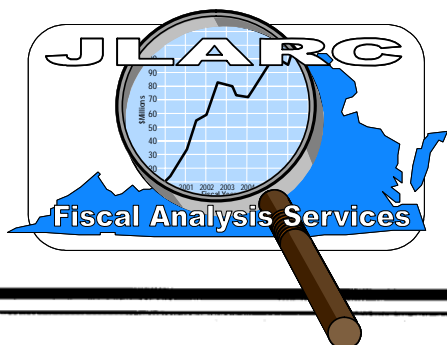


**JOINT LEGISLATIVE AUDIT AND REVIEW COMMISSION  
OF THE VIRGINIA GENERAL ASSEMBLY**

**EVALUATION OF PROPOSED  
MANDATED HEALTH INSURANCE BENEFITS**

**Evaluation of House Bill 657:  
Mandated Coverage of  
Habilitative Services for Children  
With Developmental Delays**

**October 2006**



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

**This evaluation is available on the JLARC website at <http://jlarc.state.va.us>**



# Evaluation of House Bill 657: Mandated Coverage of Habilitative Services for Children With Developmental Delays

## JLARC SUMMARY

House Bill 657 of the 2006 General Assembly Session would mandate coverage for medically necessary habilitative services for persons younger than 19 years of age with developmental delays. Habilitative services are defined as health and social services directed at either increasing or maintaining the physical, intellectual, emotional, and social functioning of developmentally delayed individuals. Similar legislation has previously been proposed. Advocates for the proposed mandate believe the medical needs of such children are not adequately met through private insurance policies or schools. Under federal law, schools are obligated to provide services to children with developmental disabilities, but they do not provide all medical services needed. Also, many private insurers do not include habilitative services in standard policies.

### MEDICAL EFFICACY AND EFFECTIVENESS

Speech and language therapy, occupational therapy, and physical therapy are widely accepted as being medically effective for treating some developmental delays. Two treatments which appear to be medically effective for addressing developmental delays based on relatively recent research include discrete trial training and positive behavioral support. However, even if a medical treatment is effective for some children with developmental delays, it may not be regarded as medically necessary for every child.

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## **SOCIAL IMPACT**

The proposed mandate is expected to have a positive impact on public health in some respects. However, ambiguity in the proposed mandate makes it difficult to predict how utilization of habilitative services would change as a result of this mandate. It appears that 28,000 children in Virginia could benefit from the proposed mandate. Less than 30 percent of insurance companies already provide the benefits described in the proposed mandate. However, coverage for some habilitative services is available through schools, the Early Intervention Services program, and Medicaid. For those without insurance coverage for habilitative services, the proposed mandate could save some families from paying as much as 73 percent of median U.S. annual household income for services.

## **FINANCIAL IMPACT**

The total cost of health care could potentially decrease. However, uncertainty regarding changes in utilization and the scarcity of relevant cost-benefit analyses make it difficult to estimate the net financial impact. Ambiguous language in the proposed mandate makes it difficult to predict how utilization of services would change and potentially affect providers. For the State, there would be large costs attributable to the new role for the Department of Mental Health, Mental Retardation and Substance Abuse Services, and this role is unnecessary because it is already fulfilled by physicians. For policyholders, monthly premiums are expected to increase, but there is a wide range of estimates. Estimates for standard individual policyholders ranged from \$0.31 to \$2.00. For standard group policyholders, estimated premium increases ranged from \$0 to \$2.94.

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

The proposed mandate is consistent with the role of insurance because it may positively impact public health, encourage preventative treatment, and shield some families from a major financial burden for health care expenses. There also appears to be a need for habilitative services for children with developmental delays. However, the costs of the proposed mandate are unclear, making it difficult to determine whether the costs would justify the benefits. Clarifying language in the proposed mandate and gathering additional data would be useful for further evaluation of HB 657.



## **Evaluation of House Bill 657: Mandated Coverage of Habilitative Services for Children With Developmental Delays**

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House Bill 657 (HB 657) of the 2006 General Assembly Session mandates coverage for medically necessary habilitative services for persons younger than 19 years of age with developmental delays. Habilitative services are defined as health and social services directed at either increasing or maintaining the physical, intellectual, emotional, and social functioning of developmentally delayed individuals. The determination as to which services are medically necessary is to be made by the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS). The proposed mandate specifically notes that it would not obligate insurance companies to pay providers for services provided through schools to students with developmental delays or disabilities. Currently schools must provide services to children with disabilities, free of charge, in order to comply with the requirements of the federal Individuals with Disabilities Education Improvement Act (IDEIA). As with other health insurance mandates, the mandate does not apply to short-term travel or accident-only insurance policies, other types of limited insurance policies, or federal plans, such as Medicare.

### **BACKGROUND**

Developmental delays span a wide range of conditions. Individuals with developmental delays could be delayed in one or several different areas. Consequently, there is a wide range of treatments for addressing developmental delays, and the amount of treatment required for each person will similarly vary. Examples of therapies that may be necessary include speech therapy, occupational therapy, physical therapy, and behavioral therapy.

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

The proposed mandate covers treatment for individuals under the age of 19 with developmental delays. Children are diagnosed as having a developmental delay if there is a major delay in their process of development, such as being unable to perform certain types of skills typical of other children of the same age. For example, most of a child's speech should be understandable by age five.

There is a wide range in the kinds and severity of developmental delays. Individuals may have a developmental delay in one or several different areas, such as motor, language, social, or cognitive skills. For example, a nine-year-old who does not show any interest in playing with other children and does not respond to people in general may have a social delay. By age nine, a child is expected to socialize with peers and respond to attention from adults. A second example is a four-year-old child that is not able to walk. This child may have a motor delay because children are expected to be walking on their own by age three. Individuals with a developmental delay may also have a diagnosis for another condition. Children diagnosed with conditions such as autism, Asperger syndrome, mental retardation, or cerebral palsy, typically have some type of developmental delay. Further descriptions of these conditions are shown in Exhibit 1. In addition, children with hearing or vision impairments could have developmental delays.

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### **Exhibit 1: Descriptions of Select Medical Conditions Associated with Developmental Delays**

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**Autism Spectrum Disorder.** Caused by an abnormality in the brain. Symptoms may include impairment in social interaction, such as a lack of social or emotional reciprocity, stereotyped and repetitive use of language, and restricted, repetitive patterns of behavior. Examples include autism, Asperger syndrome, Rett syndrome, and pervasive developmental disorder, not otherwise specified. Prevalence in U.S.: 3-6 per 1000 children.<sup>1</sup>

**Mental Retardation.** Can be caused by injury, disease, or a brain abnormality. Characterized by low intelligence and limitations in ability to function in areas such as communication, self care, and social situations.<sup>2</sup> Prevalence in U.S.: 11.4 per 1000 children<sup>3</sup>

**Cerebral Palsy.** Caused by damage to the part of the brain responsible for muscle tone. Characterized by difficulty maintaining balance and posture.<sup>4</sup> Prevalence in U.S: 2 per 1000 children <sup>5</sup>

Sources: <sup>1</sup> Centers for Disease Control and Prevention. "Programs In Brief: Birth Defects and Developmental Disabilities" Sept. 29, 2006. <http://www.cdc.gov/programs/bd02.htm>.

<sup>2</sup> Centers for Disease Control and Prevention. "Developmental Disabilities." Oct. 29, 2005. <http://www.cdc.gov/ncbddd/dd/ddmr.htm>.

<sup>3</sup> Centers for Disease Control and Prevention. "State-Specific Rates of Mental Retardation." Sept. 29, 2006. <http://www.cdc.gov/mmwr/preview/mmwrhtml/00040023.htm>.

<sup>4</sup> Center for Disease Control and Prevention. "Developmental Disabilities." Oct. 29, 2004. <http://www.cdc.gov/ncbddd/dd/ddcp.htm>.

<sup>5</sup> Boyle, CA, Decouple, P, Yeargin-Allsopp M. "Prevalence and Health Impact of Developmental Disabilities in U.S. Children." *Pediatrics*. 1994. (3):399-403.

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Similar to the wide range of conditions which may result in developmental delays, there is a wide range of treatments for addressing these delays. Therapies that may be prescribed for children

with developmental delays most frequently include speech therapy, occupational therapy, and physical therapy. Speech therapy may address oral motor functioning, non-verbal communication skills, or auditory processing problems. Occupational therapy may include treatment to improve fine motor skills or ability to perform daily living activities. Physical therapy could focus on improving strength, coordination, or balance. In addition to those therapies already mentioned, therapies such as psychotherapy, sensory integration therapy, or behavioral therapy may be prescribed. In some cases, pharmaceutical drugs may also be prescribed.

In addition to the wide range of treatments used, the amount of treatment required for addressing children's developmental delays varies widely. For example, in some cases, speech therapy for a few months may be sufficient. In other cases, 40 hours of intensive behavioral therapy may be needed each week for a year or more.

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

HB 657 was proposed primarily to address the habilitative needs of children over the age of three. Children who are under the age of three with developmental delays or who are at risk for developmental delays are eligible for many services through a joint federal and local program called Early Intervention Services (EIS). This program was established by Part C of the federal Individuals with Disabilities Education Improvement Act (IDEIA).

