HB

187

Alaska State Legislature

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Representative Pete Petersen
Representative Chris Tuck
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MEMORANDUM

DATE: January 28, 2010

TO: Rep. Wes Keller, Co-Chair
Rep. Bob Herron, Co-Chair
House Health and Social Services Committee

FROM: Rep. Pete Petersen

RE: Changes in the draft Committee Substitute for HB 187

The draft Committee Substitute I am submitting contains the following changes from the original bill. Thank you for your consideration.

- The definition of "medically necessary" was moved to sec. 21.42.397(e) to clarify that the requirement that covered treatment be medically necessary applies to the whole bill. The phrase "medically necessary" was also added to subsection (b)(5) to clarify that treatment coordinated with education plans would only be covered if they are medically necessary.
- The definition of "autism service provider" was expanded to be more specific. This new language was taken from Colorado statutes.
- The date in the effective date, and the date for inflation adjustment was changed to reflect the fact that this bill did not pass last year.

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Bailey
1/27/10

CS FOR HOUSE BILL NO. 187( )

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-SIXTH LEGISLATURE - SECOND SESSION

BY

Offered:
Referred:

Sponsor(s): REPRESENTATIVES PETERSEN, Dahlstrom, Peggy Wilson, Gruenberg, Muñoz, Kerttula, Gara, Kawasaki, Johansen

A BILL

FOR AN ACT ENTITLED

"An Act requiring insurance coverage for autism spectrum disorders, describing the method for establishing a treatment plan for those disorders, and defining the treatment required for those disorders; and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 21.42 is amended by adding a new section to read:

Sec. 21.42.397. Coverage for autism spectrum disorders. (a) Except for a fraternal benefit society, a health care insurer that offers, issues for delivery, delivers, or renews a health care insurance plan in this state shall provide coverage for the costs of the diagnosis and treatment of autism spectrum disorders. Coverage for the cost of treatment required by this subsection must cover the treatment of the disorders prescribed by a licensed physician or psychologist and provided by an autism service provider as identified in a treatment plan developed following a comprehensive evaluation. A treatment plan developed under this subsection must identify the medically necessary pharmacy care, psychiatric care, psychological care, rehabilitative

care, and therapeutic care required. In this subsection,

(1) "rehabilitative care" means professional counseling, guidance services, and treatment programs, including applied behavior analysis necessary to develop, restore, and maintain the functioning of an individual to the maximum extent practicable; in this paragraph, "applied behavior analysis" means the design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, including direct observation, measurement, and functional analysis of the relationship between environment and behavior, to produce socially significant improvement in human behavior or to prevent the loss of an attained skill or function;

(2) "therapeutic care" means services provided by or under the supervision of a speech-language pathologist licensed under AS 08.11 or an occupational therapist or physical therapist licensed under AS 08.84.

(b) Coverage under this section

(1) is required to be provided only to individuals under 21 years of age;

(2) must provide a maximum benefit of $36,000 a year, adjusted annually, beginning January 1, 2012, by the percentage change in the Consumer Price Index for all urban consumers compiled by the United States Department of Labor, Bureau of Labor Statistics; payments made by an insurer on behalf of a covered individual for treatment of a medical condition unrelated to the individual's autism spectrum disorder may not be applied toward the maximum benefit established in this paragraph;

(3) may not limit the number of visits to an autism service provider for treatment;

(4) is subject to copayment, deductible, and coinsurance provisions, and other general exclusions or limitations included in a health insurance policy to the same extent as other health care services covered by the policy; and

(5) must cover medically necessary treatment that is coordinated with an education program, but may not be contingent on the coordination of treatment with an education program.

(c) This section does not limit benefits that are otherwise available to an individual under a health care insurance plan.

(d) A health care insurer may not terminate, refuse to deliver, execute, issue, amend, or renew coverage to an individual because the individual is diagnosed with or received treatment of autism spectrum disorders.

(e) In this section,

(1) "autism service provider" means an individual who provides direct services to a person with autism spectrum disorder, is licensed, certified, or registered by the applicable state licensing board or by a nationally recognized organization, and who qualifies under one of the following:

(A) has received a doctoral degree with a specialty in psychiatry, medicine, or clinical psychology, is actively licensed in the specialty, and has one year of direct experience in behavioral therapies that are consistent with best practice and research on effectiveness for people with autism spectrum disorders;

(B) has received a doctoral degree in behavioral or health sciences and has completed one year of experience in behavioral therapies that are consistent with best practice and research on effectiveness for people with autism spectrum disorders;

(C) has received a master's degree or higher in behavioral sciences and is nationally certified as a board certified behavior analyst or certified by a similar nationally recognized organization;

(D) has received a master's degree or higher in behavior or health sciences, is licensed as a physical therapist, occupational therapist, or speech-language pathologist, and has completed one year of directly supervised experience in behavioral therapies for people with autism spectrum disorders;

(E) has received a baccalaureate degree or higher in behavioral sciences and is nationally certified as a board certified associate behavior analyst or certified by a similar nationally recognized organization;

(2) "autism spectrum disorders" are those defined by the current

edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, including autistic disorder, Asperger's disorder, and pervasive developmental disorder not otherwise specified;

(3) "health care insurance plan" has the meaning given in AS 21.54.500;

(4) "health care insurer" has the meaning given in AS 21.54.500;

(5) "medically necessary" means any care, treatment, intervention, service, or item prescribed by a licensed physician or psychologist in accordance with accepted standards of practice that will, or is reasonably expected to,

(A) prevent the onset of an illness, condition, injury, or disability;

(B) reduce or ameliorate the physical, mental, or developmental effects of an illness, condition, injury, or disability;

(C) assist in achieving or maintaining maximum functional capacity in performing daily activities;

*** Sec. 2.** The uncodified law of the State of Alaska is amended by adding a new section to read:

APPLICABILITY. AS 21.42.397, enacted by sec. 1 of this Act, applies to a health insurance policy that is offered, issued for delivery, delivered, or renewed on or after January 1, 2011.

*** Sec. 3.** This Act takes effect immediately under AS 01.10.070(c).

The Council for Affordable Health Insurance's

ISSUES & ANSWERS

Solutions for Today's Health Policy Challenges

No. 152 March 2009

The Growing Trend Toward Mandating Autism Coverage

Autism and treatment for its various complications is becoming one of the most discussed and demanded state benefit mandates. But there is a growing debate over whether, and to what extent, autism is a health-related condition as opposed to a behavioral condition or educational challenge. While health insurance does and should cover health-related aspects of autism, policymakers who want to ensure that families facing the real financial and other challenges posed by autism should develop safety net programs that meet their needs, rather than trying to impose autism-related costs on health insurance.

Mental Health or Habilitative Services? Currently, health insurance does and should cover physical medical conditions faced by those with autism. In addition, it will often cover many mental health-related conditions. However, autism advocates want to require health insurance to cover therapies more accurately described as educational.

One problem is how to categorize autism treatment: Does it fall under mental health or habilitative services? If autism is a mental health condition, it is more likely to be covered by health insurance. If under habilitative services, then it should be considered long term care.

A mental health benefit mandate provides for the payment of mental health evaluation and treatment, but sometimes at a higher out-of-pocket cost for the patient, or limitations are imposed on the coverage. Historically, mental health services have higher patient cost-sharing and shorter visit limits than services for physical illness or injury. Mental health parity laws try to minimize or eliminate this difference by requiring the same limitations and cost-sharing for mental health as for traditional medical care.

Habilitative services treatments, by contrast, include occupational, physical and speech therapies for children with a congenital or genetic birth defect, including autism. The goal of such services is to enhance the child's ability to function.

Coverage for Autism. Under a federal law passed in 2004, the Individuals with Disabilities Education Act, or IDEA, public early intervention and special education programs must provide related services and treatments to children with autism. However, only roughly 3 percent of autistic children's needs are met under IDEA, and President Obama has expressed support for even more comprehen-

State legislatures traditionally have grouped autism in the broader category of mental health, but one of the latest state legislative trends is to pass an autism mandate separately from mental health benefit mandates.

Autism support groups want mandate legislation that provides for evaluation and treatment of autism, as well as specific services such as school mainstreaming.

Which States Cover Autism? The question of whether autism is a mental health condition covered under health insurance varies from state to state. One of the problems is that scientists and doctors are not certain what causes autism, and so historically treatment differs from one person to the next. Plus autism-coverage advocates often vary in how they interpret existing laws.

- For example, Autism Speaks reports eight states with health insurance autism benefits.
- However, several autism blogs report a higher figure and point to a Connecticut Office of Legislative Research (OLR) report dated December 2006 that says 17 states have some level of coverage for autism, including 10 that require coverage for autism through their laws mandating mental illness coverage. Six of those states have specific autism laws.
- In July 2008, the Connecticut OLR came out with an additional report that broke down the autism mandate differently. Researchers reported that 22 states besides Connecticut mandate some amount of coverage for the treatment of autism — which is consistent with CAHI's own tracking of the autism mandate. Of these, eight require coverage for behavioral treatment services for autism (Arizona, Florida, Indiana, Kentucky, Louisiana, Pennsylvania, South Carolina and Texas) and five plus Connecticut require other coverage related to autism (Colorado, Georgia, Maryland, New York and Tennessee). Nine states and Connecticut include autism in their mental health mandate laws (California, Illinois, Iowa, Kansas, Maine, Montana, New Hampshire, New Jersey and Virginia).

The Autism Society of America is more consistent with the Connecticut OLR report and several autism blogs. The Society's scope is broader than Autism Speaks, and it includes all types of coverage that addresses autism benefits,

CAHI has tracked 39 states that have mental health benefit mandates on their books (of which 30 specifically include autism), 47 that have state mental health parity laws and at least three have habilitative services for children.

There was additional autism-mandate activity during the 2008 legislative session. For example, Arizona, Connecticut, Florida, Illinois, Louisiana, Pennsylvania and South Carolina now have state mandate laws. And Hawaii adopted a resolution that requests a study of the social and financial impact of adding an autism mandate to health insurance coverage.

Even so, states are increasingly looking to insurers to cover more — or all — of the costs of caring for autistic children. Not because health insurers have any particular expertise in, or even responsibility for, autism. Legislators want insurers to cover more of the costs simply so the state doesn't have to.

The Push for Expanded Autism Coverage. Autism is a serious problem in the country, and we still don't understand the causes or the cure. The Centers for Disease Control reported in 2007 that one in 150 children has this disorder. And there is a growing recognition that autism should be identified early and treated — hence the American Academy of Pediatrics' recent recommendation that all U.S. children be formally screened for autism twice by the age of two.

We do know these children need significant amounts of care. That's why Wisconsin's approach, which set up the Children's Long-Term Care Community-Based Waiver (or CTLS) to provide a range of services to qualifying individuals, makes the most sense. It provides more integrated care than could possibly be provided by health insurance.

In addition, autism support groups and their families are looking for more financial relief from and coverage for Applied Behavior Analysis and other therapies which, according to proponents, contain some of the most effective forms of treatment, best outcomes and long term economic benefits. Proponents believe that health insurance companies should assume the financial burden — typically in the range of $50,000 per year per child — for autistic children that families and school districts have borne.

Insurance carriers argue that most medically related treatments are already covered for autism. In addition, they note that autism is an individually based disorder, and so there is often no clear standard of care to determine the appropriate therapy. Further, some see behavioral therapy not as a medical benefit but an educational one. For example, "play therapies" can require up to 10 separate interactions per day, ensuring the child remains focused on the world around him. The therapy may be provided by unlicensed care providers (and/or parents) who can be trained to use the methods very effectively. Some of the other therapies address developmental delays, which are not typically covered under health insurance.

While various educational therapies for autism may be beneficial, and while we recognize that many families struggle under the related financial burdens associated with autism, we question whether some of these therapies are within the scope of traditional health insurance.

The Cost of Autism Coverage. CAHI's actuarial working team estimates that an autism mandate increases the cost of health insurance by about 1 percent. But they caution us that figure may be rising for two reasons. The incidence of autism appears to be growing, and there is a trend to cover more services, which will drive up the cost of each covered individual. If these trends continue, as we expect, the cost of mandating coverage will move into the 1-to-3 percent range.

Conclusion. Private health insurance, with companies and individuals frequently changing plans or health care networks, doesn't provide the consistent care autistic children need. If legislators want to help these families, they should create programs specifically targeted to meet their needs and properly fund them from general revenues — better than Congress did under the IDEA program — rather than try to force the costs onto health insurance, which will just increase everyone's premiums.

Prepared by Victoria C. Bunce, Research and Policy Director, Council for Affordable Health Insurance and J.P. Wieske, State Affairs Director, Council for Affordable Health Insurance

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HB 187 Questions

Note: Answers provided by the Governor's Council on Disabilities & Special Education with assistance from the Division of Public Health, Section on Women, Children and Family Health, the Center for Human Development at the University of Alaska Anchorage and Jim Bouder

1. **Who will do the recruitment, training and deployment? What has been done to date? Are there any specific strategies for recruitment, training, deployment?**

   Presently, there are four coordinated initiatives to prepare personnel to more effectively serve infant, toddlers, children and youth with Autism. The first 3 are being conducted through one state funded project – Capacity Building for Autism Interventions Project, through the UAA Center for Human Development (CHD). They also directly relate to services provided through insurance funding. The fourth, more targeted, is being funded through the AK Part C Program.

   (1) A total of 15 **Autism Specialists**, (i.e., advanced graduate professional responsible for planning, implementation and monitoring of intensive services), are being trained though a 2-year program of study. Eight are beginning their studies through the CHD project, cooperatively delivered with Northern Arizona University. Seven others are at least ½-way through their programs and are closing on the required 1500 clock hours of supervised field work. One Alaskan professional is currently nationally credentialed in this manner (i.e., Board Certified Applied Behavior Analysts – BCBA- through the through the international division of A.B. A., of the American Psychological Association), though she soon will be retiring. Based on the current population size, Alaska has need for at least 30 of these BCBA specialists.

   It is anticipated that a new cohort of at least 6 graduate students will begin their 2-year studies fall 2010. Students who already have Master's degrees must take the 5 graduate courses, complete the intensive 1500 hr field experience, and pass the national examination before becoming certified. Recruitment takes place through the numerous professional and parent Autism groups (e.g., CAII, Autism Alliance, state/local chapters of Autism Speaks and ASA) along with state and private Behavioral Health, Developmental Disability, Education and Infant Learning agencies.

   (2) **Certified direct service personnel**, both on an undergraduate degree and paraprofessional basis, are needed to implement the services designed by the Autism Specialist. An Occupational Endorsement certificate program is currently being designed and submitted for approval by the Capacity Building for Autism Interventions Project of CHD, in cooperation with the UAA Department of Human Services. This 6 course, 18-credit program is being designed to (a) stand alone as an Occupational Endorsement, or

(b) partially fulfill A.A. or B.A. degree requirements. Initial recruitment will be through similar markets as the Autism Specialist training, as well as conventional UAA channels, with the program anticipated in starting by fall 2010.

(3) **Ongoing Autism professional and paraprofessional training** through a regular week-long Summer Institute was begun by the Capacity Building for Autism Interventions Project the summer of 2009. A total of 42 professionals and paraprofessionals from state and private DD and Infant Learning Program agencies participated. Topics are limited to specific interventions directly relevant to the provision of intensive intervention services. The 2009 Institute focused solely on the needs of infants, toddlers and young children. Plans for 2010 training are to broaden the scope to include strategies for serving teens and young adults with ASD, with special relevance to those youth with Autism, targeted by BTKH for return to Alaska.

(4) **Training of Infant Learning Provider staff**. Beginning the summer of 2010, specialized training is being provided by the Part C Program to ILP staff. This 3-day training will take place in Fairbanks and will focus on the evidenced-based strategies to promote social and communication skill acquisition by very young children.

2. **Have there been any projections of how much money would be spent for travel and lodging compared to how much would be spent for actual treatment?**

At this time, the only travel and lodging associated with the ASD services from the bill potentially relate to those costs associated obtaining a diagnosis when parents chose out-of-state services, as opposed to obtaining that determination here in Alaska. It is anticipated however that most families will already have a diagnosis and not need special travel. Workers who are being prepared to serve with these youth are receiving training primarily either via distance-based delivery systems or coordinated Institutes or Conferences here in Alaska.

