetic birth defect, including autism and cerebral palsy, and allows them to do so through a managed care system; carriers must provide notice annually to members about the required coverage; carriers are not required to reimburse for habilitative services delivered through early intervention or school services if a carrier denies payment for services because it is not a congenital or genetic birth defect is considered an adverse decision.

The Texas mandate (I.C. article 21.53) requires an offer of coverage for rehabilitative and habilitative therapies, to include speech therapy, physical therapies, occupational therapy and dietary and nutritional evaluations. Coverage applies to children from birth through age six. The Texas mandate applies to HMO's, non-profit organizations, groups carriers and individual insurance carriers, as well as other health insurance arrangements. A health benefit plan that provides coverage for rehabilitative and habilitative therapies may not prohibit or restrict payment for covered services provided to a child and determined to be necessary to and provided in accordance with an individualized family service plan issued by the Interagency Council on Early Childhood Intervention. Rehabilitative and habilitative therapies must be covered in the amount, duration, scope, and service setting established in the child's individualized family service plan.

According to a JLARC evaluation of House Bill 657, the state of Indiana mandates insurance coverage for pervasive developmental disorders (PDD). The coverage specifies that covered services may not be subject to dollar limits, deductibles, copayments or coinsurance provisions that are less favorable than those for physical illness. The JLARC report indicated that any challenge to medical necessity of services is only considered reasonable if that challenge has been reviewed by a specialist in the treatment of PDDs.

Five states were found to mandate coverage for autism with varying degrees of coverage. Colorado, Kentucky, and New Hampshire require that coverage be provided for autism as for any other physical illness that would be covered under accident and sickness policies. Connecticut requires group plans to provide medical and surgical conditions for biologically based mental illnesses, including autism. Hawaii determines treatment and utilization guidelines for autism.

Forty states mandate coverage or mandate an offer of coverage for biologically based mental illness. Coverage for biologically based mental illness is regarded as the same coverage for other medical illness and disease. At least eight states, (Arkansas, California, Kansas, Louisiana, Maine, Montana, New Hampshire, New Jersey, and Virginia), specifically name autism or developmental disorders in their biologically-based mental illness coverage.

## REVIEW CRITERIA

### SOCIAL IMPACT

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

In Virginia, there are approximately 270,000 children under 17 with special needs. This number represents 15.3% of all children and adolescents.[53]

According to the Infant and Toddler online Tracking System (ITOTS), the chart below indicates the number of children served by Part C services and referred to other services by Virginia's Infant and Toddler Connection:

| | Children Served | Children Referred |
|---|---|---|
| **12/1/2001 - 12/2/2002** | 7,415 | 2,449 |
| **12/2/2002 - 12/1-2003** | 9,076 | 2,688 |
| **12/2/2003 - 12/1/2004** | 9,615 | 3,030 |

DMHMRSAS projects that almost 9,000 children ages birth to 3 years will be receiving Part C services by 2010. [54]

HB 657 addresses the habilitative needs of all children beyond the age of 3 years. Children older than age 3 who were born with mental or physical disabilities may require services to enhance and improve the individual's functional abilities which enable the child to reach age appropriate developmental milestones and to perform important tasks of daily living typical of same age peers.

Supporters of habilitative care services believe more individuals would utilize habilitative treatments if insurance companies would cover habilitative treatments as medically necessary remediation regardless of the condition originating from rehabilitative or habilitative causes. JLARC reports a probable increase in utilization of habilitative services by approximately 28,000 children. [55]

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

There is some coverage available for habailitative services, however, coverage for certain services affect access to levels of treatment. Further, many private insurers do not cover supports, services or practices recommended in the treatment of developmental delay. Access to insurance coverage may not mean that all needs for special needs children will be met.[56] Children with special needs use more health services than other children and, therefore, have significantly higher health care expenses.

A majority of insurance companies will provide coverage for rehabilitative services, but limit levels of service or the number of treatment sessions or offer no coverage for habilitative services. Of the thirty-five respondents completing the BOI survey, eighteen indicated that they currently provide coverage for developmental delay. However, of the eighteen carriers, nine indicated the company definition for habilitative services was different than the requirements of HB 657 or that the coverage provided did not include all services as required under the bill.