Part B of IDEIA obligates schools to provide children over the age of three who have disabilities with the services and support necessary for their education. However, advocates for the proposed mandate believe that the medical needs of children served under part B of IDEIA are not adequately addressed through the schools. In addition, most private insurance policies either do not cover or significantly limit the services covered by the proposed mandate, such as speech, occupational, and physical therapy. The proposed mandate is intended to provide insurance coverage for medically necessary habilitative services that are not currently covered by private insurance or provided through schools.

A proposed mandate similar to the current one, Senate Bill 1049, was considered in 2005 by the Special Advisory Commission. It would have mandated health insurance coverage for treatment of developmental delays for children from birth to age five. Ultimately, the Special Advisory Commission concluded that further analysis was required of the burden placed on the health care system. The General Assembly also chose not to enact this mandate. In prior years, there have been other attempts to provide greater insurance coverage to at least a subset of children likely to experience developmental delays, such as children with autism.

In 2000, the General Assembly enacted a health insurance mandate requiring parity with regard to mental illness that specifically covers autism. Section 38.2-3412.1 of the *Code of Virginia* requires that coverage for biologically based mental illnesses not be different from coverage for any other illness, condition, or disorder in determining deductibles, benefit year or lifetime durational limits, co-payment factors, and coinsurance factors. However, according to insurance company representatives and advocacy groups for children with autism, the mandate has not resulted in greater coverage of treatments for autism because many medical services may still be excluded.

In 2000, there was also a proposed mandate, Senate Bill 165, which as amended, would have expanded the population of children that are covered by an existing mandate for coverage of developmental disabilities. The existing mandate, section 38.2-3418.5 of the *Code of Virginia*, requires that insurers provide coverage for medically necessary early intervention services up to \$5,000 per calendar year for children under age three. Early intervention services include those that are medically necessary, such as speech and language therapy, occupational therapy, physical therapy, and assistive technology services and devices. In addition, the *Code of Virginia* states that early intervention services cannot be subject to dollar limits, deductibles, and coinsurance factors that are less favorable than for physical illness generally. The amended mandate from 2000, which the Advisory Commission considered, would have expanded the population covered by insurance for medically necessary early intervention services from children under age three to children under age 13 with diagnosed developmental disabilities. The Advisory Commission chose not to recommend the mandate based on concerns about the cost of the mandate and the lack of a definition of developmental disabilities.

Virginia is not the first state to consider an insurance mandate for habilitative services. Two other states have mandates similar to the one proposed in Virginia. Maryland's law, which was first enacted in 2000 and then amended in 2002, is most similar to the proposed mandate. Maryland's law requires that insurance companies cover habilitative services for children under age 19 who have a congenital or genetic birth defect, including autism, an autism spectrum disorder, and cerebral palsy. Habilitative services are defined to include occupational, physical, and speech therapy. Although Maryland's law appears broad, it has not resulted in significantly greater coverage of services for children with developmental delays; insurance companies are able to limit the benefit to a specific number of therapy sessions per year.

Indiana passed a mandate in 2001 requiring insurance coverage for pervasive developmental disorders (PDDs), including autism.



Indiana's law appears to provide a greater level of coverage than Maryland's law. Unlike Maryland's law, it specifies that the services covered by the mandate may not be subject to dollar limits, deductibles, copayments, or coinsurance provisions that are less favorable than those for physical illness generally. In addition, Indiana's Department of Insurance indicated that any challenge to the medical necessity of services for children with PDDs is only considered reasonable if it has been reviewed by a specialist in the treatment of PDDs.

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

Proponents and opponents of HB 657 will have the opportunity to officially express their views at a public hearing held on October 17, 2006, by the Special Advisory Commission on Mandated Health Insurance Benefits. The main proponents for the proposed mandate appear to be parents and advocacy groups for children with developmental disabilities. The main opponents to the proposed mandate appear to come from the health insurance industry.

Proponents of the mandate include advocacy groups for children with autism, some occupational therapy providers, and parents of children with developmental delays. Proponents believe that children need better access to affordable services for addressing children's developmental medical needs.

Opposition to the proposed mandate appears to stem primarily from the health insurance industry. Reasons for opposition to the mandate include the view that it is inappropriate for health insurance companies to cover habilitative services (even though some companies already provide limited coverage of these services) and concern about the new role of DMHMRSAS, which would certify the medical necessity of services for children. Another cause for opposition is concern that mandates lead to higher health insurance costs, which in turn may increase the number of uninsured people.

### **MEDICAL EFFICACY AND EFFECTIVENESS**

Speech and language therapy, occupational therapy, and physical therapy are widely accepted as being medically effective for treating some developmental delays. Therefore, the medical efficacy and effectiveness of these treatments will not be discussed in this section. Two treatments which appear to be medically effective for addressing developmental delays, based on relatively recent research, include discrete trial training and positive behavioral support. Several research studies support the medical efficacy and effectiveness of these treatments. However, even if a medical

treatment is effective for some children with developmental delays, it may not be regarded as medically necessary for every child with a particular problem or condition.

#### **Medical Efficacy**

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

#### **Medical Effectiveness**

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

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

For ease of discussion, this criterion will not be considered separately from the discussion of the medical effectiveness of treatments for developmental delays.

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

Some therapies are widely accepted as being medically effective for treating developmental delays; these therapies include speech and language therapy, occupational therapy, and physical therapy. It does not appear that insurers would generally exclude these therapies as not being medically effective. However, making a determination as to the precise amount and duration of therapy required is difficult and partly subjective. Insurers may not cover these therapies because they do not regard them as medically necessary. Further discussion of the distinction between the terms "medically necessary" and "medically effective" is included under "Availability of Coverage."

Other therapies for treating developmental delays are not widely accepted among insurers as being medically effective even though recent literature supports their use. These therapies include discrete trial training and positive behavioral support, which are both within a field called applied behavior analysis (ABA). ABA therapies entail analyzing and altering environmental factors for the purpose of modifying human behavior. Children with developmental delays receive these therapies less frequently than speech and language therapy. However, discrete trial training and positive behavioral support are discussed in detail here because there is less recognition among insurance companies of the effectiveness and potential cost savings of using these therapies even though recent research supports their medical effectiveness.

Discrete trial training focuses on managing a child's learning opportunities so that skills are more easily mastered. Learning is broken down into small steps, and instruction is typically provided one-on-one. Discrete trial training consists of four or five basic steps: (1) An instruction is given or there is an environmental cue to which the teacher would like the child to respond. An optional next step is for the teacher to prompt the child, if needed. (2) The child responds. (3) A reinforcing stimulus is given that is designed to motivate the child to respond correctly. (4) There is a pause before repeating the process. An illustration of this process is provided in Exhibit 2.

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## Exhibit 2: Basic Example of Discrete Trial Training

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Scenario: Jill is working with colors and her teacher wants her to independently select a cube of a named color from an array of cubes. The teacher knows Jill is not able to do this task.

Teacher: "Jill, show me blue." *The teacher takes Jill's hand, shapes it so that the index finger is extended and points to the blue cube.*

Teacher: "Yes! That's the blue cube. Nice job." *The teacher jots on the datasheet that Jill was unable to independently identify the blue cube on this trial. [End of first trial.]*

Teacher: "Jill, show me blue." *Jill does not respond. After a few seconds, the teacher moves to take Jill's hand, but as she does, Jill points to the blue cube.*

Teacher: "Good job! That's the blue cube." *Jill still needed a prompt, so the teacher jots down that Jill was unable to independently identify the blue cube on this trial. [End of second trial.]*

Teacher: "Jill, show me blue." *Jill points to the blue cube.*

Teacher: "Yes! Great job! That's the blue cube." The teacher gives Jill some M&Ms. She marks on the data sheet that Jill was able to identify the blue cube on this trial. *[End of third trial.]*

Source: Wallin, Jason. "The Discrete Trial: A Terribly Wooden Example." Oct. 4, 2006. <http://www.ployxo.com/discretetrial/example.html>

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A 1987 study by Ivar Lovaas is frequently cited as showing the effectiveness of discrete trial training for children with autism. In this study, one group of children under four years of age received an intensive treatment of discrete trial training for between two and three years. It was reported that 47 percent of these children achieved normal functioning compared to two percent of the control group of children who had not received the treatment. This study has been criticized for a lack of random assignment to groups, lack of a uniform assessment protocol, and the use of different instruments to measure IQ before and after treatment. However, additional, better-managed studies have since replicated some of the results of the Lovaas study. Therefore, discrete trial training appears to be a sound, scientifically based practice.

In one of the studies attempting to replicate the findings of the Lovaas study, children between 24 and 42 months of age with autism were randomly assigned to either intensive discrete trial training through a professional or to similar treatment provided by parents under the supervision of professionals for a period of two years. This study found 48 percent of all the children in the study

showed rapid learning and were succeeding in regular education classrooms at age seven. Another study examined the efficacy of intensive discrete trial training for children who began treatment at a later age, between ages four and seven and found that these children made large gains in IQ (18 points on average), similar to IQ gains for children in the Lovaas study (19 points). These two studies suggest that there may be several viable models for delivering intensive behavioral therapy and that children may benefit from these types of interventions at older ages than previously expected.

A third study examined intensive behavioral therapy, which included discrete trial training and other teaching techniques, compared to two other types of treatment: eclectic intervention in public special education classrooms and non-intensive public early intervention programs for children with an autism spectrum disorder. This study found that children receiving the intensive behavioral therapy had significantly higher average scores in all skill domains measured compared to the other groups, with the exception of motor skills. However, this study is subject to some of the same criticisms of the Lovaas study, which included a lack of random assignment and of a uniform assessment protocol.