Insurance companies do not generally cover the cost of travel and lodging although individual providers who travel to deliver services may build these costs into their indirect rate.

3. **What is the projected cost per insured at a prevalence of 1:100?**

- With an average of 11,000 births in Alaska a year (2) an estimated 111 children (1) will receive an autism diagnosis this year.
- Direct annual average costs related to the medical/behavioral interventions for an autism diagnosis is approximately $48,000
- These 111 children will cost the State of Alaska $3.3 million annually for each year of their life [*if they do not receive treatment that provides them a reasonable independent lifestyle*] (3)

(1) American Academy of Pediatrics (2009)
(2) State of Alaska Bureau of Vital Statistics (2008)
(3) Ganz, M Understanding autism: from basic neuroscience to treatment

According to a recent report (Brief Report: Quantifying the Impact of Autism Coverage on Private Insurance Premiums by James N. Bouder, Stuart Spielman,David S. Mandell), **"Our analyses imply that the percentage increases in healthcare premiums changed linearly based on changes in assumptions in annual costs and treated prevalence. It is important to note, however that the treated prevalence and the per-child expenditures may interact. That is, as treated prevalence increases, the proportion of children with less intensive medical needs may increase, thereby reducing the average per-child expenditure."** (Page 4, column 2, paragraph 2).

Only about 10% of children with ASD diagnoses in the Pennsylvania Medicaid system expend more than $36,000 per year (**Note:** $36,000 is the private insurance cap in Pennsylvania). Given the higher cost of health services in Alaska, it may make sense to bump the cap to $50,000 because the additional impact on premiums will be negligible.

4. **How much actual total premium increases are we talking about in Alaska? How many children total and how many of them would require coverage?**

The total premium increase is estimated to be no more than $3.60 per member per month. This estimate is consistent with findings in other states. Alaska currently has 1,512 children and youth under the age of 21 who have autism; approximately 454 or 30.2% need significant clinical treatment.

5. **Please describe the "Applied Behavior Analysis Treatment." Is any physician or psychologist qualified to administer this treatment?**

Applied Behavioral Analysis (ABA) describes a number of empirically validated strategies and interventions that are used to promote learning and/or change or reduction of behavior. These methods have been authenticated through hundreds of empirical studies that have demonstrated that new behaviors will happen more frequently if they are regularly reinforced, while previously demonstrated behaviors or skills will diminish if they are not. These ABA interventions achieve these outcomes by systematically responding to a child's needs through a process of rigorous data collection and analysis. Recently, the 30 member team of National Autism Standards Project (National Autism Center, http://www.nationalautismcenter.org/) developed criteria and resource lists of evidence-based interventions, suggested from over 950 studies conducted with child, youth and adults with autism. All of those assessed by this national body as being "established" empirically validated treatments were ones that were ABA-based interventions.

Applied Behavior Analysis is often employed within a highly structured context and in an intensive manner (i.e., 1:1 or small group), relying heavily on the determination of the function of behaviors or skills as a first step to selection of a specific package of interventions. Key to the child's success is s/he developing the ability to recognize (discriminate) when and how to behave (respond). For a young child with Autism, this typically first means responding consistently, correctly and quickly to simple prompts, cues or directions given by an adult. It requires teaching the child, on a 1:1 basis, to attend or jointly attend with the adult, to specific objects or actions. The interventionist chooses and delivers cues, directions or actions precisely, and consistently uses positive reinforcement to strengthen and shape the child's correct responses. Doing so increases the child's ability to participate in typical social, home, and school settings as a function of his/her regular demonstration of those skills or behaviors that are contextually applicable or appropriate there. Progress is monitored through data collected on each target skill or behavior, with performance graphed over time.

There are a large number of tested interventions based on the principles of Applied Behavioral Analysis. While many have been validated for use with children with challenging behaviors and/or autism, others have been developed for behavior change by different populations, such as for parenting, weight loss, cessation of smoking, and other major life issues or behaviors. An effective Behavior Analyst systematically selects from different ABA assessment, data analysis, and planning methods as tools in the delivery of services, so as to ensure that the match between the interventions, schedule of service activities, the delivery of services and the child's home, school and community environments are optimal for learning. While many practitioners employ ABA methods, quality is controlled through a national process of certification, through the Behavior Analyst Certification Board, Inc, (BACB), an organization with roots within the Association for Behavior Analysis, International. The graduate level certification standards and credentialing from BACB is endorsed by the Association of Professional Behavior Analysts, the Association for Behavior Analysis International and Division 25 (Behavior Analysis) of the American Psychological Association.

Typically, ABA is provided by OT/PT staff or other master-prepared staff. Physicians and psychologists do NOT typically provide this intensive therapeutic intervention.

6. **Please describe the approved screening process/practice. (no biological markers)**

A flow chart that outlines the screening process/practice used in Alaska is attached.

In FY09, 105 children were referred to the pediatric neurodevelopmental outreach clinics for screenings; 85 were actually scheduled for appointments 34 of whom were presenting autism symptoms. 17 of the 34 (50%) were referred for a full diagnostic workup at Providence Autism Diagnostic Network; 9 were placed in a "watchful waiting" status.

Additionally, 128 children received a full diagnostic workup at the Providence Autism Diagnostic Network. Of the 128 children, 57 (44.3%) were diagnosed with an Autism Spectrum Disorder and an additional 5 (3.9%) were diagnosed with Asperger's Syndrome. 9 (7%) were diagnosed with a mental health diagnosis and 57 (44.3%) were diagnosed with other neurological disorders.

During the most recent quarter (10/1-12/31/09), 97% of children referred were referred suspecting Autism Spectrum Disorder or Asperger's Syndrome. 56% received a final diagnosis of autism or Asperger's; 44% have a diagnosis of another neurological disorder or mental health condition.

A word of caution: these numbers should not be used as a proctor to calculate prevalence or incidence. They are only what the outreach clinics and the Providence Autism Diagnostic Network are experiencing. Many kids referred with a suspected autism diagnosis or "looking like autism" are not screening positive definitely and some of the younger kids screened at the outreach clinics are placed in a "watchful waiting" status – a conservative approach but in their best interests.

Additionally, without a surveillance system, we do not know how many children are being diagnoses by other providers in-state nor the number who move to the state of Alaska who were diagnosed in other states.

7. **How does the education mandate apply? What percentage of children with autism qualify as special education students – intensive needs students? Would there be a duplication of services?**

Special education services and related services (e.g., occupational therapy, speech therapy) are provided to children with a disability whose disability is interfering with their ability to receive an education. The presence of a disability is not sufficient to establish eligibility for special education. The disability must result in an educational deficit that requires specially designed instruction (special education). Special education services are provided according to each student's Individualized Education Plan during the child's school day.

On October 1, 2008, 607 children were receiving specialized education services based on a diagnosis of autism. Because the current definition of autism is restrictive, the majority of these children is on the severe end of the autism spectrum and most likely qualifies as special education intensive needs students. Children with less severe autism often receive special education services based on other categories (e.g., multiple disabilities, other health impaired, emotional disturbances, learning disabilities).

Many children with autism, particularly those who need significant clinical intervention, require services beyond the school day; these are the services that would be covered through health insurance. Ideally, both education and health insurance services are coordinated so that they are complementary of one another, build upon what each system covers, are not duplicative and ensure that the individualized needs of each child are met.

The goals of special education and the goals of health care are not one and the same. The goal of special education is to enable a child with a disability to access the regular education curriculum to the maximum extent appropriate. The goals of health care are to relieve pain, cure disease, and improve functioning. There is no Federal mandate (or state mandate I'm aware of) that requires schools to treat the symptoms of a child's disability – this remains the domain of health care. In the case of children with autism, educational benefit can be realized as a result of treating and ameliorating the varied symptoms of autism. For the most part, clinicians are generally better trained to address the clinical needs of children with autism than special educators. This is not to say that quality special education programs are not important or beneficial – but clinical services delivered under a medical model of care are necessary for many children with autism and, especially when delivered in cooperation with special education, will improve the child's overall outcome.

To sum up, clinical applications of ABA are aimed at improving the functioning of people with autism, whereas special education aims at enabling the child to make meaningful educational progress. I believe these are distinct goals, but the first certainly effects the second. Also, ABA is a psychological discipline with a broad array of applications, including (not surprisingly) clinical applications.

ABA-BASED INTERVENTIONS FOR YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDERS

As research and services are evolving relative to understanding and meeting the needs of young children with autism, several practices have emerged as being key to success. First, rarely do methods other than those that are evidence-based work with these children (i.e., shown effective with this population of children and then replicated through additional rigorous research). Second, when one examines the body of strategies that have been scientifically validated, one sees that the vast majority of these interventions have one common characteristic – each has been designed on, and to later adhere to, core principles of Applied Behavior Analysis, or ABA. A large number of ABA-based strategies have been developed, tested and employed, with some designed to have a generalized impact on the child's functioning, while other methods intended to address specific language, social or behavioral needs of these children. Lastly, evidenced-based methods have generally been shown to be far more effective the sooner and more intensively they are employed.

ABA is a scientifically-driven and validated approach to learning and/or change of behavior. The core ABA principles are based on Operant Learning Theory, which states that new behaviors will happen more frequently if they are regularly reinforced, while previously demonstrated behaviors or skills will diminish if they are not. Applied Behavior Analysis is often employed within a highly structured context and in a systematic manner, relying heavily on the regular observation of overt behaviors as a first step to individualization of intervention. Key to the child's success is s/he developing the ability to discriminate (recognize) when and how to respond (behave). For a young child with ASD, this typically first means responding consistently and quickly to simple cues and directions provided by an adult. This requires teaching the child, on a 1:1 basis, to attend or jointly attend with the adult, to specific objects or actions. The interventionist chooses and delivers cues, directions or actions precisely, and consistently uses positive reinforcement to strengthen and shape the child's correct responses. Doing so increases the child's ability to participate in typical social, home, and school settings as a function of his/her regular demonstration of those skills or behaviors that are contextually applicable or appropriate there. Progress is monitored through data collected on each target skill or behavior, with performance graphed over time.

While a Behavior Analyst who uses ABA tends not to speculate on the non-overt, internalized changes taking place with children with autism, the fact is that successful intervention often results in increased fluency and duration of responding to both verbal and visual cues (i.e., natural characteristics of an object, item or setting such as the shape of a letter, color of a ball, or correspondence of a top button to a top button hole). Doing so increases the probability of independent performance by the child in the future (maintenance of acquired skills), and tends to promote his/her use of these acquired skills in new and different settings (generalization).

There are a large number of tested interventions based on the principles of Applied Behavioral Analysis. While many have been validated for use with children with challenging behaviors and/or autism, others have been developed for behavior change by different populations, such as for parenting, weight loss, cessation of smoking, and the such. An effective Behavior Analyst systematically selects from different ABA assessment, data analysis, and planning methods as tools in the delivery of services, so as to ensure that the match between the interventions, schedule of service activities, the delivery of services and the child's home, school and community environments are optimal for learning. While many practitioners employ ABA methods, quality is controlled through a national process of certification, through the Behavior Analyst Certification Board, Inc, (BACB), an organization with roots within the Association for Behavior Analysis, International. The graduate level certification standards and credentialing from BACB is endorsed by the Association of Professional Behavior Analysts, the Association for Behavior Analysis International and Division 25 (Behavior Analysis) of the American Psychological Association.

Service delivery and workforce development needs

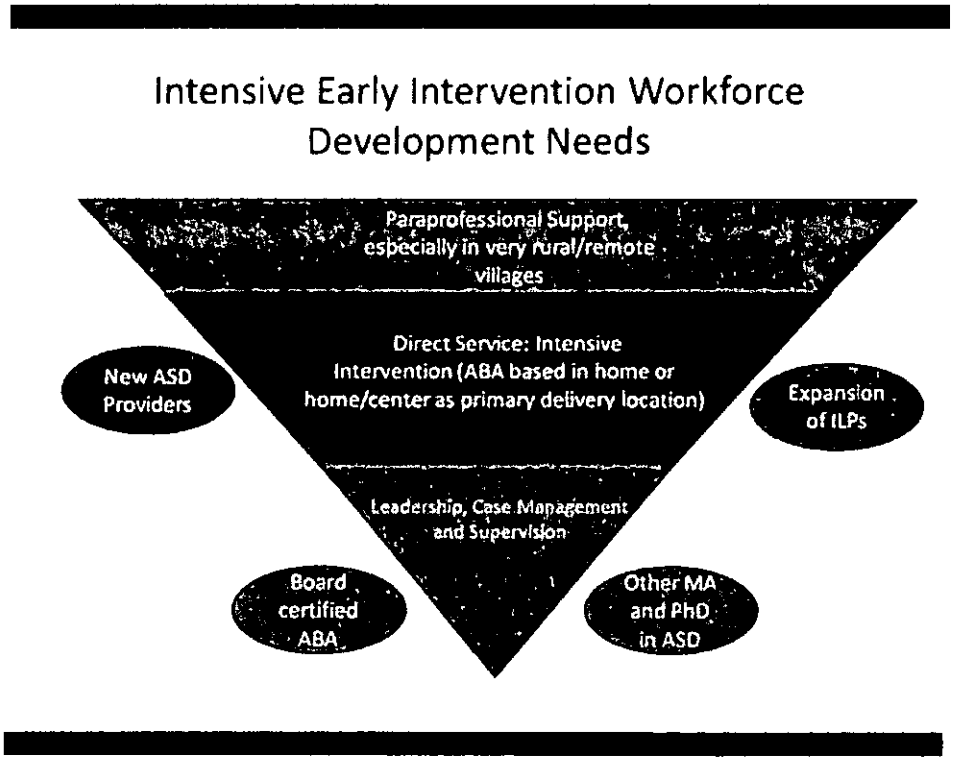
Autism Spectrum Disorders impacts each child uniquely. Age of onset, intensity of intervention and turn-around time between the date that the child is diagnosed and when services are initiated may response to intervention or the level of care needed. However, in most cases, the child him/herself will be the primary barometer to determine intensity and scope of services. For example, most children with autism discontinue

using all oral language, while some toddlers do not lose any ability to communicate whatsoever. The same variation can be said about the disorder's impact on social or behavioral functioning. It is truly a spectrum disorder, with some children demonstrating immediate benefit from conventional Early Intervention services (in Alaska, Infant Learning Programs), while others in need a highly structured daily routine of 1:1 intervention-based services, provided at home and/or in a center-based program, for up to 40 hours a week.

Professionals must guide and oversee the quality and continuity of services for these young children. Typically, Board Certified Behavior Analysts (BCBA) are employed to provide that leadership role. However, those children who require the most intense early intervention may also need services from several types of professionals beyond just those that provide daily intervention. For example, the Kansas Medicaid Waiver for young children with Autism specifies the following services:

1. Determination of eligibility (evaluation by state or contracted provider, called a *Functional Eligibility Specialist*, to determine Level of Care Determination);
2. Intensive Early Intervention, based on an annual plan of care is developed by the *Autism Specialist* (master's level) and implemented by full and part time *Behavior Specialists*
3. Respite Care
4. Consultative Clinical and Therapeutic Services by the Autism Specialist
   - Case management
   - Training and oversight of direct service staff
   - Monitoring and reporting of progress
5. *Parent Support and Training Provider* (the peer-to-peer KS equivalent to Parent Navigation and Training Services now provided through Stone Soup, Inc)
6. *Family Adjustment Counseling* – services for parents and siblings

Four of the six services (i.e., #1, 2, 4, and 6) potentially require a credentialing review prior to their delivery. Intensive intervention (2) is planned and supervised by a BCBA, and implemented either by a bachelor's level full time behavior specialist (certification not required) or a part-time paraprofessional in that same capacity. Other disciplines, including professionals who provide Speech and Language Therapy, Occupational Therapy and Social Work are often needed for these support services.