Studies show that most public and employer-sponsored plans use HMOs or carve out mental health or behavioral health benefits; private insurance plans require out-of-pocket payments for deductibles, exclude particular benefits, use exclusive definitions in their benefit plans, utilize a medical necessity standard that does not reflect developmental needs of children, and annual or lifetime benefit limits.[57]

The DOE reports that as of December 1, 2005, a total of 175,730 students with disabilities were being served through all school divisions and state operated programs, with the majority, 175,176, being assisted in school divisions.[2] The disability categories with the largest number of cases are Specific Learning Disability (65,686); Speech or Language Impairment (32,239); Other Health impairment (25,600); Developmental Delay (14,945). [58]

The VAHP opposed recommending enactment of House Bill 657 indicating in written comments that services included in the bill are already covered by federal and state law. It cited 8 VAC 20-80-10, the Code of Virginia, § 38.2-3418.5, the early intervention madate, and U. S. federal law (IDEA). VAHP also indicated that § 38.2-3412.1:01, the biologically based mental illness mandate, currently mandates coverage for autism, which is one of the most prevalent diagnoses of DD. [59]

*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.*

Although autism is the prevalent diagnosis of developmental delay, habilitative service is a treatment modality applicable to many developmental conditions. Proponents indicated that variations in coverage gaps are mostly related to direct services and are where the lack of coverage results in an inability to obtain the necessary treatments for children. Children with severe disorders or with specific treatment regimens may require several hours of direct or intense therapy. In which case, if parents choose to take advantage of those services or therapies recommended by the child's medical doctor or specialist, beyond those services offered through early intervention or early childhood special education, coverage may not be available. Additionally, some proponents believe insurance companies frequently use their own medical review to disallow the physician's recommendation when a pediatrician prescribes a habilitative treatment as medically necessary. [60]

Educating children with autism was accepted as a public responsibility as part of the Education Act of All Handicapped Children in 1975. Despite the federal mandate for appropriate education and intervention services, the goals, methods, and resources available vary considerably from state to state and from school system to school system. [61]

School systems provide direct services to children with developmental delay under separate qualificatons than the early intervention programs, and does not consider other "functional" needs. An educational determination of a developmental disability is used to determine only eligibility for special education and related services. The services a student may receive are not based on the disability category, but on the student's current learning needs. If a parent supplemented the school-based therapy or service with a provider outside of the school system, the supplemental arrangement could possibly reduce the school-based treatment. The DOE indicated that most parents expressed concern with the level of service provided their children in school-based programs.

Written comments from the VAHP opposing House Bill 657 stated that the proposed legislation is redundant and unnecessary because medically necessary services were currently covered under state and federal law. [62]

*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.*

Generally, individuals with developmental delays have access to some treatment because of mandates and federal and state laws. The financial hardship is most apparent after a child has been diagnosed, and therapies are prescribed. The extent of financial hardship will vary, based on the severity of delay and the necessary level of therapy required beyond that which is mandated or federally authorized.

Direct costs include direct medical costs, such as physician and outpatient services, prescription medications, and behavioral therapies (estimated to cost, on average, more than $29,000 per person per year) and direct non-medical costs, such as special education, camps, and child care (estimated to annually cost more than $38,000 for those with lower levels of disability and more than $43,000 for those with higher levels).[63]

A study by Michael Ganz reports that indirect costs equal the value of lost productivity resulting from a person having autism, for example, the difference in potential income between someone with autism and someone without. It also captures the value of lost productivity for an autistic person's parents. Examples include loss of income due to reduced work hours or not working altogether. Ganz estimates that annual indirect costs for autistic individuals and their parents range from more than $39,000 to nearly $130,000.[64]