Two major health insurance companies have documented the basis for their coverage decisions on treatments for autism spectrum disorders or pervasive developmental disorders, including their decisions not to cover applied behavior analysis therapies such as discrete trial training. These documents generally cite studies of discrete trial training which are a year or more older than the studies reviewed here.

Similar to discrete trial training, positive behavioral support is a type of behavioral therapy which may not be covered by insurance, but which has been shown to be effective for children with developmental delays. Positive behavioral support refers to the application of positive behavioral interventions and systems to achieve behavior changes. Other terms which may refer to positive behavioral support include functional communication training and functional behavioral assessment. Positive behavioral support was initially developed as an alternative to aversive interventions for students who engage in extreme forms of self-injury or aggression. However, it is currently used for a wider variety of individuals, including students with more moderate behavioral problems and adults with developmental disabilities who are transitioning from institutional settings to community settings. Exhibit 3 illustrates one example of positive behavioral support.

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### **Exhibit 3: Basic Example of Positive Behavioral Support**

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First, the situation in which problem behavior occurs is identified.

*Jim, a 13 year old male with autism, is disruptive when he is faced with a difficult academic challenge in school.*

Second, a decision is made regarding how the child should be taught to respond to the situation(s) identified.

*It is decided that Jim should be taught to solicit adult assistance, when faced with a difficult academic challenge. He will be taught to say the phrase, "I don't understand." This phrase will serve as a prompt for a teacher to provide help.*

Third, the child is taught to say the prompt for teacher assistance.

*In this case, Jim is taught to say "I don't understand," when asked, "Do you have any questions?"*

Fourth, a series of discrete trials begins. These trials continue until the child responds correctly with high consistency.

*If Jim responds correctly to the prompt, "Do you have any questions?" then Jim is given assistance and offered verbal praise, such as "I like the way you are working today." If Jim responds to the prompt incorrectly, he is told, "That's not correct" and the teacher adds "Do you have any questions?"*

Source: Carr, E.G. and Durand V.M. "Reducing Behavior Problems through Functional Communication Training." *Journal of Applied Behavior Analysis*. 1985 (2) 18:111-126.

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Many studies of positive behavioral supports have very small sample sizes (five or fewer individuals), which could be regarded as a weakness. However, collectively, these small studies provide consistent evidence of the efficacy and effectiveness of positive behavioral support for developmentally disabled clients. In one of these studies, five individuals who had previously been institutionalized were provided treatment and then evaluated six months, 12 months, and 24 months later. All participants were able to adjust to the less restrictive environment. Over the 24-month period following treatment, they were able to live in a less restrictive environment (for example, community-based housing with less security rather than a group care setting) and exhibited fewer challenging behaviors. Participants were also able to attain supported employment in the community.

Another study of 79 individuals with developmental disabilities who displayed self-injurious, aggressive, or other forms of aberrant behavior found that a clear majority of individuals' behavior im-

proved following treatment. Overall, 77 percent of participants exhibited either a reduction in aberrant behavior or an increase in appropriate behavior. One limitation of this study is that it took place in a clinical setting, rather than a more typical environment. However, other studies in more natural settings have produced similar results regarding the efficacy of the treatment.

Results from one extensive meta-analysis of published studies between 1985 and 1996 also support the effectiveness of positive behavior support. The meta-analysis relied on stringent criteria in both determining whether to include a study and in evaluating the effectiveness of positive behavior support. The authors of this meta-analysis concluded that positive behavior support was effective for approximately 50 percent of cases studied; success was defined as a 90 percent reduction in the problem behavior targeted by the intervention.

Additional results on the effectiveness of ABA therapies in Virginia's schools may be forthcoming. The Fairfax County school system provides ABA therapy to preschool children and young children in elementary school. The Director of Special Education for Fairfax County indicated that its ABA program is currently being evaluated, and results are not yet available. However, she also noted that most parents are satisfied with the program and that there has been significant progress for the preschool children enrolled in the program.

As previously noted, in addition to the two treatments discussed in this section there are many other treatments for children with developmental delays that are medically effective. In addition, each child's situation is unique and not every therapy is appropriate for every child. For example, a child with mental retardation would probably not benefit from psychotherapy, but this treatment could be appropriate for a child with an autism spectrum disorder. In deciding whether to authorize treatment for a child with a developmental delay, an insurer considers not only the medical effectiveness of treatment, but also its appropriateness and sometimes the availability of equally effective, but less expensive alternatives. As previously described, medically effective treatments may not be regarded as medically necessary.

## **SOCIAL IMPACT**

The proposed mandate is expected to have a positive impact on public health in some respects. However, ambiguity in the proposed mandate regarding the level of services covered makes it difficult to predict how utilization of habilitative services would change as a result of this mandate. It appears that as many as 28,000 children could benefit from the proposed mandate. In addi-

tion, the proposed mandate could save some families from paying substantial out-of-pocket costs for habilitative services. Costs could be as much as 73 percent of median annual household income.

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

There is ambiguity in the language of the legislation, and the interpretation of this language could significantly affect the utilization of habilitative services. The proposed mandate includes language which specifies that habilitative services provided through schools do not have to be covered by insurers, but insurers are obligated to cover services that are not covered by schools. It is unclear if the word services refers to the type of services or both the type and amount of services. In the former case, a child that receives some speech therapy from school, but less than the medically prescribed amount, would not have insurance coverage for speech therapy up to the amount medically prescribed. In the latter case, if both the type and amount of habilitative service regarded as medically necessary must be covered, then children would potentially be eligible for a much greater amount of services. Staff at the Department of Education (DOE) indicated that parents are typically dissatisfied with the amount of services provided by schools, rather than the types of services provided.

The intent of the proposed mandate appears to be that insurers make up the difference between the amount of habilitative services provided by schools and the amount currently provided through most private insurance. Based on this understanding, JLARC estimated the number of children that would potentially utilize the benefits in the proposed mandate.

Similar to DMHMRSAS, JLARC staff initially estimated that approximately 56,000 children could be eligible for habilitative services described in the proposed mandate. This estimate was derived from subtracting categories of children in special education who would not likely qualify for medically necessary habilitative services. For example, children whose primary disability is a specific learning disability, and who do not have a secondary disability for speech and language, are unlikely to qualify for medically necessary habilitative services. Children with only a specific learning disability generally are not defined as developmentally delayed. JLARC's estimate of the number of children eligible for services under the proposed mandate also accounts for children that may already have coverage for habilitative services through Medicaid or the Family Access to Medical Insurance Security plan (35 percent of children in special education).

As previously noted, depending on the interpretation of the language in the proposed mandate, the number of children eligible for

habilitative services could be substantially lower than 56,000. If the proposed mandate is interpreted as excluding insurance coverage for categories of habilitative services already provided to individual children through schools, then few children may qualify for insurance coverage of additional habilitative services. In addition, JLARC's estimate of 56,000 does not fully account for the percentage of the population that is not affected by mandates. If only the estimated population affected by mandates is included, approximately 28,000 children would be affected by the proposed mandate.

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

Many insurance companies do not provide coverage for habilitative services for children with developmental delays because they do not regard these services as medically necessary. The term "medically necessary" encompasses more than just the effectiveness of a medical treatment. Insurance companies generally define medically necessary interventions as those that are recommended by the treating physician, for the purpose of treating a medical condition, that are appropriate considering the potential benefits and harms, and that are known to be effective in improving health outcomes. Some insurance companies view some children with developmental delays as having educational needs or a behavioral condition, rather than a medical condition and on that basis determine that therapies for treating children's developmental delays are not medically necessary.

Besides excluding habilitative services as not being medically necessary, representatives for some insurance companies also provided another rationale for not covering habilitative services. They believe that the role of insurance is to restore health, rather than improve health or functioning to a degree which individuals never possessed. These insurers believe that providing habilitative services is not appropriate because these services would be directed at improving children's health and functioning to a level which they never possessed.

Insurers that do cover some habilitative services often provide only a limited number of sessions for services such as speech, occupational, and physical therapy. Insurers may set limitations on services through the language in contracts.

The proposed mandate attempts to limit insurers' ability to exclude coverage for habilitative services by defining the terms "habilitative services" and "medically necessary habilitative services." The definition of habilitative services in HB 657 includes "health and social services directed toward increasing and maintaining the physical, intellectual, emotional, and social functioning." Medically



necessary habilitative services are defined as those that are "designed to help an individual attain or retain the capability to function age appropriately within the individual's environment." Under the proposed mandate's definition of medically necessary habilitative services, if a child with a developmental delay needs speech therapy to function age appropriately at school or home, then insurance companies must provide coverage for it to the extent that it is not covered by the child's school. Currently, an insurance company could potentially say that speech therapy is primarily educational and does not address a medical condition.

The proposed mandate also attempts to limit insurers' ability to exclude habilitative services by assigning DMHMRSAS the role of certifying services as medically necessary. The role of DMHMRSAS as outlined in the proposed mandate is new and would fundamentally alter how insurers operate. Representatives for several insurers are adamantly opposed to this role. They believe that it is necessary for them to retain control over what is defined as medically necessary in order to operate effectively. However, the new role of DMHMRSAS would not completely remove insurance companies from the process. Insurers or another entity, such as DMHMRSAS, would still need to provide pre-authorization for services. The pre-authorization step is where insurers have the opportunity to deny coverage because one of the following conditions is met: contract provisions exclude the prescribed services; an equally effective and cheaper alternative exists; the treatment is regarded as experimental; or there is another allowable reason.