Alaska's Goals in Response to Autism

2005

Developmental "Red Flags" Identified

No babbling, pointing, or gestures by 12 month
No single words by 16 months
No 2-word spontaneous phrases by 24 months
Any loss of developmental skills that occurs at any age

Primary Care Provider

EPSDT

Administer Screening Tool
(i.e. Ages & Stages, MCHAT, etc.)
Developmental concern identified – referral for Assessment

Rural Screening Option *(Age 0-18):*
Rural Development Outreach Clinic
Developmental concern identified – referral for Assessment

Autism ruled out

[redacted]

Assessment

[redacted]

Autism ruled out

Autism suspected

Recommend Comprehensive Evaluation (Providence Neurodevelopmental Clinic)

Data Collection:

Parent questionnaire, developmental interview, history and neurological evaluation
With ROI completed, Children's Hosp @ Prov collects documentation from:

- *Private OT, SLP, PT assessments*
- *EI/ILP records*
- *School records*
- *Medical Records*
- *Vision, hearing documentation*
- *Mental health assessments*

Multi-disciplinary Record Review

Order additional testing as needed from:

- Vision evaluation
- Hearing evaluation
- PT, OT, SLP
- Psychological – Vineland / CARS
- Dental
- Neurology

If child is < 8 y.o.
R. Brennan, MD

Evaluation
Comprehensive record review
Assessment by OT, PT, ST, medical
Psychiatric and neurological evaluation
Medical Evaluation

If child is > 8 y.o.
T. Hirst, CPNP

Autism ruled out

Parent Navigator

Summary Written &
Parent Conference Conducted

Parent Navigator

Autism diagnosed

Treatment Plan

[redacted]

[redacted]

2988

J Autism Dev Disord
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BRIEF REPORT

Brief Report: Quantifying the Impact of Autism Coverage on Private Insurance Premiums

James N. Bouder · Stuart Spielman · David S. Mandell

Abstract Many states are considering legislation requiring private insurance companies to pay for autism-related services. Arguments against mandates include that they will result in higher premiums. Using Pennsylvania legislation as an example, which proposed covering services up to $36,000 per year for individuals less than 21 years of age, this paper estimates potential premium increases. The estimate relies on autism treated prevalence, the number of individuals insured by affected plans, mean annual autism expenditures, administrative costs, medical loss ratio, and total insurer revenue. Current treated prevalence and expenditures suggests that premium increases would approximate 1%, with a lower bound of 0.19% and an upper bound of 2.31%. Policy makers can use these results to assess the cost-effectiveness of similar legislation.

Keywords Health services · Insurance · Autistic disorder · Economics

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Introduction

Empirical studies of healthcare expenditures find that those of children with autism spectrum disorders (ASD) range from three to ten times those of other children, depending on the sample and methods (Croen et al. 2006; Leslie and Martin 2007; Liptak et al. 2006; Mandell et al. 2006). Synthetic estimates find even higher increases in relative expenditures, especially when categories such as educational expenditures and labor force participation are taken into account (Ganz 2006; Jarbrink and Knapp 2001). Relative to costs associated with other health conditions that manifest in childhood, the healthcare costs associated with ASD are disproportionately borne by families (Fujiura et al. 1994; Jarbrink 2007; Jarbrink et al. 2003; Krauss et al. 2003) and, in the United States, by the Medicaid system (Krauss et al. 2003), regardless of family income (Birenbaum et al. 1990; Braddock 2002; Walsh et al. 1997).

The dramatic increase in the number of children and adults diagnosed with ASD (Centers for Disease Control and Prevention 2007; Fombonne 2003, 2005), combined with the high cost of their care, has caused many states to consider other alternatives to pay for this care (Shattuck and Grosse 2007). Some states have increased the public contribution to these services. For example, Colorado, Indiana, Kansas, Maine, Maryland, Pennsylvania and Wisconsin, have or are considering Medicaid waivers, which would allow states to use Medicaid funds to pay for services not included in their Medicaid plan, or to cover individuals that otherwise would not be Medicaid eligible. Other states have increased the private contribution to these services. Many private insurance companies severely limit coverage of behavioral health services for individuals with autism or exclude coverage altogether. In response,

Arizona, California, Indiana, Kentucky, Louisiana, Mississippi, Pennsylvania, South Carolina, Texas, West Virginia and Wisconsin all recently considered legislation that would mandate private insurance companies to pay for autism-related healthcare services. This legislation has met with varying degrees of success, with legislation not passing in Mississippi, West Virginia or Wisconsin. Successful legislation has varied tremendously in the ages of covered individuals, the types and quantity of covered services, and annual caps on associated expenditures. As of this writing, many other states, including Connecticut, Florida, Illinois, Michigan, Missouri, and Oklahoma, recently have introduced similar legislation.

A major challenge to these insurance mandates has been the concern that they will result in increased premiums for policy holders. Since most policy holders are employers, increases in premiums may be passed onto employees in the form of a net loss of wages or loss of employment, although the effect of mandates on both has been debated in the literature (Collins et al. 2005; Hopkins and Zweifel 2005; Klerman and Goldman 1994; Sommers 2005; Wolaver et al. 2003). Insurance companies therefore have argued that an autism insurance mandate would result in a burdensome rate increase. Autism advocates, on the other hand, have argued that the burden associated with a rate increase would be outweighed by the benefits to individuals with autism and their families.

To help inform the debate surrounding autism insurance mandates, one of the authors (JB) developed an equation to estimate the effect of mandates on premiums, using information easily available on the Internet. In the following, we present the general equation and rationale, and use data from Pennsylvania, which has recently passed legislation, House Bill (HB) 1150, as an example. HB 1150 requires insurance companies to cover healthcare services for children with autism, from birth up to age 21. Specifically mentioned in HB 1150 are behavioral interventions such as applied behavior analysis. Annual per capita expenditures are capped at $36,000.

Methods

Percentage rate impact (%RI) was calculated as a function of the prevalence of autism, which we calculated using a range based on reports of community and treated prevalence. This was multiplied by the number of insured children in Pennsylvania, the average annual medical expenditure for children with autism, which we derived from published studies (see Table 1), and the cost to insurance companies of administering this new mandate. The product of these four numbers was divided by the proportion of revenues from health insurance premiums spent on medical services covered by the plan. This number was then divided by the total revenue to private insurance companies in Pennsylvania. More specifically, we used the formula:

$$\%\mathrm{RI} = \frac{\left(\frac{f}{Sf} \times F\right) \times (\bar{x} \times A) \div \mathrm{MLR}}{\mathrm{PR}}$$

where f is number of children in the state with autism, ages 2–20 years. This number was estimated using several strategies, ranging from the treated prevalence observed in recent studies using private insurance billing data (2 per 1,000) to the CDC-estimated prevalence (6.7 per 1,000).

Sf is number of all children in state, ages 2–20 years. This number was abstracted from US Census data.

F is number of insured children in Commonwealth, ages 2–20 years, with non-ERISA exempt healthcare insurance coverage. This number was derived from the percentage of uninsured children and youth living in Pennsylvania as reported by the Centers for Disease Control and Prevention (Cohen and Martinez 2007) and from the percentage of private-sector enrollees that are enrolled in self-insured plans at business firms offering health insurance in Pennsylvania, as reported in the Medical Expenditure Panel Survey (*Medical Expenditure Panel Survey-Insurance Component* 2005). Using these sources, the number of children and youth between the ages of 2 and 20 living in Pennsylvania and covered under state-regulated insurance plans, was estimated at 1.37 million.

$\bar{x}$ is mean annual per capita expenditure for autism-related services. This number was estimated from existing studies of healthcare utilization, and ranged from the $2,900 found by (Croen et al. 2006) to the $36,000 cap proposed by the Pennsylvania legislation. Only estimated annual expenditures of $10,000 and higher are presented here. A summary of this literature is presented in the table.

A is assumed load factor for the first year's administrative and incidental costs associated with the mandate. This number was obtained from insurer comments filed with the Pennsylvania Health Care Cost Containment Council in regard to the implementation of new insurance mandates, and assumed to be 10% of total provider payments attributable to the mandated benefits.

MLR is medical loss ratio. The MLR refers to the proportion of revenues from health insurance premiums spent on medical services covered by the plan. The MLR was calculated by dividing the total medical losses incurred by total premium revenue collected by insurers. The MLR is used to convert increased medical/clinical costs to a revenue requirement needed to encompass both the hard and soft costs attributable to administering health care coverage. An MLR of 85%, considered the industry standard, was used for these calculations (Robinson 1997).

Table 1 Summary of cost and expenditure studies for individuals with autism; all monetary amounts converted to 2006 $[a]

	Data source	Treated prevalence	Sample	Grand total	Medical					
					Total	Inpatient	Meds	Other	School	Other
(Mandell et al. 2006)	Allegheny County, PA Medicaid data 1994–1999	2.0/1,000	334 Children with autism diagnosis	$12,000	$12,000	$8,300	–	$3,700	–	–
(Croen et al. 2006)	Kaiser Permanente, Northern CA 2003–2004	–	3,053 Children with autism diagnosis	$2,900	$2,900	$1,500	$770	$600	–	–
(Liptak et al. 2006)	National sample from MEPS 1997–2000	2.1/1,000	31 Children with autism diagnoses	$7,400	$7,400	$880	$1,170	$5,300	–	
(Leslie and Martin 2007)	Large US self-insured employers 2000–2004	Per 1,000: 0.9 (2000) 1.3 (2001) 1.8 (2002) 2.1 (2003) 1.9 (2004)	256,646 Children diagnosed with a mental disorder 2000–2005	$4,965 (2000) $5,979 (2004)	–	–	–	–	–	–
(Ganz, 2006)	Synthetic estimate	–	–	Lifetime: $3,439,800	Lifetime: $333,000	Lifetime: $39,400	Lifetime: $6700	Lifetime: $286,800	Lifetime: $163,800	Lifetime: $2,943,000
(Jarbrink and Knapp 2001)	Center of Economics data & survey of 250 parents	–	228 Children with autism or high functioning autism (HFA)	Autism: $1,834,600 HFA: $687,200	Autism: $237,500 HFA: $164,000	Autism: $62,200 HFA: $71,800	Autism: $8,000 HFA: $19,400	Autism: $167,300 HFA: $72,900	Autism: $418,600 HFA: $254,100	Autism: $941,000 HFA: $1,400

[a] All studies present average per person annual expenditures, with the exception of Ganz (2007) and Jarbrink and Knapp (2001), which present average per person lifetime expenditures

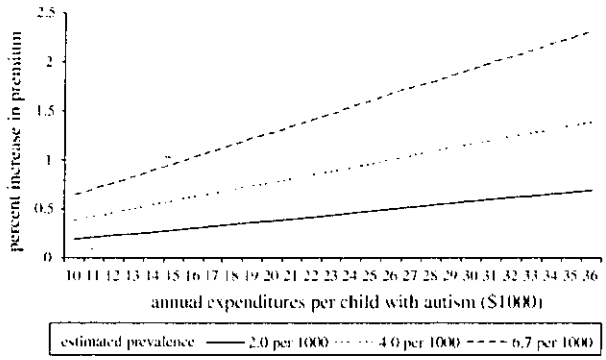

Fig. 1 Estimated increase in healthcare insurance premiums as a result of an insurance mandate requiring coverage of autism treatment

PR is total health insurer premium revenue, which was obtained from an October 2007 publication of the Pennsylvania Health Care Cost Containment Council (*Critical Condition. The State of Health Care In Pennsylvania* 2007), which aggregated premium revenue data that Pennsylvania insurers report on their annual NAIC filings. This sum was adjusted to reflect premium revenue derived from plans subject to HB 1150, as it was originally submitted for review to the Pennsylvania Health Care Cost Containment Council. This adjustment produces a total of $18.44 billion in premium revenue collected for plans subject to HB 1150.

Results

The figure presents the results of this formula based on different assumptions regarding autism prevalence and associated healthcare expenditures. The *x*-axis presents annual expenditures ranging from $10,000 to $36,000. Estimated increases in healthcare premiums ranged from 0.19% (assuming a treated prevalence of 2 per 1,000 children and annual expenditures of $10,000), to 2.31%, (assuming a treated prevalence of 6.7 per 1,000 children and annual expenditures of $36,000; Fig. 1).

Discussion

The results of this analysis suggest that even dramatic increases in the treated prevalence of autism and associated annual healthcare expenditures would result in relatively small increases to healthcare insurance premiums. The average family healthcare insurance plan in the United States costs $1,009 per month, of which families pay an average of 28% (Kaiser/HRET Survey of Employer-Sponsored Health Benefits, 1999–2005, 2007). Our analysis suggests that, using current treated prevalence estimates and an annual expenditure for children with autism of $10,000, the average family would pay an additional $0.54 a month, or $6.44 a year. If current treated prevalence were to double as a result of the new benefit and annual expenditures rose to $20,000, families' annual increased contribution would be $26.10. Even in the unlikely event that treated prevalence were to rise to the accepted community prevalence of 1 in 150 children, and per capita expenditures rose to $36,000 per year, the increase in the family contribution would reach $6.53 a month, or $78.31 per year.

Our analyses imply that the percentage increases in healthcare premiums changed linearly based on changes in assumptions in annual costs and treated prevalence. It is important to note, however that the treated prevalence and the per-child expenditures may interact. That is, as treated prevalence increases, the proportion of children with less intensive medical needs may increase, thereby reducing the average per-child expenditure.

Two study limitations should be noted. First is that these calculations were based on data from existing literature. Dramatic changes in payment available for services to individuals with ASD may affect the treated prevalence and on the provider market. While we attempted to model changes in prevalence up to the accepted community prevalence (Centers for Disease Control and Prevention 2007), we did not model any changes to the provider market. Second, estimated changes to healthcare insurance premiums were based on total costs for children with ASD, not incremental increases, because there is little information on current expenditures for children with ASD not associated with an ASD diagnosis per se (Leslie and Martin 2007; Mandell et al. 2006). Many children with ASD may receive services that are associated with a different diagnosis, as clinicians may assign diagnoses that result in a higher probability of reimbursement. To that extent, the estimates presented here may overestimate actual increases to premiums, given that some healthcare expenditures would remain the same but now would be associated with an ASD diagnosis.

Despite these limitations, the estimates present here offer an important starting point for discussion among policy makers considering the impact of changing insurance regulation. The Pennsylvania legislation upon which these calculations were based has been described as the most generous insurance mandate in the country, in terms of the age group and scope of services covered, as well as the annual expenditure cap. The more limited legislation proposed in other states should be considered in this light, weighing the relatively minimal impact on all insurance premium payers against the potential benefit for children with ASD and their families.

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January 25, 2010

PREMERA | BLUE CROSS BLUE SHIELD OF ALASKA

Representative Wes Keller
Alaska State Capitol – Room 13
Juneau, AK 99801

Jack C. McRae
Senior Vice President

Dear Representative Keller:

On behalf of Premera Blue Cross Blue Shield of Alaska, I am writing to you to express our concerns with HB 187 which mandates coverage for autism spectrum disorders (ASD).

We, too, are concerned with the challenges faced by children with autism and their families. We want to approach this issue in a manner that is in their best interest as well as all of the members we serve.

Of serious concern to us is the cost impact for employers and families already struggling to afford healthcare coverage. Our analysis of this mandate projects a rate increase of at least 3 % to our Alaska members.

Every benefit mandate adds to the overall cost of healthcare and insurance premiums. And, during a time when we are collectively looking to make healthcare more affordable, we believe employers should be able to determine their own benefit plans without additional state mandates. Financial impacts must be strongly considered for any benefit mandate proposal, especially given the current economic conditions, and the fact that many families and employers already face difficulties in affording coverage. Furthermore, this mandate will not impact self-funded plans in Alaska, which are not regulated by the state.

While the proposed mandate would provide some financial relief to families impacted by ASD whose employers can continue to afford coverage, there will be an unfortunate tradeoff for those families who would no longer be able to afford medical coverage at all, including families with ASD affected children. With an increasing load of mandates, employers may be forced to drop health insurance benefits altogether.

Also of particular concern is potentially requiring medical plan coverage for services that are essentially educational in nature, such as Applied Behavior Analysis (ABA) therapy. These services are provided by individuals with backgrounds and training in the field of education, not medical or mental health. We also question the appropriateness of mandating educational services, designed to assist with behaviors such as getting dressed, eating meals, brushing teeth, or sitting still during classes, to be included as part of medical program coverage. This would establish an inappropriate precedence. In addition, numerous reviews of ABA therapy by objective parties have concluded that evidence for the effectiveness of ABA therapy is contradictory, and at best, modest. We would recommend not mandating this therapy in the benefit.

To ensure quality treatment and patient safety, it is important that any person or entity providing treatment of ASD be licensed or certified. The definition of an ASD provider included in HB 187 is overly broad to include any person, entity, or group that provides treatment of ASD. We would recommend that providers treating ASD demonstrate specific training and experience, and that ABA therapy be provided by behavior specialists who are board certified, such as by the Behavior Analyst Certification Board.