The Virginia Autism Resource Center indicated that undisclosed expenses for habilitative treatment and nutritional needs cause hardship. Children diagnosed as DD, particularly with autism, have very odd eating habits that decrease their nutritional intake and affect their growth and development. In most cases, schools do not offer feeding programs because these habits do not usually impact the child's education. Also, insurers do not typically cover these services because the children are not usually at risk of death or illness and they cannot be cured of their condition, yet many children eat only a very narrow selection of food. Funding streams for this circumstance are difficult to find and access. [65]

Most parents pay out of pocket for habilitative services, which may include Intensive behavioral intervention for 20 to 40 hours per week 12 months a year. These treatments can range in cost from approximately $85 per treatment session to $120 per treatment session. In the case of a child with severe neurological problems, services could be required twice weekly from each discipline (physical therapy, occupational therapy, speech therapy). It is not uncommon in the case of a severely disabled child to require services five to six times per week. In the case of a moderately involved child, services may be required from each discipline one time per week or every other week, depending on the presenting problems. Known estimated costs of habilitative treatments, ranging from $29,000 to $130,000 per year are considerable expenses for most families. Without insurance, costs for therapies could be significant, particularly over a lifetime. [66]

The VAHP testified against recommending HB 657 stating that public programs already acknowledge the need for habilitative services and are designed to provide direct services to this population. [67]

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

In its analysis of this issue for the Advisory Commission, JLARC estimated that approximately 56,000 children could be eligible for habilitative services described in the proposed mandate.[68]

Based on the DOE definition of "Autism", students identified with autism increased to 5,674 in 2005, up from 4,751 in 2004. In 2003, 3,966 students were reported in this category. Relevant research supports evidence that the prevalence of those conditions diagnosed as DD will continue to increase. [69]

According to the U. S. Department of Education, from the 1991-1992 to the 2002-2003 school year, the number of students with ASDs in special education increased by more than 2000%. [70]

In Virginia, prior review of coverage associated with the issues included in this mandate occurred in 2005, when the Advisory Commission considered a mandated offer of coverage for the treatment of developmental delay for children from birth to age five. 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, and encouraged relevant entities to take certain actions to improve the education and treatment of individuals with autism spectrum disorders, and to expand training opportunities that include approaches specifically addressing the needs of children with autism spectrum disorders.[71, 72]

The Virginia Autism Resource Center reported to the BHCS that autism is emerging as a leader among disabilites when considering those conditions affecting, cognitive, learning, behavioral or sensory motor disabilities.[73]

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

According to a practicing occupational therapist in Northern Virginia, when an insurer denies coverage to children with developmental difficulties asserting that treatment is not considered "rehabilitative" nor does it "restore the patient to his prior level of functioning," the distinction denies treatment to a child with a developmental difficulty that would otherwise be granted to a child who was a victim of an accident or acute illness. [74]

Determining the level of demand for coverage of habilitative services is difficult. Because of different points of entry into the "system" in which services may be delivered, and because different programs have diverse eligibility requirements for services, compiling true number counts without duplication is complex. However, a review of the issue indicates that proposed disability-specific mandates are a consistent constituent concern.

A review of information available from the National Association of Insurance Commissioners (NAIC), National Insurance Law Service (NILS), and various other sources reveal similar coverage requirements as House Bill 657 are imposed in other states, particularly Maryland and Texas. Maryland Insurance Code (§15-835) mandates coverage for habilitative services for children under 19 years of age; it applies to HMOs, non-profits, group insurers and individual insurance carriers; The Texas mandate (I.C. Article 21.53) requires an offer of coverage for rehabilitative and habilitative therapies, to include speech therapy, physical therapies, occupational therapy and dietary and nutritional evaluations. Coverage applies to children from birth through age six. The Texas mandate applies to HMOs, non-profit organizations, groups carriers and individual insurance carriers, as well as other health insurance arrangements.

Three states require that coverage be provided for autism as for any other physical illness that would be covered under accident and sickness policies. Connecticut requires group plans to provide medical and surgical conditions for biologically based mental illnesses, including autism. Hawaii determines treatment and utilization guidelines for autism.

Forty states mandate coverage or mandate an offer of coverage for biologically based mental illness. Coverage for biologically based mental illness is regarded as the same coverage for other medical illness and disease. At least eight states specifically name autism or developmental disorders in their biologically based mental illness coverage.