Results from the Bureau of Insurance's (BOI) survey show that approximately 51 percent of insurance companies who responded already provide the benefit in the proposed mandate. However, half of these insurance companies qualified their response, indicating that they provide only part of the benefit in the proposed mandate. For example, some companies stated that they provide occupational, physical, and speech therapy on a short-term basis, if the condition improves with treatment.

The results from the BOI survey of insurers should be interpreted with caution. It may be the case that some of the insurance companies who indicated that they already provide coverage for habilitative services actually provide only limited coverage, rather than the more comprehensive coverage sought by advocates. In addition, as written, the proposed mandate would potentially allow insurance companies to write policies that limit the amount of habilitative services covered by their policies. It is standard for insurers to limit coverage for many services. Furthermore, the proposed mandate may allow insurance carriers to impose different, less favorable, cost sharing arrangements for habilitative services than would apply to other illnesses.

### **c. Availability of Treatment**

According to the Department of Medical Assistance Services, providers of habilitative services appear to be available throughout the Commonwealth. However, a study by Price Waterhouse Coopers noted that in northern Virginia there may be shortages of physical, occupational, and speech therapists. This conclusion was based on a survey conducted of providers in 2004 regarding unfilled staff positions. In addition, based on a 2002 report from DOE that examined the services available for individuals with autism and pervasive developmental disorders, a shortage of providers may be a problem in a few areas of the state. This report also included the results of a survey of parents who were asked about why their children were not receiving needed services. Among parents whose children with autism spectrum disorders are not receiving needed treatments, 11 percent indicated that services were not available in their area. Although parents of children with autism spectrum disorders may not be representative of all parents of children with developmental delays, the types of service providers needed by their children are likely similar.

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

Individuals with developmental delays have some access to treatment even without insurance coverage for their conditions. Children under age three who are eligible for Early Intervention Services (EIS) have access to treatment even if the family lacks insurance coverage for developmental delays or a condition resulting in developmental delays, or faces financial hardships. For children that qualify for the EIS program, some services are provided free of charge. For other services, there is a sliding scale for payment, based on ability to pay. For individuals between the ages of two and 21 with developmental delays, schools provide some services, and families do not have to pay out-of-pocket for these services.

Although schools provide some habilitative services to children, both a lack of insurance and the cost of services could pose significant barriers for some families seeking services for their child. As described in the 2002 DOE report, almost 30 percent of parents who responded to the DOE survey disagreed that children with autism spectrum disorders receive the types of services they need. In addition, among parents whose children were not receiving needed services, the two most frequently cited reasons were inability to afford needed services (33 percent) and insurance refusing to cover the cost of services (28 percent).

### **e. Financial Hardship**

For families without health insurance coverage for their child's developmental delay, the level of financial hardship will depend on the severity of a child's disability. A child may need only one additional speech therapy session each week or a child may need 40 hours of intensive therapy each week for a year or longer. In the latter case, where many hours of intensive therapy are required, the therapy would be prohibitively expensive for many families. One author who examined the costs of intensive behavioral therapy for children with autism estimated that the cost of this type of therapy is \$41,295 annually (for 2003).

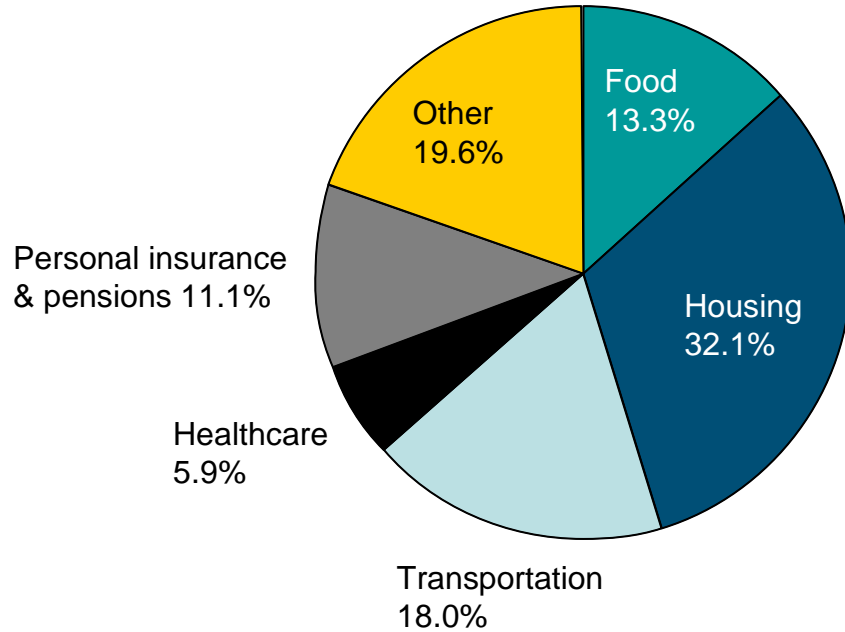
For its 2002 report, DOE surveyed parents of children with autism spectrum disorders regarding their monthly out-of-pocket expenditures for various types of services. Although children with autism spectrum disorders constitute only a fraction of children with developmental delays, the DOE survey illustrates the average out-of-pocket expenses for treating at least some developmental delays. Parents that responded to the DOE survey most frequently reported paying for medical treatment (34 percent), and the average monthly cost reported was \$179. Parents also frequently reported paying for speech and occupational therapy (27 percent and 16 percent, respectively) with average monthly costs of \$273 and \$244, respectively. The service with the highest average monthly cost was behavior therapy at \$726, and 16 percent of parents reported having used this therapy.

For a small percentage of families, those with children with severe developmental delays, the costs of treating a child's developmental delay could be a substantial proportion of household income. Based on data from the U.S. Census Bureau that has been adjusted for inflation, the median household income in Virginia in 2006 is \$56,575. The costs for some services, such as intensive behavior therapy, could be more than double the largest typical expenditure for households, which is housing. As shown in Figure 1, according to the Bureau of Labor Statistics annual Consumer Expenditure Survey for 2004, housing costs accounted for an average of 32 percent of household income expended annually. The cost of intensive behavioral therapy for a year (\$41,295) would be 73 percent of median household income. For many families, the cost of services would likely be much lower. Speech difficulties are one of the most common areas of developmental delays. Based on the DOE survey, the average annual cost of speech therapy (\$3,276) would be six percent of median household income.

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**Figure 1: Distribution of Total Annual Household Expenditures by Major Category, 2004**

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Source: Bureau of Labor Statistics, Consumer Expenditure Survey

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

The term developmental delay, as used in the proposed mandate, is very broad, which makes it difficult to ascertain the prevalence of developmental delays. Children with developmental delays include those with many different diagnoses, such as mental retardation, autism, and cerebral palsy. For some children, their diagnoses may simply be a speech delay or motor delay. There also tends to be overlap between certain conditions that both result in developmental delays. For example, some studies indicate that 55 percent of children with autism also have mental retardation.

The number of children enrolled in special education and the EIS program could provide one estimate of the prevalence of developmental delays; however, results from surveys conducted by the Centers for Disease Control (CDC) may provide a better estimate. Some children enrolled in special education have difficulties which are not regarded as developmental delays, such as a specific learning disability. Based on recent CDC surveys, between 5 percent and 17 percent of children under age 18 have developmental delays. The wide range stems from a difference in the definition of

developmental delay and the method for collecting data. The low estimate reflects a more restrictive definition and relies on parents' reports. Based on Virginia's population from the 2000 Census, the estimated number of children under the age of 18 with developmental delays ranges from 86,913 to 295,505.

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

Statistics are not available regarding the level of demand for coverage of habilitative services. However, DOE's 2002 report on services available for individuals with autism and pervasive developmental disorders suggests the potential level of demand for coverage of habilitative services. In addition, given Virginia's history of proposed mandates for habilitative services, there appears to be persistent demand for coverage.

As noted in DOE's 2002 report, in a survey of parents who have children with autism spectrum disorders, few parents reported that their insurance policy fully covers their child (14.4 percent), and a substantial percentage of parents (41.4 percent) reported that their policy does not cover services related to autism or their child lacked insurance. In addition, when asked in the survey about the reasons their children had not received needed services, the most frequently cited reasons were inability to afford services (33 percent) and insurance refusing to cover the cost of services (28 percent). DOE's survey results are not necessarily representative of the level of health insurance coverage for treatment of developmental delays among all parents of children with developmental delays because children with autism spectrum disorders constitute only a small proportion of children with developmental delays. However, the survey results suggest that many parents of children with developmental delays may want greater insurance coverage for treating their children's condition.

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

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

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

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

In 2005, DMHMRSAS reported to the General Assembly on the cost and feasibility of alternatives to the State's five mental retardation training centers. In this report, DMHMRSAS noted that the high costs of institutional care make it difficult to support institutional services. It recommended that the current Medicaid waiver for persons with mental retardation allow reimbursement for therapeutic behavioral consultation. It stated that allowing reimbursement for therapeutic behavioral consultation services would enable more people to receive services such as positive behavior support or other types of ABA therapy. This change was implemented effective June 28, 2006.