Thank you for considering our concerns on this issue.

Sincerely,

Jack C. McRae
Senior Vice President

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Tax Limit
RE: HB137

Purchasing Health Insurance

- Executive Summary
- Descriptive Results
- Tables
- Data Collection Methods
- Demographics

Background

Employee health insurance is a major business and political issue. Virtually everyone agrees that restraining the rate of health care cost (and resultant health insurance price) increases as well as expanding health insurance coverage are pressing matters. The disagreement occurs over the means to reach those objectives. Small businesses are near the center of this controversy. Their employee health insurance costs are rising much faster than inflation. Further, their health insurance dollar purchases relatively fewer benefits. One result is that small employers are less likely to purchase employee health coverage than large employers or public entities. Recent trends only exacerbate these problems, raising serious question about the long-term viability of the entire employer-based health insurance system. Purchasing Health Insurance is a key background component to the employer-based system of employee health insurance and the subject of this issue of the *National Small Business Poll.*

It is well known that about half of employing small businesses offer employee health insurance and the other half does not. It is also well known that provision of employee health insurance is tied to employee size of business, even within the small business population. The data from this survey reflect both. Forty-seven (47) percent of small employers offer employee health benefits and 52 percent do not (Q#1). Those employing 20 or more people are more than twice as likely to offer employee health benefits as those with fewer than 10. Further, 36 percent offer the benefit to *all* or *most* full-time employees and another 5 percent offer it to *some* or a *few*. However, provision of employee health insurance is not synonymous with provision of

employee health benefits. About one in 10 small employers who offer employee health benefits (6%) offer premium reimbursement for health insurance purchased by employees on their own rather than through the business.

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Dropping Insurance or Never Buying It

Good employees are difficult to attract and keep. Provision of benefits is one method small employers use to compete for them. So, most are reticent to antagonize employees by eliminating a benefit or privilege once given; it is much better for morale to have not given the benefit or privilege in the first place. At the same time, small firms experience considerable turmoil in their early years. They often experience cash flow problems and are reluctant to incur marginally necessary expenses. Just short of half survive the first five years, though the odds of exit in any one year decline progressively as businesses age. These two seemingly unrelated facts lead to the hypothesis that stagnation and/or decline in the number of small businesses offering employee health insurance stems not so much from some small employers dropping insurance altogether as from newcomers introducing the benefit relatively late or not at all. The evidence gathered here suggests that the hypothesis is correct.

Twenty (20) percent of small firms offering employee health insurance started offering the benefit in the last three years (Q#1a). The proportion initiating it compared to those already offering it declines as businesses age even though the total percentage offering rises. Unfortunately, we have no benchmark to compare these numbers over time. The data cannot tell us, therefore, if small employers are introducing employee health insurance as a benefit later at the present time than they did in the past. However, 9 percent of those not now offering health insurance (5% of all employing, small businesses) offered it within the last three years (Q#1b). About one third (34%) of those dropping it moved to premium reimbursement rather than eliminating the health benefit altogether. The remainder eliminated the benefit entirely. The consequence is about 3 – 4 percent of all small employers dropped employee health insurance in the last three years (or 1 – 2% a year). One percent annually means virtually no small businesses drop employee health insurance, though they may increase the cost share, etc. If virtually no firm drops employee health insurance and the trend in its provision is stable to lower, new small firms are likely to be slower on the uptake than in the past.

The importance of this point is that it exhibits rising small employer resistance to offering the benefit. As the small business population turns over (and assuming the trend continues), the share of small employers adopting this view will grow. Growing reluctance to initially offer will reduce the pool of potential employees from which to choose, dampening the trend. But, a shrinking pool will also direct small business recruiting efforts toward people who are willing to trade relatively higher wages (or premium reimbursement) for health insurance. This situation is not beneficial to either the small employer or their employees, but it represents the direction current conditions are driving them.

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Shopping for Health Insurance

The overwhelming majority of small employers think that the cost of health insurance is a serious business problem. The logical consequence is that large numbers should be out shopping for a new or different plan, a better buy, or just certainty that they enjoy the best in a series of bad alternatives. Yet, aggressive shopping is not necessarily occurring, particularly among owners of the smallest businesses. Forty-eight (48) percent of all small employers indicate that they or someone on their behalf shopped for employee health insurance in the last three years (Q#2). Owners of the smallest (1 – 9 employees) shopped in only 43 percent of cases compared to 78 percent among the largest (20 – 250 employees).

Not all small employers with insurance shopped nor did all small employers without insurance not shop. Still, the trend was strongly in that direction. Seventy-five (75) percent offering insurance to *all* or *most* full-time employees shopped, compared to 68 percent offering health insurance to *some* or a *few*. Sixty-one (61) percent offering premium reimbursement shopped, but only 26 percent offering neither did. The reason 61 percent of non-shoppers offering insurance gave for not exploring options was that they simply renewed the policy or plan they had (Q#2a). Apparently, they were satisfied or thought they couldn't do any better. Another 29 percent did not shop because they were locked into a longer term commitment. The latter group seems to have avoided the problem of cost uncertainty, a major concern of small employers.

The two principal reasons small-business owners shopped were to look for a lower per employee cost (45%) and just to see what was available (42%) (Q#4). Only 5 percent searched for a different benefit package and 1 percent a different provider network. Three percent searched specifically to cut administrative cost and hassle. The two major reasons for shopping, one

specific and one general, were associated with offers of insurance. Over 60 percent of those offering health insurance shopped for a lower per employee cost, while over 60 percent of those offering premium reimbursement or not offering were looking to see what was available.

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a. Who Shops

The most frequent shopper is the business owner or manager. He or she was the shopper on the firm's behalf in 46 percent of cases (Q#3). This was particularly common among owners of the smallest (52%) though much less so among owners of the largest (28%). Still, half engaged either an employee (23%) or an agent or broker (27%) on their behalf. The largest employers were much more likely to use them (an employee, 33% - an agent or broker, 36%) for the task than the smallest (an employee, 23% - an agent or broker, 27%).

The amount of time small employers spend shopping for employee health insurance (including learning about different plans, analyzing options, making inquiries, and determining employee needs) is limited. The median is about six hours (Q#3a). However, 26 percent spend two hours or less while 13 percent spend 16 hours (2 full days) or more. While the number of respondents is thin, shoppers offering health insurance appear to shop longer than shoppers not offering it and owners of larger firms appear to spend more time than owners of smaller firms. Still, it seems odd that small employers spend so relatively little time on a major cost item with which they are generally displeased. It also challenges the idea that small employers are better consumers of employee health insurance than is the employee him/herself.

The search time data do not account for the time employees or outside agents spend shopping for employee health insurance on the firm's behalf. That means the calculation is dominated by the smallest employers. As a result, the calculation is not equivalent to the total time spent searching for employee health insurance.

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b. Exploring Options

Small employers searching for employee health insurance can investigate a broad variety of information sources to help them. One of the most accessible and intriguing is the Internet. Yet, relatively few small employers use the Internet to explore their options for purchasing employee health insurance. Just 24 percent used the Internet for that purpose in the last three years (Q#5). Reversing the typical distribution of Internet use, shoppers from the smallest firms (employing 1 – 9 people) used the Internet more frequently than did others. Twenty-nine (29) percent of owners with the smallest businesses explored the Internet for information on their employee health insurance options compared to 12 percent of owners with the largest. These numbers are somewhat deceptive since owners of larger firms more often delegate responsibility for shopping. Survey respondents may not be familiar with the agent's search process in those instances.

Another area of potential search is directly with a network of health care providers, such as an HMO. Contacting Kaiser directly is an example. Nearly half (48%) took this step in the search process (Q#6). Differing from the Internet, employee size-of-business was not associated with these contacts. But while making this contact twice as frequently as searching the Internet, few small employers actually purchase their health insurance from a provider network.

State governments have increasingly become active in efforts to help small employers obtain employee health insurance. They range from matching services, such as in Maryland, to subsidized products, such as in Tennessee. These activities appear to be generating interest. Sixteen (16) percent of small employers explored options in a government-organized or sponsored small-business health insurance program (Q#7), though a very small percentage participate as will be seen later.

The survey asked those who did not explore the potential government option, why they had not done so. The most common answer (60%) was that they did not know of any (Q#7a). This response reflects the limited help that most states provide; it does not constitute out-of-hand rejection of them. Twenty-one (21) percent do reject them. These owners say that they would not participate in a government program. Nine percent did not explore such options because they believed better options exist in the commercial market and 6 percent think they are not eligible to participate.

Another source of employee health insurance might be a business trade organization or association. About half of all small employers belong to such organizations. Legislation was recently impaled by the Congress that would have allowed associations of small businesses to broaden insurance pools, effectively giving them greater market access. Still, many

business groups have arrangements with insurers to sell small employers employee health insurance. Thirty-four (34) percent of small employers explored the trade association option the last time they shopped for health insurance (Q#8).

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c. Agents and Brokers

The insurance agent or broker dominates the insurance knowledge base and insurance transactions of most small employers when they shop for employee health insurance. Eighty-seven (87) percent of those who either have employee health insurance or who have shopped for it in the last three years have discussed their options with an insurance agent or broker (Q#9). The employee size of the employer's enterprise is unrelated to the likelihood of discussing options with these insurance professionals.

Most small employers speak with a limited number of agents or brokers. Thirty-one (31) percent discuss their options with a single agent or broker, though discussions with two (27%) or three (26%) are common (Q#9a). Few shop with more. Owners currently covering all or most full-time employees constitute the group most likely to consult only one.

The relationship between agents/brokers and small employers vary, though the former is obviously always a potential vendor and the latter is always a potential customer. Asymmetric information and a lack of competition can influence and even effectively change those roles, however. Such changes appear more than hypothetical. The small employer appears to dominate the relationship in 15 percent of cases, telling the agent/broker what he/she wanted and giving him/her a budget within which to work (Q#10). Another 22 percent simply told the agent/broker what he wanted. These situations are what one would expect in a vendor/customer relationship except under conditions of scarcity. Save the 3 percent who offered another answer or did not know, the agent/broker appeared to dominate the relationship in the remainder of cases. Twenty-four (24) percent had the agent/broker simply explain the available options. A plurality (35%) had the agent/broker explain the available options and make a recommendation. The result is that in 37 percent of cases, the small employer told the agent/broker what he/she wanted. In 59 percent of cases, the agent/broker told the small employer what was available.

The presence of Health Savings Accounts (HSAs) in discussions of potential employee health insurance puts dominance in the relationship in perspective. Health Savings Accounts (HSAs) are an insurance option that is attractive to some, though not all, small employers. It offers them the prospect of considerable cost saving and the possibility of offering some employee health insurance coverage when they otherwise might not. So, HSAs should be at least a topic for discussion between agents/brokers in their role of advisor and their small-business customers. That often does not happen. Forty-six (46) percent of small employers report that in such discussions, the topic never arose; HSAs were not mentioned (Q#11). Still, 30 percent thoroughly discussed HSAs and another 18 percent mentioned them. Among the 48 percent who discussed HSAs, however, small employers were the party who raised the subject in one of three cases (Q#11a). Thus, agents/brokers did not raise the HAS option 59 percent of the time; raised it in 29 percent of cases; and, no information is available on the remaining 12 percent. Since agents/brokers have little financial incentive to sell HSAs compared to traditional insurance, the failure of almost three in five to mention the HSA option suggests the agent/broker role is more a role of vendor than a role of advisor/information provider.

Insurance is not the only industry where asymmetric information puts the vendor in an advantageous business position. The vendor is often, if not usually, more likely to know more about the product or service than the customer, particularly when the purchase is infrequent, small or both. The cost of employee health insurance argues that the owner or a designee should not be in a position where the information asymmetries are not as great as they currently appear to be.

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d. Employee Input

A majority of small employers (55%) asked for employee input when shopping for or making decisions about employee health insurance (Q#12). Forty-five (45) percent did not.

According to small employers who engage their employees, employees were more likely to express concern about cost than any other aspect of health insurance. Half (50%) of the small employers who asked for employee input got the general sense that employees most wanted low out-of- pocket costs (Q#12a). They, therefore, preferred things like minimal cost sharing, modest deductibles and co-pays, etc. Another 20 percent wanted substantial benefits in their plan. The word substantial is open

to interpretation, but it is clear this segment of employees focused on the benefit package. Eleven (11) percent just wanted some health insurance coverage. Presumably, this group wanted to be covered in case of a financially consequential event. Such a preference was typically expressed by employees in firms without coverage. Eight percent of small employers discovered no discernable employee consensus in benefit preference. That number appears modest given the diversity of employees in many small businesses, e.g., young and old, and the inability to offer no more than one plan. Another 7 percent reported that their inquiries yielded little or no employee interest in health insurance. Only 2 percent volunteered other interests with a different provider network scarcely ever mentioned.

The reasons small employers gave for not gathering employee input, when they did not, varied much more than the small employer summation of employee preferences. The most frequent response, though registered by only 12 percent, is that they did not want employee input (Q#12b). To paraphrase one employer comment, I pay for it so I decide what it will be. Another 12 percent reported that they did not ask employees because they did not want to raise employee hopes when it was not yet clear what they would do, i.e., have a plan or not. Eight percent thought employees would not know what they wanted (so, why ask?); another 8 percent cited various cost issues; 7 percent believed the decisiontime was too short to ask; 6 percent were concerned that employees would have different preferences and the business could only offer a single option; and, another 6 percent had a plan and presumably did not want to change it. The remaining reasons created a groaning smorgasbord as 30 percent were clumped in the "Other" category with no single component constituting even 5 percent.

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Purchasing Health Insurance

Seven of 10 (71%) small employers offering employee health insurance purchased their coverage through an insurance agent or broker (Q#13). The next most frequent source was directly from an insurer, not over the Internet. Still, just 11 percent purchased their employee health insurance in that manner. Through a business organization or trade group was the third most frequent (8%) followed by direct purchase from an association of providers (5%). Finally, only 1 percent purchased theirs directly from an insurer over the Internet.

Though nearly 12 percent of small employers explored government options when searching for employee health insurance, few purchases either directly or indirectly involved government. Just 2 percent of purchases involved some government program such as sponsoring or organizing a program, matching businesses with private insurers, etc. (Q#13a).

While the present focus is on the purchase of employee health insurance, some small employers purchase other forms of employee health care and wellness. Thirteen (13) percent of small employers, including 23 percent employing more than 20 people, provide full-time employees health benefits other than health insurance or premium reimbursement (Q#14). These benefits usually are over-and-above the health insurance or premium reimbursement already given rather than in lieu of them. In other words, they are not substitutes, but complements to the more conventional health benefits offered.

The specific additional health benefits offered vary notably. Various types of reimbursements head the list of the largest share (57%), followed by health club memberships (18%), and paid physicals or screenings, e.g., blood pressure, cholesterol (9%) (Q#14a).

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The Magic 7.5 Percent of Payroll

Some authority apparently suggested that 7.5 percent of payroll is the "right" amount for an employer to spend on employee health care benefits. Though entirely arbitrary and arguable, the 7.5 percent figure has found its way into legislative ideas and proposals. So, the question for present purposes becomes: how much are small businesses spending for employee health care?

Forty-three (43) percent of small businesses offering employee health insurance or premium reimbursement spend 7.5 percent or more of payroll on employee health benefits (Q#15). Thirteen (13) percent do not know, underscoring the artificiality of the number. But assuming those not offering either health insurance or premium reimbursement do not have employee health care spending that reaches that magic number, no more than 20 percent of small, employing businesses pass the spending litmus test. Twenty-seven (27) percent of those spending at least 7.5 percent of payroll or about one in 20 small employers actually spend 15 percent or more of payroll on employee health benefits (Q#15a).

Reaching the 7.5 percent spending level is not associated with providing employee health insurance to *all* or *most*, rather than

some or *few*, of one's full-time employees. But it is associated with premium reimbursement. Those who offer premium reimbursement have proportionally fewer who reach the 7.5 percent threshold than those who offer insurance regardless of the proportion of full time employees covered.