The VAHP provided written comments indicating that the market is not demanding this product or coverage. VAHP asserts that the competitive market is the more appropriate mechanism to determine the types of benefits to include in health insurance products.

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

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

*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.*

The Virginia Treatment Center for Children, in describing ASD for the BHCS, concurs with the evidence indicating an increase in the prevalence of ASD. The agency indicated that it is important to include children with ASD in a regular classroom curriculum and environment taught by regular education teachers to the greatest extent possible and appropriate. [75]

However, the characteristics of students with ASD make inclusion challenging due to the children's difficulty to relate to others; their limited range of language, communication and cognitive abilities; a difficulty for children with ASD to follow traditional curriculums, the children's resistance to change, and the children's unusual behaviors, stereotypes, and self-stimulatory behaviors. [76]

## 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.*

JLARC reports a probable increase in utilization of habilitative services by approximately 28,000 children. However, it is difficult to estimate changes in the cost of treatments due to ambiguity in the language of the proposed mandate. Research does not conclude that having insurance coverage for habilitative services would change costs for services regardless of how services are delivered. [77]

JLARC also reports that the new role MHMRSAS plays in determining eligibility of children for habilitative services would approximately cost the state between $2.7 and $3.1 million annually.[78]

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

It does not appear that an increased use of services would be due to an inappropriate overuse of services. Insurance coverage may increase the amount of diagnostic testing per individual, which may lead to earlier, more accurate diagnosis.

Parents indicated in written comments that House Bill 657 would allow them an opportunity to afford the recommended, appropriate level or number of therapy sessions for their child. Because recommended speech therapy sessions, occupational sessions or physical therapy sessions cost more than what private health insurance will cover, many parents are unable to meet the expense of the recommended treatments, thereby further delaying the child's progress.

The VAHP commented in writing that services provided under House Bill 657 were not considered "medically necessary" under the common insurance definition. Further, the VAHP stated that the proposed legislation would change the original definition of medical necessity pertaining to habilitative services.[79]

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

Supporters of House Bill 657 believe enacting the legislation would allow children with developmental delays in need of habilitative services to receive a greater number of treatments or more intense levels of services. Several research studies conclude that early and intensive behavioral and educational intervention can make a significant and positive impact on long-term outcomes.[80] Ultimately, the cost to Virginia and its tax-paying citizens would be higher when therapies are not delivered at all or early in life. Without therapeutic interventions, other costlier medical or behavioral conditions can develop.

Although there is evidence that early interventions lead to improvements, there does not appear to be a clear, direct relationship between any particular intervention and children's progress. While substantial evidence exists that treatments can reach short-term goals in many areas, gaps remain in addressing larger questions of the relationships between particular techniques and specific changes.[81]

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

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.*

The VCC, through written comments, stated that mandates have the effect of making health care too costly for employers and, ultimately, individuals and those least able to afford health insurance. Further, the VCC stated that when the number of mandates increases, the costs of insurance premiums will also increase, and employers, particularly small employers, are less likely to offer coverage to their employees.[82]

Respondents to the BOI survey provided cost figures of between $.00 and $2.00 per month per standard individual policy. Cost figures for individual optional coverage ranged from $.78 to $10.00. Cost figures were between $.00 and $2.94 per month per standard group certificate, to provide the coverage required by House Bill 657. Group optional coverage cost estimates ranged from $.00 to $22.53 per month per group certificate.