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

Medicaid provides greater coverage for developmental delays than many private insurance policies. The State's Medicaid plan provides coverage for physical, occupational, and speech therapy for children with developmental delays that is medically necessary. In the context of treating children with developmental delays, these therapies are habilitative because they are used to help children attain functioning which they have never possessed. Although insurers often distinguish between habilitative and rehabilitative services and only cover rehabilitative services, Medicaid does not make this distinction. Many insurers may exclude speech therapy for children with developmental delays because they regard it as primarily educational. Although Medicaid's policy states that it does not provide coverage for services which are solely for educational purposes, speech therapy for children with developmental delays is not considered solely educational. The Department of Medical Assistance Services (DMAS) provider manual describing coverage for rehabilitative services specifically states that "rehabilitation services for speech impairments secondary to developmental delays, autism, and other related communication disorders are also covered services." Finally, while many insurers do not cover ABA therapies, DMAS's review of the evidence for the effectiveness of ABA therapies led to the recent decision to include coverage for ABA therapy in Medicaid waivers.

For children receiving services through the Medicaid waiver programs for children with developmental delays (DD) and mental retardation (MR), some habilitative services are available which would not otherwise be covered by the State's plan. The MR waiver covers children with a developmental delay up to age six; the DD waiver covers individuals that are age six and older who have developmental disabilities and not mental retardation. The habilitative services available through these waivers include congregate residential, in-home residential, day support, prevocational services, and supported employment.

In addition to the State's Medicaid coverage, children with developmental delays may be eligible to receive services through a federal Medicaid program called Early Periodic Screening, Diagnosis and Treatment (EPSDT). This program covers therapies considered medically necessary that are not covered by the State's plan. The program was established specifically to identify and address developmental health needs in children. However, staff at DMAS indicated that the vast majority of services needed by children with developmental delays should be available through the State's Medicaid program, for those who qualify for the program.

#### **k. Public Health Impact**

##### **Public Health**

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

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

#### **FINANCIAL IMPACT**

The financial impact of the proposed mandate is uncertain in some areas, and significant administrative costs are possible. For policyholders, there is a wide range of estimates regarding the premium impact. For the State, there would be substantial costs attributable to the new role for DMHMRSAS in certifying medically necessary services. With regard to the long-term total cost of health care, there is some potential for a decrease in costs. However, uncertainty regarding expected changes in utilization and the scarcity of relevant cost-effectiveness analyses make it difficult to draw strong conclusions.

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

Uncertainty regarding the change in utilization of treatments as a result of the proposed mandate makes it difficult to predict the impact of the proposed mandate on the cost of treatment. Because some parents already pay out of pocket for habilitative services and health insurance mandates affect only an estimated one-third of the health insurance market, there may not be a large enough increase in the demand for services to alter the costs of treatment.

The proposed mandate could result in new opportunities for providers to contract with insurance companies that do not have a sufficient number of providers of habilitative services in their networks. These opportunities for new contracts could put pressure on providers to accept lower reimbursement rates in exchange for a higher volume of patients. However, if providers already have a sufficient client base that is willing to pay out of pocket for services or who already have insurance coverage, the provider may choose not to enter into contracts with insurance companies that require accepting lower reimbursement rates.

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

Utilization of habilitative services would probably increase as a result of the proposed mandate. Approximately 28,000 children could increase their utilization of these services. However, ambiguity in the language of the proposed mandate makes it difficult to estimate the expected change in utilization of services.

It does not appear that an increased utilization of habilitative services would be due to an inappropriate overuse of services. Children would need a diagnosis from a provider in order to access services, and only services regarded as medically necessary would be covered by the proposed mandate. Therefore, the potential for inappropriate utilization should be minimal. Also, it appears that the proposed mandate would still allow insurers to retain some control over the utilization of services through contract language and the pre-authorization process.

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

For most children with developmental delays, there is not an alternative treatment to the habilitative services in the proposed mandate, but some children may avoid institutional placement through receiving habilitative services or could receive pharmaceutical treatments instead. For most children, the proposed mandate would potentially allow them to receive a greater amount of habilitative services. In some cases, providing more treatment for children at a young age could result in later savings. However, there



are few rigorous studies of the savings resulting from providing intense treatment at a young age for children with developmental delays. Studies of high-quality preschool programs have found a long term savings from the investment. There are few studies related to the savings from providing medically necessary habilitative services to children up to the age of 19. However, some studies suggest that savings are possible through providing discrete trial training to children with autism. Also, other studies suggest that providing support services to persons with developmental delays that enable them to remain in their communities, instead of institutions, is cost effective.

One study that examined the savings possible through using discrete trial training to treat children with autism estimated savings that ranged from \$187,000 to \$203,000 per child for ages 3-22 years. The range of values reflects a range of assumptions about the percentage of children treated with discrete trial training that would function in the normal range as a result of the therapy (between 20 and 50 percent). One criticism of this study was that the effectiveness of discrete trial training had not yet been sufficiently proven, but studies since the publication of this criticism have bolstered the evidence for the therapy's effectiveness.

Other studies have documented the high costs of autism and have estimated the lifetime costs for individuals with severe autism. These studies also suggest that providing discrete trial training therapy to children with autism for three years at a young age is cost effective, due to the potential for some children to function normally as a result of the therapy.

The evidence regarding the cost effectiveness of positive behavior support for individuals with developmental disabilities stems mainly from analyses of the cost of providing services to these persons in the community or less restrictive settings, rather than institutions. As previously discussed, positive behavior support has been shown to enable persons to successfully move from institutional settings to less restrictive environments. Studies conclude that it is more cost effective to treat individuals in less restrictive settings, even if some support is still required. For example, one study examined data on 50 people with mental retardation and challenging behavior who were in residences where either most persons had similar challenging conditions (congregate setting) or most persons did not have these conditions (non-congregate setting). The study concluded that average costs were significantly higher for persons in the congregate setting (\$115,830) compared to the less restrictive non-congregate setting (\$96,010).

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

The effect on providers will depend on the level of increased demand for services resulting from the proposed mandate. As previously noted, uncertainty in the language of the proposed mandate makes it difficult to predict the extent to which the demand for habilitative services would increase. If there is strong demand for services, the number of providers would probably increase to meet this demand in most areas. (In northern Virginia, where there may be a shortage of physical, occupational, and speech therapists, meeting a large increase in demand for services may prove difficult.) However, two factors will probably temper any increase in demand for services resulting from the proposed mandate. First, some parents already pay out of pocket for habilitative services, so the proposed mandate will only change who pays for services. Second, health insurance mandates affect only an estimated one-third of Virginia's population.

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

For insurance companies, the administrative costs of the proposed mandate would likely be higher than the costs of other health insurance mandates. Similarly, for DMHMRSAS, which would be taking on a new responsibility, there would be substantial administrative costs. The proposed mandate is expected to result in higher premiums for policyholders. These estimated higher premium costs are greater than those for most existing health care mandates.

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

As a result of the proposed mandate, the administrative expenses for insurance companies would likely be higher than the costs for other mandates. In its survey, BOI does not ask insurance companies to provide separate estimates for the administrative expenses. However, in interviews, representatives for some insurance companies indicated that administrative expenses would probably be high. The higher costs would be the result of a need to create contracts with providers who previously have not been included by insurers and the need to track a wide range of conditions and treatments.

As a result of the proposed mandate, the State is expected to incur substantial administrative costs. DMHMRSAS developed two cost estimates based on different ways of implementing the proposed mandate. Under the first option, Community Services Boards would conduct evaluations and assessments to determine eligibility for habilitative services and to certify medical necessity of these services. With this option, insurance companies would still have to authorize services. The primary cost for the State would be the ad-

ditional staff required to certify medical necessity. In fiscal year (FY) 2008, costs for the State are estimated to be \$2.7 million for this option. The costs are expected to rise over the next three years as caseload increases; it is assumed that not everyone who is eligible will immediately request services through DMHMRSAS. In FY 2011, costs are estimated to be \$5.6 million.

Under the second option described by DMHMRSAS, preauthorization of services is moved from insurance companies to DMHMRSAS. Due to the additional staff needed to handle pre-authorizations, for FY 2008, DMHMRSAS estimates an additional higher cost of \$414,944 and a total cost of \$3.1 million. Cost estimates for other fiscal years are similar to those for the first option. The second option would likely be less acceptable to insurance companies which have always retained preauthorization authority.

The costs to the State that would result from the proposed mandate are substantial because DMHMRSAS currently does not have the expertise or staff to determine the medical necessity of services for children with developmental delays. In addition, there does not appear to be a clear benefit to including DMHMRSAS in this role. Certifying the medical necessity of services is just one aspect that influences whether or not an insurer will cover the services. In addition, the determination regarding medical necessity should be a relatively objective process or would be similar to individual physicians determining medical necessity, as they currently do, which makes the proposed new role of DMHMRSAS appear unnecessary.

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

Table 1 show the monthly premium estimates provided by insurance companies for the proposed mandate. Only five insurance companies provided estimates for the monthly premium cost for individual policyholders. The estimates for a standard individual policy cover a wide range, from \$0.31 to \$2.00. These amounts range from 0.2 percent and one percent, respectively, of the average monthly premium for a standard contract (\$191.90), as defined in BOI's 2004 report on the financial impact of mandated health insurance benefits. Compared to other mandates enacted in Virginia, a 0.2 percent increase is lower than the premium impacts of most mandates. However, few existing mandates cost one percent or more of the average premium for a standard contract (7 of 42).