Treatment of part-time employees and their share of payroll can exercise an enormous influence on calculating the 7.5 percent. Part-time employees can be included, included on a pro-rata basis or excluded. The choice is significant in numerous ways given that 47 percent of small employers not offering employee health insurance currently have part-time employees only (Q#16). These firms accounted for one-third of the employees (full-time and part-time) within small businesses that do not offer health insurance. The figures presented here intuitively seem high. The apparently large percentage could be explained by allowing the respondent to define the term "part-time" and the difference in the concepts of currently having part-time employees only and having only part-time employees throughout the year. Regardless, there is no doubt part-time employees are staples in many small businesses. Keeping the survey numbers and excluding firms currently with part-time employees only, means that the proportion of small employers affected by a 7.5 percent of payroll mandate falls from about 80 percent of the population to between 60 and 65 percent.

The survey asked small employers not offering either employee health insurance or premium reimbursement or whose firms do not consist entirely of part-time employees their reaction to two basic legislative approaches to increasing health care coverage. The first involved requiring small employers to spend at least 7.5 percent of payroll on employee health benefits or pay a tax amounting to 7.5 percent of payroll. The idea would apply to full-time employees only. The term of art for the generic proposal is "pay or play."

The most frequently mentioned reaction (25%) to a pay or play proposal (7.5% of payroll qualifies as playing) is to shift some full-time employees to part-time work (Q#17). The purpose of shifting an employee(s)' status would be to avoid counting them either for insurance or tax purposes thereby eliminating new payroll costs. The second most frequent reaction (20%) to the pay or play proposal is to increase payroll and health benefits to 7.5 percent of payroll as proponents of such a proposal hope. But, 13 percent indicate that they will eliminate some employees altogether; 13 percent more indicate that they would not increase payroll costs, but would pay for the 7.5 percent in health care by shifting non-health benefits and/or wages into health; and 10 percent would pay the tax. Six percent volunteered other reactions, though they did not include offering health insurance. Still, another 10 percent were not certain what they would do and 4 percent volunteered they would have to close. Those figures sum to 33 percent who would likely institute health coverage and 57 percent who likely would not (10% undecided). They also sum to 30 percent who expect to directly increase their costs in the short term and 54 percent who expect to directly shift the cost to their employees (in the form of less employment and/or reallocated compensation) in the short term (6% not clear and 10% undecided). While it is doubtful those expected compensation shifts could always be made immediately, they will likely be made on an expedited schedule with employees paying the bill sooner rather than later.

Some small employers may combine their first course of action with a second. But in this instance, 48 percent who identified a course of action to the pay or play proposal indicate that they would use only the first one they selected (Q#18). Another 9 percent were undecided. The remaining responses were scattered, but more often focused on eliminating employees and/or shifting hours than paying the tax or increasing insurance offerings.

A variant of the prior pay or play proposal would require small employers to offer employee health insurance and pay a specified minimum, in this case 60 percent of the premium, or pay a tax, in this case 7.5 percent of payroll. The choice was presented small employers not offering either employee health insurance or premium reimbursement, or whose firms consist entirely of part-time employees. No option to adjust was included; the choice was simply to buy insurance or pay the tax. Thirty (30) percent selected the purchase health insurance option of which half said they would do so definitely (Q#19). Thirty-six (36) percent chose to pay the tax, 13 percentage points said they would do so definitely. Again, 11 percent did not know what they would do under the circumstances and 5 percent created alternatives to the direct choice. But 20 percent, one in five, volunteered that neither was possible; they could not do either; they would be forced out of business. That is 20 percent of the number who do not already offer or whose firms do not currently consist exclusively of part-time employees. Still, the figure is in the high single digits (6 – 9%) of the small employer population.

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Final Comments

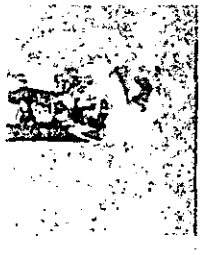
A small, but likely growing, segment of the small-business population is moving toward a defined contribution-type funding mechanism for their employee health insurance. The current survey shows about 6 percent of the population (almost 13 percent of those funding insurance) adopt this course. Some analysts think the practice may not be legal under HIPPA, but without a

definitive legal ruling to the contrary the practice will continue and grow. As a practical matter in addition, the practice is almost impossible to regulate as premium reimbursement could appear in an infinite variety of forms. The lack of a tax exclusion for employees (differing from those obtaining insurance through their employer) is a financial handicap, limiting use of the option. Equalizing the tax treatment of health insurance through private purchase would change the incentive structure both for employers and employees to encourage greater use of it and create more equitable treatment for those exercising the option. But this development, coupled with new firms being more reluctant to introduce the benefit, argues that market conditions are pushing small employers in new and different directions in their relationship to employee health insurance.

Shopping for employee health insurance is infrequent (48% shopped over the last three years) and limited (the median shopping time for owners being about five to six hours) considering the significant costs involved. These responses to a real problem are counter-intuitive. The question then becomes: why? Why is it that small employers do not spend more time and effort shopping when the cost for employee health insurance is so high? There are two likely answers, neither of which is encouraging. The first is that insurance is so complicated and the owner is so busy that they cannot allocate enough time to become sufficiently knowledgeable. One manifestation is that the owner designates someone to shop on the firm's behalf. In 30 percent of cases that person is not associated with the firm and is almost always a vendor. The second is that there is effectively no difference in plans. They all provide about the same benefits and at very high prices. There is no choice, no competition. And, in fact, the small group market in many states has a limited number of competitors and is all but dictated by a Blues monopoly. So, why shop?

The relationship between small-business owners and their insurance agents or brokers, many of which are small-business owners themselves, is curious and not necessarily healthy. Small-business owners typically lack knowledge about insurance and do not help themselves by avoiding that readily available on the Internet to neutralize the information asymmetry. Still, insurance professionals often provide valuable information not unlike other professionals in their specialties. So, the question becomes: when is the agent working in the client's best interests and when is he working in his own? There is no good answer. But the small-business owner must understand enough insurance to suspect he knows the answer in his particular case.

Finally, pay or play legislative proposals are likely to encounter the law of unanticipated consequences, at least for many proponents. When presented a choice that they might face under such proposals, comparatively few small employers chose the insurance option and comparatively many chose the employment reduction (hours or people) option. Moving people to part-time work is a particularly attractive option. In fact, the treatment of part-time employees will have an enormous influence on the response of small-businesses to any pay or play proposal. The treatment of these employees will alter relative costs in one direction or the other, providing small employers' strong relative incentive to change employment among the two groups. If part-time employees are included, small employers have an incentive to eliminate as many part-time employees as possible and spread a fixed health care cost over full-time employees. If part-time employees are excluded, small employers have an incentive to curb full-time employment and transform them into part-time positions. The capacity to eliminate full-time employees and substitute part-timers was illustrated earlier by the number of firms that currently have no full-time employees. This trade-off raises an interesting policy dilemma, one that has drawn little attention to date. But the idea that pay or play will yield huge new numbers of covered employees or vast sums to pay to cover the uninsured is likely a panacea.



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Representative Pete Petersen
District 19

Sponsor Statement

HB 187
INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS

Autism is a devastating disorder affecting at least 1 in 100 children, accounting for 1% of America's youth and 1 in 58 boys, according to the most recent study by the Center for Disease Control and Prevention. Despite being treatable, many children diagnosed with an Autism Spectrum Disorder (ASD) never receive the treatment they need. Families go bankrupt mortgaging their future, trying to provide their children with the treatment to ameliorate their condition. Families are forced to dig into their savings, retirement funds, and their other children's college savings because ASD is not covered by insurance plans. In fact, most insurance plans explicitly exclude the treatment of ASD, even when the service is otherwise covered by the health plan.

HB 187 would require insurance coverage for autism spectrum disorders, including the behavior therapies that after 30 years of study have shown to be the only effective treatment of these disorders. Treatment has been shown to improve the symptoms of ASD and in some cases even eliminate the need for special education services for a child with ASD. The cost savings in special education alone would amount to approximately $208,500 per capita during the school years. This number rises to over $1.08 million over the autistic person's lifespan.

The incremental societal cost of not treating autism has been estimated by Michael Ganz, a Harvard economist, to be approximately $3.2 million per capita. The cost to policy holders to implement such coverage is minimal: estimated at less than a 1% increase in their premiums, or $3.60 per member per month.

Furthermore, President Obama has stated the coverage of treatment and other types of funding for ASD would be a priority of his administration. Sens. Durbin, Casey and Menendez introduced the Autism Treatment Acceleration Act of 2009 in April, mandating the insurance coverage of ASD. While the federal legislation is currently pending, HB 187 allows Alaska to start this process on our own terms, and gives the state the needed time to meet the demands created in HB 187.

Implementing this legislation in Alaska before a federal mandate is enacted would bring well-paying healthcare jobs to the state and bring those interested in this field to Alaska. It is in the best interest of Alaska and autistic Alaskans to have this implemented as soon as possible.

Since HB 187 was introduced in March of 2009, 11 states have passed legislation regarding mandatory insurance coverage of treatment for ASD, with 8 states having enacted legislation prior to March of 2009. The District of Columbia, Puerto Rico and 19 additional states currently have similar legislation pending. These enacted and pending bills and the pending Autism Treatment Acceleration Act demonstrate the nationwide need for relief for families of autistic individuals. Autism is not a state- or region-specific condition. Families burdened with the costs of autism are unlikely to relocate to one of those 11 states that require insurance companies to cover the cost of ASD treatment. Families of any state should not be burdened with the great cost of treating a disorder they could not prevent or predict; they should not find themselves a victim of discrimination by health insurance companies.

Insurance coverage of ASD would not only provide a much needed service to those families burdened with the effects of a child with autism, but also save the state and taxpayers exponentially over the lifespan of those diagnosed with autism. Though there is no cure for ASD, this legislation would help significantly to treat those suffering from these disorders. In addition, a state that covers ASD treatment will be desirable to those in the field and will bring jobs and professionals in the field to Alaska. It will also allow more flexibility for families with autistic children who wish to move to Alaska to do so. Prompt passage of this legislation would allow the state to reap the health and economic benefits that would result from being among the first states to cover ASD.

I respectfully ask for your careful consideration and support of HB 187.

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Representative Pete Petersen
District 19

MEMORANDUM

TO: Members of the House Health & Social Services Committee

FROM: Representative Pete Petersen

DATE: January 18, 2010

RE: Redistribution of April 3, 2009, memo regarding hearing held March 24, 2009

The following information pertains to questions received during the (H) HSS meeting held on March 24, 2009:

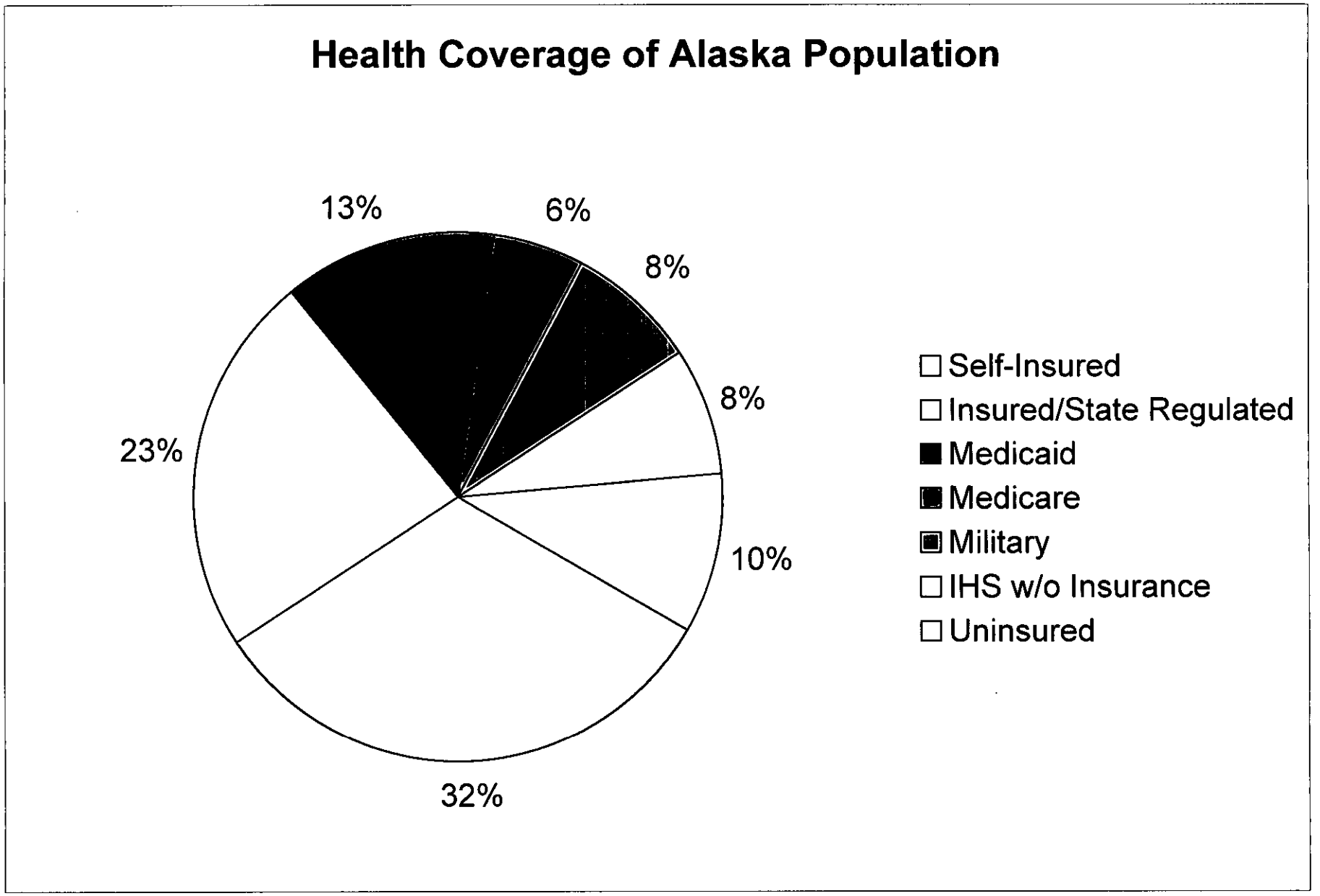
1. RE: Age of covered participants. The bill allows those under the age of 21 to access services for Autism Spectrum Disorders (ASD). This age is consistent with both Medicaid coverage in Alaska, and is a reasonable age in regards to private insurance coverage. Many plans cover dependent children up to a certain age, generally through the college years. Therefore 21 is a reasonable age at which to discontinue these services.

2. RE: out-of-state coverage. If services rendered out-of-state were not available in Alaska, yes, insurance companies would have to cover those out-of-state services—just like they cover those services not available here in Alaska for any number of other health related issues. However, the claims cap would still remain at $36,000 per year per child. As noted by many of the parents who testified, even the $36,000 doesn't always cover the needs of the child. Seeking services outside of Alaska would raise the cost for services, and that $36,000 would not go very far. In addition, except for children who require hospitalization care, ABA is best delivered in the child's own environment which could include home or school. Behavioral treatment sought outside of Alaska would likely be for the most severe cases, including aggression and self-injury, that could not be managed in facilities in the state. Moreover, it is unlikely these more costly forms of treatment would be sought out-of-state due to the nature of such treatment. While ABA

professionals may have to come into the state from outside for the initial treatment plan prescription, the 1-on-1 services are customarily given by someone in the child's immediate community. The treatment is then monitored by the ABA professional, a process that could be done utilizing telemedicine.