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

The impact on the total cost of health care if House Bill 657 was enacted is difficult to determine. Having insurance coverage improves access to care and reduces out-of-pocket expenditures; however, the benefit of insurance coverage is dependant on several variables, including those services parents already pay for that are not covered by insurance or those services not provided through schools. The variables associated with habilitative services distinctively impact coverage in different ways. Access to insurance coverage may not mean that all needs for special needs children will be met.[83]

A recent U.S. study estimated it could cost approximately $3.2 million to take care of an autistic person over his or her lifetime. Caring for all people with autism over their lifetimes could cost an estimated $35 billion per year. However, the $35 billion annual societal cost of caring for and treating people with autism is an underestimated figure because it does not include those other services that are used to support individuals with autism, such as alternative therapies and other family out-of-pocket expenses that are difficult to measure.[84]

The author of the study suggests that the level of cost could be higher if there were more useful and widespread treatment options available. He noted that the federal budget for autism is, historically, less than $100 million. [85]

Research suggests there would be a social cost if public school districts were unable to provide services. Parents without ample financial means would be left with few options for their children. The majority of parents are not Medicaid eligible. There are few studies associated with the cost savings of specific treatment for developmental delay.

## 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.*

Education at home, at school, and in community settings remains the primary treatment for young children with developmental delays, particularly, ASD. Research suggests that many specific techniques and several comprehensive programs have clear effects on important aspects of these children's learning. Links between interventions and improvements are also dependent on characteristics of the children and aspects of the treatments that are not yet fully understood. The challenges are to ensure implementation of what is already known so that every child benefits from this knowledge and to work from existing research to identify more effective educational interventions for all children.[86]

The general concensus in the medical community is that improved prognosis depends on the early implementation of appropriate intervention strategies tailored to the individual developmental needs of the child and his or her family. Managing a behavioral delay in children is challenging because there is no medical cure or no consensus regarding the best intervention strategy.[87]

Generally, accepted broad management goals of habilitative services or therapies are to improve the overall functional status of the child by promoting the development of communication, social, adaptive, behavioral and academic skills while lessening maladaptive and repetitive behaviors and helping the family manage the stress associated with raising a special needs child. Speech therapy and occupational therapy are accepted therapies to reach these goals. [88]

A controlled study conducted by Ivar Lovaas in 1987 recorded outcomes of treating young children with ASD with 40 hours per week of one-on-one behavioral training for two years. This therapy, also called applied behavioral analysis or discrete trial learning, concluded that delivering interventions for more than 20 hours per week that were individualized, well-planned and targeted language development and other areas of skill development significantly increased a child's developmental rate, especially in language skills. Other comparative studies have duplicated the results of the Lovaas study and agree that groups of children receiving intense behavioral treatment showed greater group gains in IQ and language than did children in comparison groups. [89]

Although intensive behavior treatment is an emerging therapy with promise and is being implemented in some EI programs and school districts, more studies need to replicate Lovaas' outcomes before it can become a recommended course of action, particularly as an educational intervention. There are other therapies available in the treatment of developmental delay, although they may not be as widely accepted as speech, occupational or physical therapies.[90]

There is a substantial body of research on the treatment and education of children with developmental delay. However, research has not been clearly integrated into educational decision-making and policy at local or state levels. For example, many treatment approaches and demonstration projects have disseminated information, yet most have not yet provided appropriate, scientifically rigorous documentation of effectiveness and efficiency. While research in developmental psychology, child psychiatry, and pediatric neurology has become increasingly well integrated, there is a need for more effective communication between professionals in these disciplines and the educators and other professionals who carry out the bulk of treatment and intervention-oriented research.[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.*

The benefit is consistent with the role of health insurance as it seeks to expand coverage of children with special needs. A study conducted in 1999 concluded that lack of access to services experienced by insured children with special needs could be attributable to inadequate breadth and depth of service coverage. Previous studies which had examined the scope of private health insurance benefits for children with special needs identified gaps in coverage for services, including ancillary therapies, home health care, mental health services and durable medical equipment. Other studies documented low reimbursement levels provided under public programs.[92]

The JLARC evaluation cited the 51% affirmative response rate to the BOI survey as evidence that private insurance companies cover some habilitative services for children with developmental delay. The review also indicated that the state's Medicaid plan and the insurance plan for state employees cover a minimum of physical and occupational therapies.[93]

There has been a significant rise in the incidence of developmental disabilities in a relatively short span of time. In approximately 10 years, the number of students with ASDs in special education increased by more than 2000%, according to the U. S. Department of Education.[94]