**Table 1: Estimated Monthly Premium Impact for HB 657**

	<b># of Responses</b>	<b>Median Estimate</b>	<b>Highest Estimate</b>	<b>Lowest Estimate</b>
Individual (standard)	5	\$1.57	\$2.00	\$0.31
Individual (optional)	5	\$0.86	\$10.00	\$0.00
Group (standard)	20	\$1.77	\$2.94	\$0.00
Group (optional)	15	\$6.00	\$22.47	\$0.00

Source: Bureau of Insurance survey of the top 50 health insurers based on premium volume, 2006.

With regard to the estimated monthly premium for group certificate holders, 20 insurance companies provided estimates. These estimates ranged from \$0 to \$2.94. The median estimated monthly premium estimate was \$1.77. BOI did not explicitly include the average premium for group certificate holders in its 2004 report on the financial impact of mandated health insurance benefits. Therefore, it is difficult to provide further context for the premium impact estimates for group certificate holders.

For optional coverage, the range of estimates are much higher for both individual and group policies than for a mandated benefit. The high premium estimates are likely due to insurers anticipating adverse selection; most purchasers of the optional coverage will probably be those who expect to need it.

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

The impact of the proposed mandate on the total cost of health care is uncertain, due in part to the ambiguity in the language of the proposed mandate. Children could receive many more services as a result of the mandate or very few additional services. In addition, the impact on the total cost of health care will depend on the extent to which parents already pay for services that are not provided through schools or their private insurance. If parents already pay for these services, the total cost of health care would be similar; there would only be cost shifting. JLARC staff were not able to determine the extent to which parents already pay out of pocket for medically necessary habilitative services.

An increase in the utilization of habilitative services by parents whose children do not currently receive these services would result in an increase in spending on health care. However, there is some potential for a decrease in the long-term total cost of health care, based on studies of the cost effectiveness of discrete trial training for children with autism and positive behavior support for some

individuals with other developmental delays. There are few studies related to the potential cost savings of other specific treatments for children with developmental delays.

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

The proposed mandate is consistent with the role of insurance because it may positively impact public health, encourage preventative treatment, and shield some families from a major financial burden for health care expenditures. In addition, there appears to be a clear need for habilitative services for children with developmental delays. The costs of the proposed mandate are unclear, making it difficult to determine whether the costs would justify the benefits. However, clarifying the language in the proposed mandate and gathering additional data would prove useful for further analysis of the costs and benefits.

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

Based on the premise that the role of insurance is to promote public health, encourage the use of preventative care, and provide financial protection for catastrophic financial expenses for unexpected illnesses, the proposed mandate appears consistent with the role of health insurance. The proposed mandate may have a positive impact on public health through improvements in the mental and emotional well being of caregivers of children with severe developmental delays. The mandate will also 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.

The proposed mandate also appears to be consistent with the role of insurance because some insurers, both public and private, already provide the health insurance coverage described by the proposed mandate. Among private insurance companies that responded to the BOI survey, 51 percent indicated that they already cover some habilitative services for children with developmental delays. Similarly, the State's Medicaid plan provides coverage for medically necessary services for children with developmental delays, such as speech, occupational, and physical therapy. In addition, the insurance plan for State employees (which is not subject to the proposed mandate) covers both physical and occupational therapy for children with developmental delays, as long as progress is shown.

## **b. Need Versus Cost**

The proposed mandate appears to reflect many parents' frustration in trying to get medically prescribed habilitative services through schools. Children between the ages of two and 21 are eligible to receive special education and related services, such as habilitative services, through schools as a result of a program established by IDEIA. However, schools are not obligated to provide all services prescribed by a physician. Schools are only obligated to provide those services that are necessary to provide a child with an education. In addition, educators must weigh the importance of a child getting speech therapy or other therapies against the educational opportunities lost for a child that misses other classes in order to receive those therapies. Educators may decide that it is best for the child, from an educational perspective, to miss a class only once a week instead of three times a week.

There appears to be persistent interest in providing habilitative services for children with developmental delays through legislation. In addition, 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.

Despite the need for habilitative services, the costs of the proposed mandate are uncertain or in some cases appear unreasonable. For example, the cost of including DMHMRSAS in the process, relative to the benefits, appears excessive. As previously noted, there is ambiguity in the language of the bill regarding the use of the term "services" which could strongly affect the level of utilization of habilitative services. In addition, it appears that insurance companies could potentially limit the amount of coverage for habilitative services through cost sharing arrangements or benefit limitations. Therefore, it is not possible to draw conclusions about whether the costs of the proposed mandate would outweigh the benefits.

Clarifying the language in the proposed mandate and gathering additional data could allow stronger conclusions to be drawn regarding its cost-effectiveness. For example, including language on the cost sharing arrangements allowed by the proposed mandate or setting a maximum annual payout amount would make it easier to identify the maximum potential costs for insurers (and benefits for the insured). In addition, specific data that show the gap between the amount of medically prescribed habilitative services that children with developmental delays need, compared to the amount that they actually receive through schools, is not currently available. Such data would provide a better indication as to the ex-

tent that habilitative services may be underprovided and allow for a better approximation of the benefits of providing these services.

### **c. Mandated Offer**

#### **Mandated Offer**

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

For the proposed mandated benefits, a mandated offer would probably not meet the need for health insurance coverage. As an option, the estimated premium impact is often much higher, which may discourage potential purchasers. The median estimated monthly premium impact for optional group coverage is \$6 compared to less than \$2 for group coverage with a mandate. For individual coverage, the median estimated monthly premium impact for individual optional coverage is lower than the median for a standard policy. However, only five estimates were provided, and the two highest estimates for the optional coverage are much higher (\$10) compared to the two highest estimates for a standard individual policy (\$2). Texas has a law requiring a mandated offer for coverage of habilitative services. However, the Texas Department of Insurance did not have any information on the costs or utilization of this mandated offer.

## **ACKNOWLEDGMENTS**

JLARC staff would like to acknowledge the expertise, assistance, and information provided by staff at the Virginia Commonwealth University Children's Treatment Center. JLARC would also like to thank Dr. Robert Valdez, President of Valdez and Associates, for his suggestions and expertise as a public health consultant. In addition, JLARC would like to thank the State Corporation Commission Bureau of Insurance, the Virginia Association of Health Plans, Anthem Blue Cross and Blue Shield, the Department of Education, the Department of Medical Assistance Services, and the Department of Mental Health, Mental Retardation and Substance Abuse Services for their assistance.





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

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## CHAPTER 413

*An Act to amend and reenact §§ [2.2-2503](#) and [30-58.1](#) of the Code of Virginia, relating to staffing of the Special Advisory Commission on Mandated Health Insurance Benefits; Joint Legislative Audit and Review Commission.*

[H 614]

Approved March 31, 2006

Be it enacted by the General Assembly of Virginia:

1. That §§ [2.2-2503](#) and [30-58.1](#) of the Code of Virginia are amended and reenacted as follows:

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

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

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

C. All nonlegislative citizen members shall be appointed for terms of four years. Legislative and ex officio members shall serve terms coincident with their terms of office. All members may be reappointed. However, no House member shall serve more than four consecutive two-year terms, no Senate member shall serve more than two consecutive four-year terms, and no nonlegislative citizen member shall serve more than two consecutive four-year terms. Vacancies occurring other than by expiration of a term shall be filled for the unexpired term. Vacancies shall be filled in the manner as the original appointments. The remainder of any term to which a member is ap-

pointed to fill a vacancy shall not constitute a term in determining the member's eligibility for reappointment.

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

E. Legislative members of the Commission shall receive such compensation as provided in § [30-19.12](#), and nonlegislative citizen members shall receive such compensation for the performance of their duties as provided in § [2.2-2813](#). All members shall be reimbursed for all reasonable and necessary expenses incurred in the performance of their duties as provided in §§ [2.2-2813](#) and [2.2-2825](#). Funding for the compensation and costs of expenses of the members shall be provided by the State Corporation Commission.

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

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

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

The Commission shall have the following powers and duties:

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

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

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

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

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

1. Ways in which the agencies may operate more economically and efficiently;
2. Ways in which agencies can provide better services to the Commonwealth and to the people;  
and
3. Areas in which functions of state agencies are duplicative, overlapping, or failing to accomplish legislative objectives or for any other reason should be redefined or redistributed.



# Proposed Mandated Benefit Requiring Coverage of Habilitative Services for Children With Developmental Delays

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**HOUSE BILL NO. 657**

Offered January 11, 2006

Prefiled January 10, 2006

*A BILL to amend and reenact § [38.2-4319](#) of the Code of Virginia and to amend the Code of Virginia by adding a section numbered [38.2-3418.15](#), relating to mandated coverage for habilitative services for children.*

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Patron-- Plum

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Referred to Committee on Commerce and Labor  
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Be it enacted by the General Assembly of Virginia:

1. That § [38.2-4319](#) of the Code of Virginia is amended and reenacted and that the Code of Virginia is amended by adding a section numbered [38.2-3418.15](#), as follows:

§ [38.2-3418.15](#). *Coverage for habilitative services for children.*

*A. Notwithstanding the provisions of § [38.2-3419](#), each insurer proposing to issue individual or group accident and sickness insurance policies providing hospital, medical and surgical, or major medical coverage on an expense-incurred basis; corporation providing individual or group accident and sickness subscription contracts; and health maintenance organization providing a health care plan for health care services 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.*

*B. For the purposes of this section:*

*"Habilitative services" means health and social services directed toward increasing and maintaining the physical, intellectual, emotional, and social functioning of developmentally delayed individuals, including occupational, physical, and speech therapy; assistance, training, supervision, and monitoring 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" mean habilitative services that are certified by the Department of Mental Health, Mental Retardation and Substance Abuse Services as designed to help an individual attain or retain the capability to function age appropriately within the indi-*

vidual's environment and shall include habilitative services that enhance functional ability without effecting a cure.