3. RE: Sustainable market for ASD service providers. There was a question posed as to whether the percentage of Alaskans covered by this legislation would be enough to sustain the industry of autism service providers. For this question I think it is important to refer to the pie chart provided by Linda Hall at the Division of Insurance (attached). This chart identifies the types of insurance held by Alaskans. The original report containing this breakdown of Alaska's population was done in 2003. However, the division has adjusted the numbers for the 2008 population. I will discuss each section beginning with the Self-Insured at the top of the key:

    a. Self-Insured plans are not currently subject to state mandates. They are protected, as was stated in the committee, by Federal ERISA preemption. There is a Federal ERISA mandate that was filed on April 2, 2009, that made this 32% of Alaskans subject as well, and allow those families to access services.
    b. Insured/State Regulated are the plans that are directly affected by HB 187. This 23% is very close to the 25.3% projected by the cost analysis done by Jim Bouder. His figure of 45.5% was in reference to group-insured Alaskans, which fall under HB 187, and contains about 25.3% of the total population of Alaska—not far off from the 23% cited by the Division of Insurance.
    c. Medicaid in Alaska currently provides some treatment for ASD. It is the primary method by which Alaskan families access these services, however limited the coverage might be. Many families, as we heard, are fully insured, but don't have coverage for the treatments their children need. These families persistently apply for Medicaid waivers to access these funds, but the waiting list can be years, which is not time that autistic children have to spare. In addition, insured families are adding stress to what is already an overburdened system.
    d. Medicare would likely not be a significant contributor to or drawer from any of these services.
    e. Military families already have access to some ASD treatments, including ABA as provided in the federal TRICARE ECHO program for families with children with disabilities.
    f. IHS, or Indian Health Services, is a benefits program for American Indians and Alaskan Natives. IHS draws funds to cover treatment, for those who qualify, from several different sources including Medicaid and private health insurance. The issue of coverage for the treatment of ASD has not come up with IHS due to the fact that they currently draw from places like Medicaid and private insurance to cover other services and it is likely they would do the same for services requested to treat ASD.
    g. HB 187 would not affect the uninsured group of Alaskans.


Health Coverage of Alaska Population
13%
6%
8%
8%
23%
10%
32%
Self-Insured
Insured/State Regulated
Medicaid
Medicare
Military
IHS w/o Insurance
Uninsured

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Archive for Monday, October 05, 2009

CDC survey finds higher incidence of autism

1 in 100 8-year-olds in U.S. diagnosed

By Trine Tsouderos
October 05, 2009

About 1 in 100 8-year-old children in the U.S. have been diagnosed with autism spectrum disorder, according to U.S. Centers for Disease Control and Prevention researchers who will be releasing details of their study later this year.

The rate – significantly higher than the government's 2007 estimate of 1 in 150 – is sure to make waves in the world of autism and beyond, prompting advocates and researchers to call for more research and more funding for services.

Calling autism "an urgent public health concern," CDC Deputy Director Dr. Ileana Arias said the agency considers the disorder "a significant issue that needs immediate attention."

But researchers cautioned that the higher rate might not mean that more kids have autism spectrum disorder.

"It is not entirely clear what (the) increase is due to," said Dr. Thomas Insel, director of the National Institute of Mental Health. "It is not clear more children are affected rather than just changes in our ability to detect."

The rate, calculated by reviewing records in communities across the U.S., echoes findings of a national telephone survey of parents that is being published Monday in the journal Pediatrics.

The survey, conducted by the CDC and the Health Resources and Services Administration, asked parents of 78,000 children ages 3 to 17 whether a health care worker or doctor had ever told them their child had autism spectrum disorder.

Parents of 1 in 91 children said yes and also said their child currently has the disorder. For boys, the figure was 1 in 58.

Dr. Steven Goodman, an epidemiologist with Johns Hopkins Bloomberg School of Public Health, said he agrees prevalence is higher than years ago and merits concern, but warned against panic.

"This has the tremendous potential to scare people," Goodman said. "It is very unlikely that there has been an explosive increase in the way that has been portrayed in the media."

Autism has no known cause and no cure. Scientists think it may be many distinct problems that manifest themselves similarly. Children afflicted often have trouble communicating and socializing, and can exhibit repetitive, rigid behavior.

Diagnosing autism relies on observation, behavioral checklists and expert assessment rather than lab tests or X-rays, making it hard to determine how common it is.

Interpreting data can be a thicket too. Growing awareness, wider screening and a push to identify children earlier accompany the rise in the rate, but scientists have not figured out whether other factors are also at play.

Advocates in the autism community called for more funding for research.

"We have this amazing terrible national health crisis on our hands at this moment," said Lee Grossman, president of the Bethesda, Md.-based Autism Society and the father of a child with autism. "We have millions of people affected by this, and the services and supports available to them are inappropriate and inadequate and in some cases a detriment."

The grandfather of a child with autism, Bob Wright, co-founder of New York City-based Autism Speaks, said: "We are trying desperately to have the health and research assets to be aligned with the prevalence of autism and so far they are way behind."

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Doing the math

The researchers' new estimate would mean about 673,000 U.S. children have autism. Previous estimates put the number at about 560,000.

But figuring out how many children have autism is difficult because diagnosis is based on behavior, said Dr. Susan Levy of the Children's Hospital of Philadelphia and the American Academy of Pediatrics subcommittee on autism.

"As of yet, there's no consistent biologic marker we can use to make the diagnosis of autism," Levy said.

President Barack Obama has made autism a priority for research, said Dr. Thomas Insel, director of the National Institute of Mental Health. Federal stimulus money has been earmarked for autism.

And before Obama took office, a 2006 law pumped millions in federal money into research, screening and treatment. For more information on autism go to:

American Academy of Pediatrics: www.aap.org

CDC: www.cdc.gov/ncbddd/autism/

Health Resources and Services Administration www.hrsa.gov/

– *Associated Press*

ON WORLD AUTISM DAY, DURBIN, CASEY, MENENDEZ INTRODUCE BILL TO ESTABLISH A NATIONAL COMPREHENSIVE AUTISM STRATEGY

Legislation would require insurers to cover autism diagnosis and treatment

April 2, 2009

WASHINGTON, DC- On a day designated by the United Nations to highlight the growing global health crisis of autism, Assistant Senate Majority Leader Dick Durbin (D-IL) and U.S. Senators Bob Casey (D-PA) and Robert Menendez (D- NJ) today introduced legislation that would create a comprehensive strategy to address the needs of families affected by autism spectrum disorder. The Autism Treatment Acceleration Act requires health insurers to provide coverage for the diagnosis and treatment of autism and authorizes federal funding for a wide range of service, treatment, support and research initiatives.

"Almost 26,000 families in Illinois struggle with autism," said Durbin. "Because the cost of autism-related services is so overwhelming for these families, Illinois passed legislation last year requiring health plans to provide coverage for the diagnosis and treatment of autism. It's time now for the federal government to renew and build upon the commitments it has already made in helping the millions of families across the nation struggling with autism. Our legislation would do that."

"Children and adults with autism spectrum disorders and their families have long struggled to get the services and treatment they need to lead rich and productive lives," said Casey. "Today, we launch a momentous effort to change an unacceptable status quo for the 18,500 children who are diagnosed in Pennsylvania each year with autism spectrum disorders and the hundreds of thousands of additional individuals across the country. This bill will help children get the services and treatment they need for the most positive life outcomes, for young adults and adults to have the support they need for satisfying and independent lives, and for families to have the peace of mind to provide and afford the proven treatments that will allow their children and loved ones to reach their fullest

04/02/09 ON WORLD AUTISM DAY, DURBIN, CASEY, MENENDEZ INTRODUCE BILL TO ESTABLISH A NATIONAL COMPREHENSIVE AUTISM STRATEGY »

04/02/09 Casey, Snowe Launch Effort to Expand and Enhance Recovery.gov »

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04/01/09 Casey Applauds Tax Break for 4.8m Pennsylvania Families »

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potential."

"With the growing reach of this disorder, millions of families are personally affected by autism and millions more new families are wondering if they will be too. Nowhere is this felt more than in my home state of New Jersey, where we have the highest rate of autism in the country at an astounding one in every 94 children. We badly need a national strategy that will ensure families affected by autism not only have a strong support structure but also are not left to drown in the financial costs of caring for their loved ones. From services to insurance coverage to public awareness, this legislation would make a real difference in the lives of these families, and we are hopeful that we can get it passed into law," said Menendez.

Today's legislation builds on the Combating Autism Act, signed into law in December 2006. That bill called on the federal government to increase research into the causes and treatment of autism, and to improve training and support for individuals with autism and their caretakers. This bill demonstrated the commitment of Congress to begin to delve deeper into this critically important issue for millions of families.

The Centers for Disease Control (CDC) estimate that approximately 1 in 150 people in the United States has autism or autism spectrum disorder. Individuals with autism often need assistance in the areas of comprehensive early intervention, health, recreation, job training, employment, housing, transportation, and early, primary, and secondary education. Greater coordination within these service delivery systems will enable individuals with autism and their families to access the best and most current treatment, services and research for their individualized needs - and to do so throughout the lifespan of individuals.

The Autism Treatment Acceleration Act aims to meet the comprehensive needs of, and improve the quality of life for, individuals with autism and their families by:

- Requiring that insurers provide coverage for the diagnosis and treatment of autism including Applied Behavioral Analysis therapy and assistive communication devices;

- Creating a demonstration project to develop Autism Care Centers. These centers would provide a full array of medical, behavioral, mental health, educational and family care services to individuals and families in a single location. These comprehensive treatment facilities would increase access to quality health care services and communication among health care providers, educator and other providers of services;

- Creating a demonstration project to provide a full array of services to adults with autism to improve their quality of life and enable them to live as independently as possible;

- Establishing a voluntary population-based autism case registry to help understand the root causes, rates, and trends of autism;

- Developing a national multimedia campaign to increase public education and

awareness about healthy developmental milestones and autism throughout the lifespan;

- Establishing an Interdepartmental Coordinating Committee - consisting of representatives from relevant governmental agencies, researchers and the public - to coordinate government activities relating to autism;

- Establishing a national autism network to strengthen linkages between research and service initiatives at the federal, regional, state and local levels and facilitate the translation of research on autism into services and treatments that will improve the quality of life for individuals with autism and their families;

- Creating a national training initiative on autism and a technical assistance center to develop and expand interdisciplinary training and continuing education on autism.

"Autism Speaks is proud to have worked with Senators Durbin, Casey and Menendez on this legislation, which represents a remarkable leap forward in the federal government's commitment to addressing the challenges faced by individuals with autism and their families," said Elizabeth Emken, Autism Speaks vice president of Government Relations. "The insurance reform section of the bill, in particular, will have an enormous impact by finally requiring insurers to cover therapies that are literally causing families across the country to go broke as they try to provide their children with the services they need and deserve."

"This is the bill we have been waiting for for generations," said Lee Grossman, President and CEO of the Autism Society of America. "The adult services focus, care centers, national teacher training, and insurance components of this bill will complement and strengthen the important research currently underway. Moreover, this bill creates opportunities for states to develop solutions that are locally driven and relevant. As an advocate, and as a father, my heartfelt thanks to Senators Durbin, Casey, and Menendez for their efforts to help the millions of Americans affected by autism today."

Children and adults with autism spectrum disorders can show difficulties in verbal and nonverbal communication, social interactions, and sensory processing. Symptoms and behaviors may range from mild to significant, and require varying degrees of support from friends, families, service providers, and communities. There is strong consensus within the research community that intensive treatment as soon as possible following diagnosis not only can reduce the cost of lifelong care by two-thirds, but also yields the most positive life outcomes for children with autism spectrum disorders. These individuals have a right to live lives that are as full, productive and independent as possible - and with the right services, support, and treatments, they can do just that.

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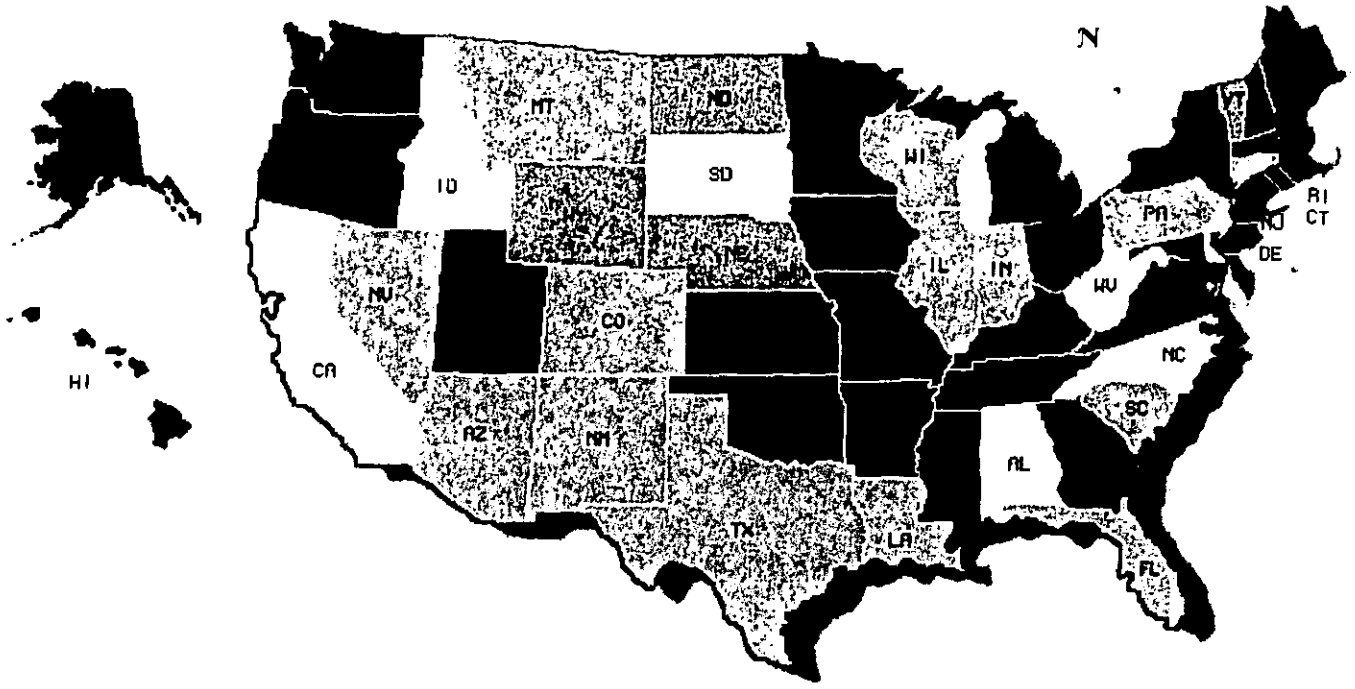
Press Contact
Larry Smar - (202) 228-6367

Autism Speaks
Government Relations Department

updated
8/18/2009

Autism Speaks 2009 State Autism Insurance Reform Initiatives



			States with Pending Autism Insurance Reform Bills	
Arizona	Maine	Alaska	Alabama	Nebraska
Colorado	Massachusetts	Arkansas	California	North Dakota
Connecticut	Michigan	Georgia	Delaware	Rhode Island
Florida	New Hampshire	Hawaii	Idaho	Vermont
Illinois	New York	Iowa	North Carolina	Wyoming
Indiana	Ohio	Kansas	South Dakota	
Louisiana		Kentucky	Wash., DC	
Montana		Maryland	West Virginia	
Nevada		Minnesota		
New Jersey		Mississippi		
New Mexico		Missouri		
Pennsylvania		Oklahoma		
South Carolina		Oregon		
Texas		Tennessee		
Wisconsin		Utah		
		Virginia		
		Washington		

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Representative Pete Petersen
District 19

MEMORANDUM

TO: Representative Wes Keller, Co-Chair
Representative Bob Herron, Co-Chair
Health & Social Services Committee

FROM: Representative Pete Petersen

DATE: March 13, 2009

RE: Hearing Request for HB 187

Dear Representatives Keller and Herron,

I respectfully ask that you schedule a hearing for **HB 187 Insurance Coverage: Autism Spectrum Disorders**, in the House Health and Social Services Committee. Attached is the information requested. Please feel free to contact my aide Ashley Rousson at 465-4939 if you need anything further.

Thank you for your consideration of HB 187.

Alaska State Legislature

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Representative Pete Petersen
District 19

MEMORANDUM

TO: House Health & Social Services Committee

FROM: Representative Petersen

DATE: 3 March 2009

RE: HB 187

Thank you for considering HB 187 Insurance Coverage: Autism Spectrum Disorders. The following information for the House Committee on Health & Social Services pertains to questions received in the March 24th, 2009 hearing on HB 187. I have a diagnostic model forthcoming, to help explain the process of diagnosis. Please contact me or my aide Ashley Rousson 465-4939, if you have any further questions or concerns. We would be happy to work with members on this important piece of legislation.

1. Regarding the age of covered participants. The bill allows those under the age of 21 to access services for Autism Spectrum Disorders (ASDs). This age is consistent with both Medicaid coverage in Alaska, and is a reasonable age in regards to private insurance coverage. Many plans cover dependant children up to a certain age generally through the college years. Therefore, 21 is a reasonable age at which to discontinue these services.