The JLARC evaluation concludes that this proposed mandate is consistent with the role of insurance because of its overall potential to have a positive impact on public health, encourage preventative treatment, and protect some families from major financial burden for health care costs. The JLARC review stated:

> '...with the increasing numbers of children with autism, as indicated by the CDC statistics, there is a growing need for services for children with developmental delays. Furthermore, it appears as many as 28,000 children in special education could potentially benefit from the proposed mandate.' [95]

Children diagnosed as developmental delay with specific disabilities and their families experience various symptoms, which may be unclear in young children. Also, it is possible that a child with a developmental delay who receives services will not develop a disability; if the same child did not receive services, the delay would become a disability.[96]

The unique and independent variables associated with diagnosing and treatment therapies for developmental delay challenge parents, medical professionals and the current delivery system because it is difficult to match the exact needs or the expected prognosis on a case-by-case basis. The JLARC evaluation states that the mandate will serve to encourage the treatment of developmental delays earlier in a child's life, thereby potentially reducing the future need for some services and improving the overall health of the child. In addition, for some parents, the cost of providing medically necessary habilitative services is cost prohibitive and the proposed mandate could address their need for financial assistance in paying for these services.[97]

VAHP opposes HB 657 indicating in written comments that rehabilitative services is one of the many benefits added to the insurance industry and marketplace as it has evolved. It argues that habilitative services or treatment should not be a mandated covered benefit because it would require the insurance industry to cover restoration of a capability or individual function for which the individual never had the ability to perform.[98]

The Virginia Chamber of Commerce (VCC) opposes the legislation stating in written comments that mandates, generally, increase the cost of health care and will cause health insurance costs to increase, thereby causing employers to either consider alternatives to offering health insurance as a benefit to employees and dependents or otherwise reduce benefit programs in order to continue some level of health care coverage. [99]

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

It is difficult to determine if the need for coverage outweighs the costs of mandating benefit for all policyholders because research in this area is lacking comparative data for individual children that would permit analysis of the impact of disability characteristics on expenditures. To date, cost benefits associated with home-based early intensive intervention and center-based early intensive intervention (schools) have not been analyzed with emphasis on (a) level and type of intervention or treatment (b) logistical factors that affect timing, pacing, content, staffing, and organizational performance of the two alternatives.[100]

Children with severe disorders or with specific treatment regimens may require several hours of direct or intense therapy. If parents choose to take advantage of those services or therapies recommended by the child's medical doctor or specialist beyond those services offered through early intervention or early childhood special education, coverage may not be available. Despite the federal mandate for appropriate education and intervention services for children between the ages of two and twenty-one, the goals, methods, and resources available vary considerably from state to state and from school system to school system.[101]

The JLARC evaluation reports although the public school system is obligated to provide therapy to students because it is educationally necessary to have a free, appropriate public education, schools are not obligated to provide all services prescribed by a physician. Other experts in the field of study indicate that most parents are concerned with the level of medically necessary services or habilitative care services which is characteristic of therapeutic intervention. As a result, parents may find themselves in a position of submitting a claim for a medically necessary service a carrier may deny since the school system is providing some therapy.[102]

The JLARC report indicated that educators must weigh the importance of providing therapies to a student against the educational opportunities lost because the student misses other classes in order to receive certain therapies. Parents and supporters of habilitative services voice their disappointment when recommended services related to developmental delay are sometimes disputed as medical or educational. The DOE corroborated reports of parents' dissatisfaction with the level of service provided their children in school-based programs. [103]

Opponents believe that the continual mandating of additional benefits is not good public policy and can have the ultimate effect of making health care too costly for individuals and small businesses least able to afford it. The impact is reflected in employers shifting more premium costs to employees or reducing the benefits offered or negotiating deductible levels.

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

The cost of a mandated offer for coverage would probably be more expensive than a mandate of coverage because of the small population affected. Although supporters agree that some coverage exists, it is uncertain if a mandated option will facilitate access to limited coverage.

## RECOMMENDATION

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

## CONCLUSION

The Advisory Commission identified three major challenges to recommending House Bill 657. The Advisory Commission expressed concern with 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.

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