*C. An insurer, corporation, or health maintenance organization 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 health maintenance organization to provide coverage for medically necessary habilitative services that are not provided through the individual's school.*

*D. An insurer, corporation, or health maintenance organization subject to this section shall provide notice annually to its insured and enrollees about the coverage required under this section.*

*E. The provisions of this section shall not apply to short-term travel, accident-only, limited or specified disease policies, 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, or to short-term nonrenewable policies of not more than six months' duration.*

§ [38.2-4319](#). Statutory construction and relationship to other laws.

A. No provisions of this title except this chapter and, insofar as they are not inconsistent with this chapter, §§ [38.2-100](#), [38.2-136](#), [38.2-200](#), [38.2-203](#), [38.2-209](#) through [38.2-213](#), [38.2-216](#), [38.2-218](#) through [38.2-225](#), [38.2-229](#), [38.2-232](#), [38.2-305](#), [38.2-316](#), [38.2-322](#), [38.2-400](#), [38.2-402](#) through [38.2-413](#), [38.2-500](#) through [38.2-515](#), [38.2-600](#) through [38.2-620](#), Chapter 9 (§ [38.2-900](#) et seq.), §§ [38.2-1017](#) through [38.2-1023](#), [38.2-1057](#), Article 2 (§ [38.2-1306.2](#) et seq.), § [38.2-1315.1](#), Articles 3.1 (§ [38.2-1316.1](#) et seq.), 4 (§ [38.2-1317](#) et seq.) and 5 (§ [38.2-1322](#) et seq.) of Chapter 13, Articles 1 (§ [38.2-1400](#) et seq.) and 2 (§ [38.2-1412](#) et seq.) of Chapter 14, §§ [38.2-1800](#) through [38.2-1836](#), [38.2-3401](#), [38.2-3405](#), [38.2-3405.1](#), [38.2-3407.2](#) through [38.2-3407.6:1](#), [38.2-3407.9](#) through [38.2-3407.16](#), [38.2-3411.2](#), [38.2-3411.3](#), [38.2-3411.4](#), [38.2-3412.1:01](#), [38.2-3414.1](#), [38.2-3418.1](#) through ~~[38.2-3418.14](#)~~ [38.2-3418.15](#), [38.2-3419.1](#), [38.2-3430.1](#) through [38.2-3437](#), [38.2-3500](#), subdivision 13 of § [38.2-3503](#), subdivision 8 of § [38.2-3504](#), §§ [38.2-3514.1](#), [38.2-3514.2](#), [38.2-3522.1](#) through [38.2-3523.4](#), [38.2-3525](#), [38.2-3540.1](#), [38.2-3542](#), [38.2-3543.2](#), Chapter 52 (§ [38.2-5200](#) et seq.), Chapter 55 (§ [38.2-5500](#) et seq.), Chapter 58 (§ [38.2-5800](#) et seq.) and § [38.2-5903](#) of this title shall be applicable to any health maintenance organization granted a license under this chapter. This chapter shall not apply to an insurer or health services plan licensed and regulated in conformance with the insurance laws or Chapter 42 (§ [38.2-4200](#) et seq.) of this title except with respect to the activities of its health maintenance organization.

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

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

D. Notwithstanding the definition of an eligible employee as set forth in § [38.2-3431](#), a health maintenance organization providing health care plans pursuant to § [38.2-3431](#) shall not be re-

quired to offer coverage to or accept applications from an employee who does not reside within the health maintenance organization's service area.

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





Appendix **C**

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

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

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

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

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

# Annotated Bibliography

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## PEER-REVIEWED RESEARCH

### Discrete Trial Training

**Cohen, H, Amerine-Dickens, M, Smith, T (2006).** Early Intensive Behavioral Treatment: Replication of the UCLA Model in a Community Setting. *Developmental and Behavioral Pediatrics*, 27(2): 145-155.

*Methodology: 42 children with autism or pervasive developmental disorders participated in either treatment that replicated Lovaas' model for intensive behavioral treatment or special education classes in public schools, based on parental preference. Age and IQ were matched for children in each group. Conclusion: Children in the intensive behavioral treatment group showed higher IQ and adaptive behavior scores at the end of treatment (3 years later), but there was no difference between groups for language comprehension or nonverbal skill. A greater number of children in the intensive behavioral group were included in regular education with and without some assistance. However, a lack of random assignment and some differences in groups are significant limitations.*

**Doughty, C (2004).** What is the Evidence for Effectiveness of Behavioral and Skill-Based Early Intervention in Young Children with Autism Spectrum Disorder (ASD)? *New Zealand Health Technology Assessment*, 3(1). Available at: [http://nzhta.chmeds.ac.nz/publications/early\\_autism.pdf](http://nzhta.chmeds.ac.nz/publications/early_autism.pdf). Accessed September 21, 2006.

*Methodology: Literature review of studies published between January 2000 and December 2003 in English, including both primary and secondary research of interventions for children under age eight with ASDs. Conclusion: All of the secondary studies appraised highlighted the lack of well-conducted research on early intervention for autism in young children and concluded that there is insufficient evidence to draw conclusions about best practice. Four of the five primary studies appraised provide some support for the efficacy of approaches studied; however, further research is needed to overcome methodological limitations or replicate findings.*

**Eikeseth S, Smith, T, Jahr, E, Eldevik, S (2002).** Intensive Behavioral Treatment at School for 4-7 Year Old Children with Autism: A One year Comparison Controlled Study. *Behavior Modification*, 26(1):49-68.

*Methodology: 25 children with autism were assigned to either discrete trial training treatment or an eclectic treatment, for one year of treatment. Conclusion: Children in the discrete trial training treatment made significantly greater gains on standardized tests than children in the eclectic treatment group.*

**Howard, JS, Sparkman, CR, Cohen. HG, Green, G. and Stanislaw, H (2005).** A Comparison of Intensive Behavior Analytic and Eclectic Treatments for Young Children with Autism. *Research in Developmental Disabilities*, 26: 359-383.

*Methodology: 29 children received intense discrete trial training and were compared to both a group of 16 children receiving an eclectic intervention and a second group of 16 children in public early intervention programs. Conclusion: Children that received intense discrete trial training had higher mean standard scores on tests of cognitive, language, and adaptive skills, but not tests for motor skills.*

**Sallows, GO and Graupner T D (2005).** Intensive Behavioral Treatment for Children with Autism: Four Year Outcome Predictors. *American Journal of Mental Retardation*, 110 (6): 417-438.

*Methodology: 24 children with autism between the ages of 24 and 42 months were randomly assigned to a clinic-directed group or a parent-directed group that provided intensive discrete trial training to children for two years. Conclusion: 48 percent of all children showed rapid learning and at age seven were in regular education classrooms.*

**Smith, T, Groen, AD, Wynn, JW (2000).** Randomized Trial of Intensive Early Intervention for Children with Pervasive Developmental Disorder. *American Journal on Mental Retardation*, 105 (4): 269-285.

*Methodology: 28 children with pervasive developmental disorder were randomly assigned either to discrete trial training or a parent training group. Conclusion: The discrete trial training group outperformed the other group on measures of intelligence, visual-spatial skills, language and academics, but not always with regard to behavior.*

## Peer Reviewed Research for Positive Behavior Support (PBS)

**Bird, FL and Luiselli, JK (2000).** Positive Behavioral Support of Adults with Developmental Disabilities: Assessment of Long-term Adjustment and Habilitation Following Restrictive Treatment Histories. *Journal of Behavior Therapy and Experimental Psychiatry*, 31: 5-19.

*Methodology: Five individuals previously in a residential treatment facility were transitioned to new less restrictive settings through treatment with positive behavior support and followed over a 24-month period. Conclusion: Individuals' challenging behaviors were within clinically acceptable levels in their new settings, and individuals had greater independence.*

**Carr, EG, and Durand, M (1985).** Reducing Behavior Problems Through Functional Communication Training. *Journal of Applied Behavior Analysis*, 18:111-126.

*Methodology: The participants were four children in a day school program for developmentally disabled children that had at least one problem behavior per hour in class and had expressive language skill of at least one word utterances. Researchers identified situations when problem behavior was likely to occur and then selected replacements for the misbehavior. Conclusion: Both low level of adult attention and high level of task difficulty led to misbehavior, and teaching children alternative ways of communicating resulted in a replicable suppression of behavior problems.*

**Derby, KM, Wacker, DP, Berg, W, DeRaad, A, Ulrich, S, Asmus, J, Harding, J, Prouty, A, Laffey, P, Stoner, EA, (1997).** The Long-Term Effects of Functional Communication Training in Home Settings. *Journal of Applied Behavior Analysis*, (3):507-531.