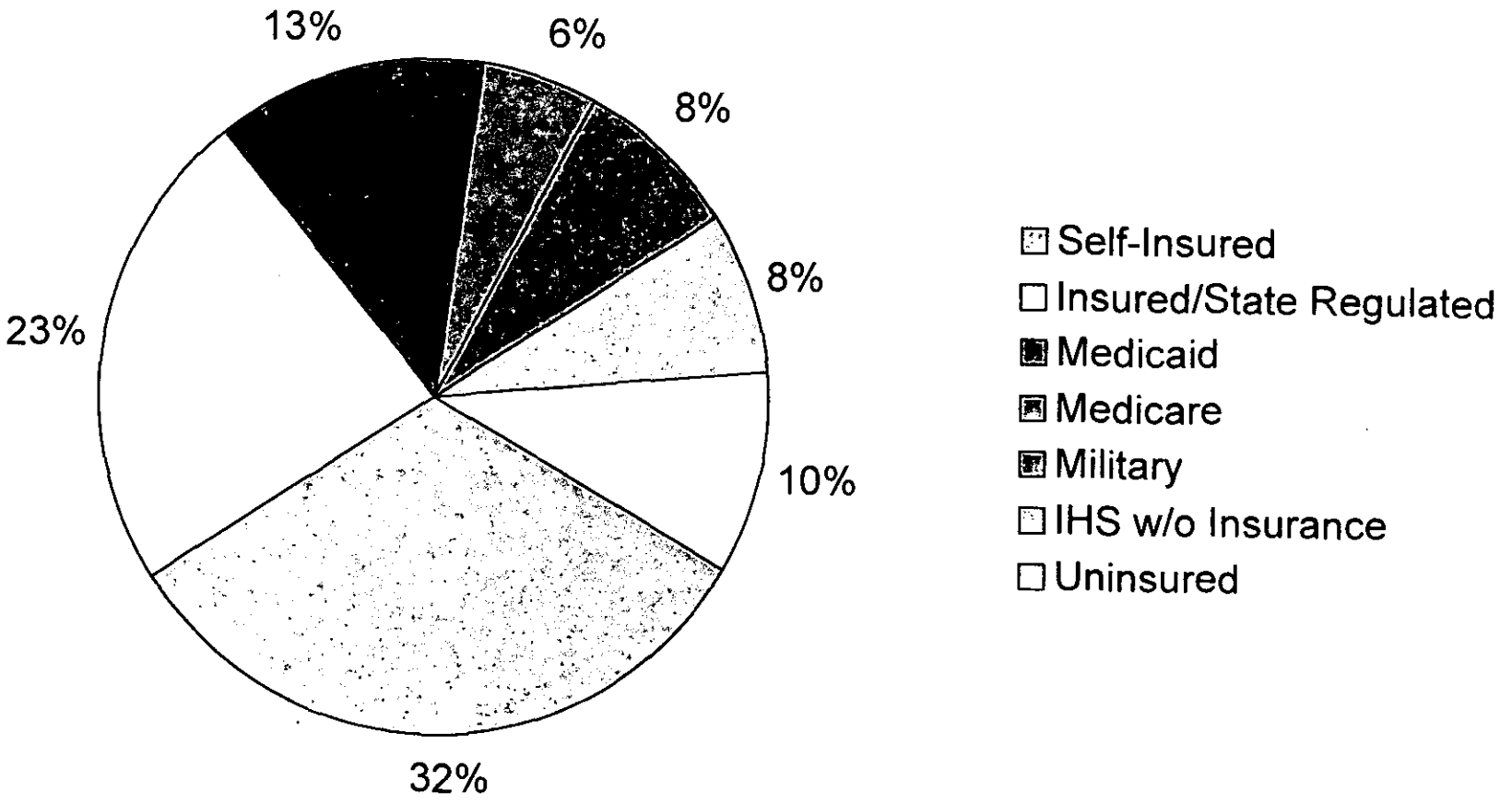
2. Regarding out of state coverage. The answer to whether insurance companies would have to cover services out of state, if those services were not available in Alaska is, yes--just like they cover those services not available here in Alaska for any number of other health related issues. However, the claims cap would still remain at $36,000 per year per child. Seeking services out of state would raise the cost for services, and that $36,000 would not go very far. In addition, except for children who require hospitalization care ABA is best delivered in the child's own environment which could include home or school. Behavioral treatment sought outside AK would likely be for the most severe cases including aggression and self-injury that could not be managed in facilities in the state. Moreover, it is unlikely that these more costly forms of treatment would be sought out of state, due to the nature of such treatment. While ABA professionals may have to come into the state from outside for

the initial treatment plan prescription, the 1 to 1 services are customarily given by someone in the child's immediate community. The treatment is then monitored by the ABA professional; a process that could be done utilizing telemedicine.

3. Regarding a sustainable market for ASD service providers. There was a question posed as to whether the percentage of Alaskans covered by this legislation would be enough to sustain the industry of autism service providers. For this question I think it is important to refer to the pie chart provided by Linda Hall at the Division of Insurance. This chart identifies the types of benefits by percentage that Alaskans draw from. The report that contained this breakdown of Alaska's population is from 2003 however the division has adjusted the numbers for the 2008 population. I will discuss each section beginning with the self-insured at the top of the key.

    - Self-insured plans are not currently subject to state mandates. They are protected, as was stated in the committee, by Federal ERISA preemption. There is a Federal ERISA mandate that has been filed just this Thursday that would make this 32% of Alaskans subject as well, and allow those families to access services.
    - Insured/state regulated are the plans that are directly affected by HB 187. This 23% is very close to the 25.3% projected by the cost analysis done by Jim Bouder. His figure of 45.5% which he cited, was in reference to group-insured Alaskans. 45.5% of group-insured Alaskans fall under HB 187, which is about 25.3% of the total population of Alaska—not far off from the 23% cited by the Division of Insurance.
    - Medicaid in Alaska currently provides some treatment for ASDs. It is the primary method by which Alaskan families access these services, however limited the coverage might be. Many families, as we heard, are fully insured, but don't have coverage for the treatments their children need. These families resort to applying for Medicaid waivers to access these funds, but the waiting list can be years. Time that these kids don't have. In addition, insured families are adding stress to what is already an overburdened system.
    - Medicare would likely not be a significant contributor to, or drawer from any of these services.
    - Military families already have access to some ASD treatments including applied behavior analysis (ABA) as provided for in the Federal Governments TRICARE ECHO program for military families who have children with disabilities.
    - IHS or Indian Health Services is a benefits program for American Indians and Alaskan Natives. IHS draws funds to cover treatment, for those who qualify, from several different pots including Medicaid, and private health insurance. The issue of coverage for the treatment of ASD has not come up with IHS, however, due to the fact that they currently draw from places like Medicaid and private insurance to cover other services, it is likely they would do the same for services requested to treat ASDs.
    - Uninsured is the category that unfortunately we have no bearing on.

Health Coverage of Alaska Population



What is ABA?

ABA is a science devoted to the understanding and improvement of human behavior, and has been used effectively as a treatment for the symptoms of Autism for more than 20 years. ABA focuses on shaping behavior systematically, often in a highly structured environment. Every skill a child with autism does not demonstrate - from relatively simple responses like looking at others to more complex acts like spontaneous communication and social interaction - is broken down into small steps. Successful completion of each step is rewarded to encourage its mastery and data is carefully taken and evaluated to ensure the fastest rate of skill acquisition. Problematic behavior, such as tantrums, self-injury, and withdrawal, are analyzed to determine what functions they serve and plans are developed to replace the challenging behavior with more functional, contextually appropriate behavior. By tailoring reinforcement to each child, and by teaching replacement skills, many problem behaviors can be reduced or eliminated and many new skills gained.

*The Vista School website (www.thevistaschool.org)

NFIB
The Voice of Small Business®

Alaska

March 16, 2009

The Honorable Pete Petersen
Alaska House of Representatives
State Capitol Building
Juneau, Alaska 99801-1182

RE: House Bill 187

Dear Representative Petersen,

On behalf of the National Federation of Independent Business/Alaska, I wish to express our opposition to House Bill 187. The National Federation of Independent Business is the largest small-business advocacy group in Alaska.

Health-care costs have been the No. 1 issue facing small-business owners since 1986, and those concerns are growing, according to NFIB's members. As health-care costs go through the roof, small-business owners have very few choices when selecting insurance coverage for their employees. The tipping point is here, and small businesses are begging for solutions to rising health-care costs, lack of access and other issues.

For many small employers in Alaska insurance premiums for small groups or single coverage have increased by more than 82 percent since 2000, a jaw-dropping statistic. This is completely unsustainable over the long-term. Much of the increase is driven by the additions to coverage by state mandates

Unfortunately HB 187 mandates coverage for autism spectrum disorders that may not fit employee's needs but for which small employers providing health insurance bear the cost. Increased mandates force employers to consider whether they can afford to continue coverage or are forced by increased prices to eliminate health

National Federation of Independent Business — ALASKA
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insurance for their employees. Mandates prevent small employers from providing affordable insurance programs tailored to its specific work force.

HB 187 is discriminatory against small employers as the mandate applies to those who provide coverage regulated by state insurance statutes, but not programs offered by the state and other governmental entities, unions, or large employers who typically offer ERISA programs. Thus it creates a less fair business environment for small employers.

Sincerely yours,

Dennis L. DeWitt
Alaska State Lobbyist

cc: Health and Social Services Committee

Alaska State Legislature

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Representative Pete Petersen
District 19

Sponsor Statement

HB 187
INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS

Autism is a devastating disorder affecting at least 1 in 150 children. Despite being treatable, many children diagnosed with an Autism Spectrum Disorder (ASD) never receive the treatment they need. Families go bankrupt, mortgaging their future, trying to provide their children with the treatment to ameliorate their condition; paying down their savings, retirement funds, and college savings plans for their other children because ASDs are not covered by insurance plans. In fact, most insurance plans explicitly exclude the treatment of ASDs, even when the service is otherwise covered by the health plan.

HB 187 would require insurance coverage for autism spectrum disorders, including the behavior therapies that after 30 years of study have shown to be the only effective treatment of these disorders. Treatment has been shown to improve, sometimes significantly, the symptoms of ASD and in some cases even eliminate the need for special education services for a child with ASD. The cost savings in special education alone, during the school years, amounts to approximately $208,500 per capita. This number rises to over $1.08 million over the autistic person's lifespan.

As well, the incremental societal cost of not treating autism has been estimated by Michael Ganz, a Harvard economist to be approximately $3.2 million per capita.

The cost to policy holders to implement such coverage is minimal; estimated at less than a 1% increase in their premiums, or $3.60 per member per month. That's less than the cost of a latte, per month to allow coverage for ASDs.

Furthermore, it has been stated by President Obama, that coverage of treatment, and other types of funding for ASDs would be a priority of his administration. It is likely that we will see a Federal law mandating the coverage of ASDs. This legislation allows Alaska to start this process on our own terms, and gives the state the needed time to build capacity within our state to meet the

demands created HB 187. Establishing this legislation in Alaska before a possible Federal mandate, would bring well paying jobs to the state, and bring those interested in this area of the health field to Alaska as well. The Governor has already included funding in her budget for programs at the University level to help establish a greater field of masters level autism service providers that would help to meet the need, should HB 187 be passed.

Coverage of ASDs by insurers would not only provide a needed service to those families suffering directly from the affects of a child with autism, but saves the state, and taxpayers exponentially over the lifespan of those diagnosed with autism. Though there is no cure for ASDs, this legislation would help significantly to treat those suffering from these disorders. In addition, a state that covers ASDs treatment will be desirable to those in the field and will bring jobs, and professionals in the field to Alaska. Prompt passage of this legislation would allow the state to reap the health and economic benefits that would result from being among the first few states to cover ASDs.

Therefore, I respectfully ask for your careful consideration and support of HB 187.

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Representative Pete Petersen
District 19

Sectional Analysis HB 187
Insurance Coverage: Autism Spectrum Disorders

Sec. 1: Amends current insurance statute (AS 21.42) to include coverage for autism spectrum disorders.

- Must cover treatment of the disorders as prescribed by a licensed physician or psychologist.
- The treatment will be provided by an autism service provider.
- The treatment will be outlined in a treatment plan (prescribed by the physician or psychologist) following a comprehensive evaluation
- Treatment includes: medically necessary pharmacy care, psychiatric care, psychological care, rehabilitative care, and therapeutic care

Coverage includes those under the age of 21 years, and there is a maximum yearly benefit of $36,000, adjusted annually for inflation.

Sec. 2: Regarding applicability: applies to policies issued on or after January 1, 2010.

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Representative Pete Petersen
District 19

Departments Affected by HB 187

- Health & Social Services
- Commerce, Community and Economic Development: Division of Insurance

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Representative Pete Petersen
District 19

Table of Contents: Background Information for HB 187
Insurance Coverage: Autism Spectrum Disorders

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(717) 808-9910
jbouder@ptd.net

March 9, 2009

The Honorable Pete Petersen
Alaska State Capitol
Juneau, AK 99801

VIA FIRST CLASS MAIL

RE: Cost Analysis – Alaska House Bill 187 pertaining to Insurance Coverage for Autism Diagnosis and Treatment

Dear Representative Petersen:

I thank you for the opportunity to complete an analysis of the likely effect of insuring the treatment of autism on commercial insurance rates in the State of Alaska. I am pleased to provide you with this information to assist you and your colleagues in making an informed public policy decision with regard to this proposed legislation. As you are aware, autism is a serious developmental disability that affects approximately 1 in 150 children across the United States. The cause is uncertain, but a significant research base indicates that the most debilitating symptoms of autism can be remediated using intensive services based on the principles of Applied Behavior Analysis ("ABA"). If enacted, House Bill 187 would require insurance policies to provide coverage for the diagnosis and treatment of autism spectrum disorder ("autism" or "ASD"), including coverage for behavioral therapy.

Based on my review of the available data and literature, I estimate that the likely effect on commercial insurance rates in Alaska will be approximately 0.92% or $3.60 per member per month ("pmpm"). This estimate is consistent with my findings in other states and with the actuarial findings pertaining to similar legislation recently enacted or pending in Pennsylvania, Arizona, Georgia, Louisiana, Maryland, and Virginia. A detailed narrative describing my findings is set forth below.

Also, as requested, I assessed the likely claims increase that could be expected should Alaska extend this coverage to children of Alaska state employees. I found that the State of Alaska could expect approximately $543,000 in additional claims, which translates into approximately $3.02 per government employee per month.

Again, I thank you for this opportunity. Should you require copies of any studies cited, please do not hesitate to contact me. I hope you find this information helpful. If you have any questions or would like additional information, please feel free to contact me at (717) 808-9910 or by email at jbouder@ptd.net.

With Kind Regards,

James N. Bouder, MPA

Cc: The Honorable Nancy Dahlstrom

Cost Analysis – Alaska Autism Insurance Coverage

James N. Bouder, MPA

- **Autism** is a devastating disorder affecting at least 1 in 150 children, with approximately 1 in 500 requiring significant clinical treatment;
- **Autism is treatable** – with treatment, 30 years of research has shown us that many children overcome the severe symptoms of their disorder, but most private insurance policies specifically exclude coverage for treating autism, even when the service is otherwise covered by the health plan;
- The coverage of autism treatment in Alaska will enable many children to access services they need;
- The maximum likely cost of such coverage to the private insurance ratepayer is approximately **0.92%** or **$3.60** per policyholder per month;
- If the State of Alaska chooses to extend this coverage to dependents of state employees, this will likely result in an increase in claims costs of approximately **$3.02** per government employee per month;
- Other States Confirm this Finding: **The Pennsylvania Insurance Department** found that similar legislation will result in a rate impact of **at or less than 1%**; in **Arizona**, an independent actuary forecasted a cost impact of **0.501%; in Louisiana**, the consulting actuaries for the **Louisiana Office of Group Benefits** forecast a cost impact of **less than 0.50%**; in Oklahoma, the **Oklahoma State Education Employees Group Insurance Board** estimated a cost impact between **one-third of 1% and 1%**; and in the most comprehensive actuarial report on autism coverage to date, **Mercer** reported to the **Maryland Health Care Commission** an estimated premium increase of approximately **0.85%**
- With treatment, Alaska can save approximately **$208,500 per capita** in avoided special education costs during the school years alone and **$1.08 million per capita** during the autistic person's lifespan;
- The incremental societal cost of not treating autism has been estimated by Michael Ganz, a Harvard economist, to be **approximately $3.2 million per capita.**

Section 1. Private Insurance Premium Rate Impact

The likely, maximum premium impact of autism coverage will be less than 1%, amounting to approximately $3.60 per member per month (pmpm) for single policy rates and $9.49 pmpm for family rates.