*Methodology: The participants were four children who were enrolled in an in-home early intervention project. Parents delivered all assessment and treatment plans with weekly consultation from a professional. During the first phase of the study, aberrant behavior was analyzed to identify the conditions that maintained it. Treatment was delivered for approximately six months, and follow-up was conducted for a period of up to 20 months. Conclusion: Long-term suppression of aberrant behavior is possible when treatment is delivered by parents in a home setting.*

**Derby, KM, Wacker, DP, Sasso, G, Steege, M, Northup, J, Cigrand, K, and Asmus, J (1992).** Brief Functional Assessment Techniques to Evaluate Aberrant Behavior in an Outpatient Setting: A Summary of 79 Cases. *Journal of Applied Behavior Analysis*, 25:713-721.

*Methodology: 79 individuals between the ages of 12 months and 35 years that have displayed self-injurious, aggressive, stereotypic, or other forms of aggressive behaviors were evaluated in a clinical setting to identify conditions when aberrant behavior is displayed. Behavior was then targeted with an intervention of positive behavior support, based on hypotheses regarding the reasons for behavior. Both the success of reversing aberrant behavior and eliciting appropriate behavior were analyzed. Overall, in 77 percent of cases altering participants' behavior was achieved. Limitations of this study are that it took place in a clinical setting and aberrant behavior was displayed during the evaluation in only 63 percent of cases.*

**Kurtz, PF, Chin, MD, Huete, JM, Tarbox, RSF, O'Conner, JT, Paclawskyj, TR, and Rush, KS (2003).** Functional Analysis and Treatment of Self-Injurious Behavior in Young Children: A Summary of 30 Cases. *Journal of Applied Behavior Analysis*, 36(2):205-219.

*Methodology: Participants were 30 children under the age of five that exhibited self-injurious behavior on a daily basis with tissue damage. Analysis and treatment were conducted in a clinical setting. For most participants caregivers were training to serve as therapists during functional analyses. Conclusion: The source for reinforcement of self-injurious behavior was identified in 62.1 percent of cases and the source of other forms of aberrant behavior was identified in 87.5 percent of cases. For very young children in the early states of exhibiting self-injurious or other aberrant behavior, the behavior is maintained primarily by social reinforcement.*

**Moes, DR, and Frea, WD (2002).** Contextualized Behavioral Support in Early Intervention for Children with Autism and Their Families. *Journal of Autism and Developmental Disorders*, 32(6):519-533.

*Methodology: Participants were three families raising children age three with autism who exhibit challenging behavior, such as self-stimulatory behavior, hitting, screaming, and throwing objects. Families observed between one and five times for the purpose of identifying problem behavior. Hypotheses on the source of problem behavior were tested. Then, during the intervention phase of the study, the primary caregiver was training to follow the functional communication treatment plan. The functional communication treatment consisted of words or sign language taught as an appropriate response to children's aberrant behavior. Once the caregiver was able to implement the plan with 80 percent accuracy, observation was reduced to once every two-months for a year. Conclusion: Contextualizing functional communication training does not appear to compromise the efficacy of standardized behavioral interventions. However, the study is of limited value for generalization.*

## Sources for Cost Effectiveness Discussion

**British Columbia Office of Health Technology Assessment (2000).** Critical Appraisal of Submitted Cost-Benefit Models of Lovaas Early Intensive Behavioural Intervention for Autism. The University of British Columbia. Available at: <http://www.chspr.ubc.ca/bcohta/pdf/bco00-28T.pdf>. Accessed September 21, 2006.

*Methodology: Two cost-benefit analyses were reviewed, including the one by authors Jacobson, Mulick, and Green, titled "Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism: General Model and Single State Case." Conclusion: Both cost-benefit analyses are based on models biased in favor of the Lovaas treatment, and there is insufficient evidence regarding the effectiveness of the intervention, so there is no basis for a cost-benefit analyses.*

**Ganz, M (2006).** "The Costs of Autism." In Mouldin, SO and Rubenstein, JLR, eds., Understanding Autism from Basic Neuroscience to Treatment. Boca Raton: CRC/Taylor and Frances. 475-502.

*Methodology: A cost-benefit analysis of the cost of autism for society based on a literature review of estimated costs. Both direct and indirect costs are described. Conclusion: The total societal cost of caring for and treating individuals with autism over their lifetimes is approximately \$35 billion.*

**Jacobson, JW, Mulick, JA, Green, G (1998).** Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism: General Model and Single State Case. Behavioral Interventions, 13:201-226.

*Methodology: Costs from Pennsylvania, including costs for educational and adult developmental disability services were applied to a cost-benefit model, assuming average participation in an early intensive behavioral intervention (EIBI) for three years between the age of 2 years and school entry. Conclusion: At varying rates of effectiveness for EIBI, estimated savings range from \$187,00 to \$203,000 per child for ages 3-22 years; therefore, significant cost avoidance may be possible with EIBI.*

**Marcus, LM, Rubin, JS, Rubin, MA (2000).** Benefit-Cost Analysis and Autism Services: A Response to Jacobson and Mulick. Journal of Autism and Developmental Disorders,30(6):595-597.

*Methodology: The authors critiqued the cost-benefit analysis by the authors Jacobson, Mulick, and Green, titled "Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism: General Model and Single State Case" Conclusion: The assumptions made regarding the effectiveness of early intensive behavioral interventions for children with autism are not supported by the literature and ignores alternative treatment methods.*

**Motiwala, SS, Gupta, S, Lilly, MB (2006).** The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario. *Healthcare Policy*, 1(2): 135-151. Available at [http://www.hcerc.utoronto.ca/PDF/autism\\_healthcarePolicy.pdf](http://www.hcerc.utoronto.ca/PDF/autism_healthcarePolicy.pdf). Accessed September 21, 2006.

*Methodology: A cost-benefit analyses for the costs of expanding the current intensive behavioral intervention from one-third of all autistic children age two to five to all children showed total saving of \$45,133,011 over the cohort's lifetime (ages 2-65) in 2003 Canadian dollars. However, sensitivity analyses to address uncertainty and lack of good evidence on treatment efficacy yield mixed results.*

**Robertson, J, Emerson, E, Pinkney, L, Caesar, E, Felce, D Meek, A, Carr, D, Lowe, K, Knapp, M, Hallam, A. (2004).** Quality and Cost of Community-Based Residential Supports for People with Mental Retardation and Challenging Behavior. *American Journal on Mental Retardation*, 109(4): 332-344.

*Methodology: 25 adults with mental retardation and challenging behavior between the age of 18 and 65 in residential, non-congregate facilities were or compared to 25 adults in congregate facilities based on direct observation and interviews with personnel in each setting twice over a ten-month period. There were no statistically significant differences between the two groups with regard to age, ethnicity, overall ability, or challenging behavior as measured by an aberrant behavior checklist. Conclusion: Non-congregate residential supports may be more cost effective than congregate residential support.*

**Spreat, S, Conroy, J, Fullerton, A (2005).** A Cost-Benefit Analysis of Community and Institutional Placements for Persons with Mental Retardation in Oklahoma. *Research in Developmental Disabilities*, (26):17-31.

*Methodology: A sample of 174 persons with mental retardation living in community settings were compared to a matched sample of 174 persons living in congregate settings. Costs, services, and level*



*of community integration were evaluated, primarily using data provided by the Oklahoma Department of Human Services. Conclusion: Community programs provide greater service levels and more community integration than institutional programs. There was a low correlation between setting and costs for matched pairs. However, the mean adjusted cost was \$138,720 per year in institutional settings compared to \$123,384 in community settings.*

### **Other Sources**

Carr, EG, Horner, RH, Turnbull, AP, Marquis, McLaughlin, DM, McAtee, ML, Smith, CE, Ryan, KA, Ruef, MB, Doolabh, A, Brad-dock, D. (1999). Positive Behavior Support for People with Developmental Disabilities: A Research Synthesis. American Association on Mental Retardation. Washington, DC.

*Methodology: Review of research on positive behavior support published between 1985 and 1996. Conclusion: Based on stringent criteria, positive behavior support is effective in reducing problem behavior in approximately 50 percent of cases.*

Law, J, Garrett, Z, Nye C. (2006). Speech and Language Therapy Interventions for Children with Primary Speech and Language Delay or Disorder. The Cochrane Library, Issue 3.

*Methodology: Review of research on speech and language therapy for children with primary speech and language delay. Conclusion: Language therapy is effective for children with phonological or vocabulary difficulties. However, there is less evidence that interventions are effective for children with receptive difficulties and mixed evidence regarding the effectiveness of expressive syntax interventions.*

Michaud, LJ. and Committee on Children with Disabilities. (2004). Prescribing Therapy Services for Children with Motor Disabilities. Pediatrics, 113:1836-1838.

*This article offers guidance on the context in which therapies for motor disabilities should be prescribed.*

Ramey, SL and Ramey, CT. (1999). Early Experience and Early Intervention for Children "At Risk" for Developmental Delay and Mental Retardation. Mental Retardation and Developmental Disabilities Research Reviews, 5:1-10.

*Methodology: Summary and review of research on early intervention for infants and children. Conclusion: All five of the major studies reviewed demonstrated benefits in terms of IQ increases. However, more substantial benefits appear in terms of decreased grade*

*retention and improved school achievement. One study did not show long-term benefits for the entire treated group.*

Simpson, RL. (2005). Evidence-Based Practices and Students with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 20(3):140-149.

*Methodology: Review of research on commonly used interventions and treatments for children with autism spectrum disorders. Conclusions: Applied behavior analysis, discrete trial teaching, and pivotal response training are scientifically based practices.*





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