Number of Eligible Beneficiaries of Autism Coverage in Alaska

My first task in estimating the likely cost of extending treatment to Alaskans with autism is to determine how many people in Alaska are eligible for and likely to utilize the benefits mandated by the bill.

According to estimates provided by the U.S. Census Bureau, there are approximately 190,947 persons living in Alaska between the ages of 2 and 20 who could be eligible for the benefits under the House Bill 187.[1] It is also estimated that approximately 66.6% of children with special health care needs living in Alaska under the age of 18 have private health insurance and approximately 55.9% of such children living in Alaska are insured under group health insurance plans.[2] The number of persons living in Alaska between the ages of 2 and 20 who are insured under group plans, therefore, is approximately 106,664.

Based on information published by the Medical Expenditures Panel Survey ("MEPS"), 54.6% of private-sector enrollees working in Alaska are enrolled in self-insured plans (MEPS 2005 Report, p. 1).[3] The potential pool of beneficiaries between age 2 and 20, therefore, after accounting for ERISA preemption and the uninsured, is approximately 48,425.

Treated Prevalence Rate of Children with Autism in Alaska

Actuarial analyses and insurer criticisms of bills similar to the bill contemplated for Alaska often utilize the CDC's statistic on community prevalence in pricing such bills, notwithstanding actual treated prevalence rates within existing systems or present in the research record. Recently, the Commonwealth of Pennsylvania Insurance Department utilized the 1 in 150 statistic in deriving their estimated rate impact of approximately 1.1%, with regard to very similar legislation introduced in that state.

While the latter example reports an estimated rate impact that is very low, utilizing a 1 in 150 prevalence rate demonstrates a lack of understanding of the range of symptom severity exhibited by people with ASD, and thus overstates the

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[1] U.S. Bureau of the Census, "Table DP-1. Profile of General Demographic Characteristics: 2006 Population Estimates."
[2] Health and Disability Working Group. "The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs." Boston University School of Public Health, Boston, MA (2007), p. 43.
[3] See The Kaiser Family Foundation State Health Facts Website: <http://www.statehealthfacts.org/profileind.jsp?ind=236&cat=4&rgn=50>

number of persons with autism likely to require and seek significant clinical treatment.

Several examinations of health care utilization and expenditures associated with treating autism have been published in recent years that call into question the appropriateness of using epidemiological prevalence data to forecast the magnitude of health care utilization resulting from passage of House Bill 187. In 2007, Douglas L. Leslie and Andres Martin compiled data from the Thomson/Medstat MarketScan database, "which compiles claims information from private health insurance plans of large employers ... across the United States ... [with] covered individuals includ[ing] employees, their dependents, and early retirees" (Leslie, p. 351).[4] Leslie et al. note that the *treated prevalence* of autism in the claims database was 19.2 per 10,000 (i.e., 1 in 520.83) (p. 352). Independently, Gregoral S. Liptak et al. obtained data from three national surveys and identified a treated prevalence of autism of 21 in 10,000 (i.e., 1 in 476.19) (Liptak et al., p. 872).[5] Similarly, in a previous article, David S. Mandell et al. reported a treated prevalence rate of youth diagnosed with autism in Allegheny County, PA of 0.2% (i.e., 1 in 500) (Mandell et al., p. 477).[6] More recently, Shimabukuro et al.'s examination of MarketScan® data found a treated prevalence rate of 1.9 per 1,000 (or approximately 1 in 526) (p. 549).[7] Most recently, the nationally recognized actuarial firm, Mercer, completed an evaluation of Maryland's proposed autism insurance mandate, which is substantively similar to House Bill 187, but has a $50,000 annual cost cap.[8] Mercer included both treated prevalence rates and cost per treated child estimates broken down by age bands to establish low, mid, and high estimates of premium impact, resulting in a mid-range estimate of 0.85%.

These findings are consistent with other medical conditions, which present with a treated prevalence rate much lower than the community prevalence rate. The consistency of these data suggest that the treated prevalence of autism is a better measure to apply to premium impact analyses because, unlike community prevalence data, which simply report the number of persons satisfying the diagnostic criteria for Autism Spectrum Disorders, treated prevalence accounts for those persons with autism actually seeking and consuming health care services related to their disorder.

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[4] Leslie, Douglas L. and Andres Margin (2007) "Health Care Expenditures Associated with Autism Spectrum Disorders." *Archives of Pediatric and Adolescent Medicine*. Vol. 161, Apr. 2007, pp. 350-355.

[5] Liptak, Gregory S., Tami Stuart, and Peggy Auinger (2006). "Health Care Utilization and Expenditures for Children with Autism: Data from U.S. National Samples." *Journal of Autism and Developmental Disorders*. Vol. 36, pp. 871-879.

[6] Mandell, David S., Jun Cao, Richard Ittenbach, and Jennifer Pinto-Martin (2006). "Medicaid Expenditures for Children with Autistic Spectrum Disorders: 1994 to 1999." *Journal of Autism and Developmental Disorders*, Vol. 36, No. 4, pp. 475-485.

[7] Shimabukuro, Tom T., Scott D. Grosse, and Catherine Rice (2008). "Medical Expenditures for Children with an Autism Spectrum Disorder in a Privately Insured Population" *Journal of Autism and Developmental Disorders*, Vol. 38, No. 4, pp. 546-552.

[8] Mercer/Oliver Wyman (2008) *Annual Mandated Health Insurance Services Evaluation, Coverage for Autism Spectrum Disorder*, pp. 3-33.

Assumptions

While much of the data included in this analysis was derived from primary sources, some assumptions were necessary due to my inability to independently confirm certain data elements from primary sources or required statistical calculations to forecast future sums. These assumptions are set forth below.

- Using data published by the Alaska Division of Insurance, I estimate a premium base of $346.0 million in 2009.[9]
- Based on claims history of insurers in Alaska, I assumed an 85% Medical Loss Ratio, which is considered an industry standard. The Medical Loss Ratio was used to convert cost effect to revenue requirement.
- 45.4% of health insurance plans offered by private firms in Alaska that are not subject to ERISA preemption remains an accurate figure, as reported by the MEPS for 2005 (cited above).
- In order to produce a conservative estimate, 100% of likely, increased costs attributable to services provided under House Bill 187 will be passed on to private insurance ratepayers participating in eligible plans (i.e., private insurers will choose not absorb any additional costs).
- Calculations assume an adequate provider network is in place on the legislation's effective date to meet the demand for services.

Cost Analysis

The next step in my cost analysis is to establish the likely cost of covering these services and their potential rate effect. In the interest of providing a range of rate impact resulting from the coverage of services contemplated for Alaska autism coverage, I have provided calculations based on a number of variables. I attempted to do so using credible data available to the general public. For your convenience, attached is a spreadsheet detailing the likely range of impact the covered services will have on private insurance ratepayers in Alaska (**See Exhibit "A" attached).**

The most likely scenarios are derived in part from peer-reviewed research evaluating real-life data concerning the treated prevalence of autism and average expenditures per treated person with autism and prevalence rates assumed by Mercer in their actuarial estimate of increased costs associated with a similar bill pending in Maryland (cited above). Persons living with autism present with varied symptoms requiring differing levels of attention based on the severity of symptoms. The more severe symptoms requiring intensive behavioral health and other clinical interventions are not necessarily present in every person diagnosed with an Autistic Spectrum Disorder, especially when those less severely affected reach the school age. This is evidenced by the treated prevalence rates reported in Mandell et al (2006), Leslie et al. (2007), Liptak et al. (2007), and Shimabukuru et al. (2008) noted and cited above, which consistently report a treated prevalence rate of

[9] Report of the Alaska Division of Insurance (2008)., retrieved from <http://www.commerce.state.ak.us/insurance/>

approximately 1 in 500 (or 0.20%). One should expect, therefore, that actual utilization rates will track more closely along treated prevalence rates noted in the abovementioned reviews of actual health care utilization data than community prevalence rates reported from epidemiological studies such as the recent report of the CDC.

While I was unable to locate any Alaska-specific data on average treatment costs, the findings of the Mercer actuaries in Maryland are instructive. Relying on the research of Harvard economist Michael Ganz, Mercer recognized that the heaviest utilization of services would fall in the preschool years, and drop considerably as the child reaches school age and approaches adulthood. Mercer assumed a cost per treated child between the ages of 18 and 20 to be from $2,525 to $3,500, as the biggest cost drivers for adult services are vocational support and supported housing (i.e., non-medical expenses).[10]

Three possible expenditure scenarios are included in my cost analysis, establishing Low, Mid, and High Estimates, using the treated prevalence rates and cost per treated child estimates similar to those Mercer relied upon in Maryland. Overall, the treated prevalence rates for Low, Mid, and High estimates were 1:400, 1:325, and 1:250, respectively.

Table 1 below illustrates the likely utilization rates and cost per treated person by age band. Based on these assumptions, the percentage increase in premium costs for Alaska falls in the 0.57% to 1.49% range, with a mid-range estimate of 0.92% (see attached **Exhibit "A"** attached for more detail).

[10] Ganz, Michael L. (2007). "The Lifetime Incremental Societal Costs of Autism." *Archives of Pediatric and Adolescent Medicine*. Vol. 161, Apr. 2007, pp. 343-349.

TABLE 1: Treated Prevalence and Cost per Treated Person Assumptions.

Low Estimate		
Age Band	ASD Treated Prevalence for Age Band	Cost per Treated Person
2 to 4	0.25%	$30,000
5 to 9	0.35%	$19,660
10 to 14	0.25%	$6,758
15 to 19	0.20%	$2,525
20 years	0.20%	$2,525
	Premium Increase % of Premium	**0.57%**

Mid Estimate		
Age Band	ASD Treated Prevalence for Age Band	Cost per Treated Person
2 to 4	0.30%	$36,000
5 to 9	0.45%	$26,200
10 to 14	0.30%	$9,000
15 to 19	0.25%	$3,500
20 years	0.20%	$3,500
	Premium Increase % of Premium	**0.92%**

High Estimate		
Age Band	ASD Treated Prevalence for Age Band	Cost per Treated Person
2 to 4	0.45%	$36,000
5 to 9	0.67%	$30,500
10 to 14	0.35%	$12,000
15 to 19	0.30%	$3,500
20 years	0.25%	$3,500
	Premium Increase % of Premium	**1.49%**

Based on statistical data published by the Kaiser Family Foundation reporting average annual single and family policy rates in 2008, single policy rates will likely experience an increase no greater $3.60 per member per month (pmpm) and $9.49 pmpm for family rates as a result of implementing coverage provided by the proposed legislation.[11]

[11] As cited above, see the *Kaiser Family Foundation and Health Research and Educational Trust* publication, "Employer Health Benefits – 2008 Annual Survey," which reports that the average annual total premium cost for single coverage in the Western United States is $4,683 and $12,351 for family coverage.

Section 2. State Employee Cost Impact

The likely, cost impact of autism coverage for dependents of state workers will be approximately $554,000, which is less than 1% over current claims experience.

Not all state employees in Alaska receive health insurance coverage through the state's health care plan (Select Benefits), but rather through self-funded union trust plans ("Union Plans") that are primarily funded through state contributions. While I was not able to obtain copies of financial statements for the various Union Plans, I was able to obtain claims and census data for the Select Benefits plan and determine the total number of full-time government employees from the 2008 Comprehensive Annual Financial Report to be approximately 15,000.[12] Together, this information provided me with sufficient data to estimate the total added claims that the State of Alaska could anticipate if it decided extend coverage mandated by House Bill 187 to dependents of state employees.

According to the State of Alaska, Department of Administration, Division of Retirement and Benefits, approximately 40% of Alaska's +/- 15,000 state employees are insured under the Select Benefits plan, which includes approximately 6,000 employees. The Division of Retirement and Benefits also provided me with the numbers of insured children by age band between the ages of 2 and 20 as follows:

TABLE 2: # of Children by Age Band (Aged 2 to 20) Participating in Select Benefits[13]

Insured Dependents by Age Band	%	# Children
2 to 4 years	9.68%	428
5 to 9 years	20.90%	924
10 to 14 years	27.65%	1,222
15 to 19 years	35.34%	1,562
20 years	6.43%	284
TOTAL		**4,420**

Based on data provided by the Division of Retirement and Benefits, I was able to determine that the average household of employees participating in the State of Alaska's Select Benefits plan has 0.74 children (derived from the estimated 6,000 employees participating in the plan and 4,420 dependents between the ages of 2 and 20 who are also covered). Additionally, according to the Division of Retirement and Benefits, total claims paid by the Select Benefits plans in 2008 were $62.4 million.

This data provides a sufficient sample to estimate the likely number of dependents between the ages of 2 and 20 who are insured by either the Select Benefits or Union Plans as follows:

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[12] 2008 Alaska Comprehensive Annual Financial Report, p. 252.
[13] Source: Personal Correspondence with the Division of Retirement and Benefits.

TABLE 3: Estimated # Children Insured Under Both Select Benefits and Union Plans

Insured Dependents by Age Band	%	# Children
2 to 4 years	9.68%	1,070
5 to 9 years	20.90%	2,310
10 to 14 years	27.65%	3,055
15 to 19 years	35.34%	3,905
20 years	6.43%	710
TOTAL		**11,050**

Additionally, knowing that 40% of state employees and their dependents are enrolled in the Select Benefits plan, it is reasonable to assume that approximately 40% of claims funded by state contributions are paid for claims incurred by enrollees in the Select Benefits plan. Therefore, I estimate total claims paid for both Select Benefits and Union Plans in 2008 were approximately $155.9 million.

With this data and prevalence and per capita expenditure assumptions used to estimate the rate effect of House Bill 187 in **Section 1** above (See **Table 1**), I estimate the total increased claims for all state employees in **Table 4** below (see also **Exhibit "B"** attached for more detail). This fiscal impact translates into approximately $1.86 to $4.86 per government employee per month, with a mid-range estimate of $3.02 per government employee per month.

TABLE 4: Total Estimated Claims by Age Band

	Low Estimate	
Age Band	ASD Treated Prevalence for Age Band	Cost per Treated Person
2 to 4	0.25%	$30,000
5 to 9	0.35%	$19,660
10 to 14	0.25%	$6,758
15 to 19	0.20%	$2,525
20 years	0.20%	$2,525
	Total Increased Claims	**$334,990**
	Mid Estimate	
Age Band	ASD Treated Prevalence for Age Band	Cost per Treated Person
2 to 4	0.30%	$36,000
5 to 9	0.45%	$26,200
10 to 14	0.30%	$9,000
15 to 19	0.25%	$3,500
20 years	0.20%	$3,500
	Total Increased Claims	**$543,384**

	High Estimate	
Age Band	ASD Treated Prevalence for Age Band	Cost per Treated Person
2 to 4	0.45%	$36,000
5 to 9	0.67%	$30,500
10 to 14	0.35%	$12,000
15 to 19	0.30%	$3,500
20 years	0.25%	$3,500
	Total Increased Claims	**$875,452**

Section 3. Long Term Considerations

The long-term savings attributable to effectively treating children with autism is significant, with cost-benefit peer review studies estimating a per capita avoided special education cost savings of $208,500 and over $1 million in total avoided human service cost savings per person over the lifespan.

In April 2007, Michael L. Ganz published an article in *Archives of Pediatric and Adolescent Medicine* entitled "The Lifetime Distribution of the Incremental Societal Costs of Autism," which sets forth his findings in describing "the age-specific and lifetime incremental societal costs of autism in the United States" (p. 343).[14] Ganz determined that the "lifetime per capita incremental societal cost of autism is $3.2 million" and that "[l]ost productivity and adult care are the largest components of costs" (p. 343). Based on the extant literature demonstrating the efficacy of behavioral interventions, we believe that the "lifetime per capita incremental societal cost of autism" can be mitigated substantially by services included in House Bill 187. In short, autism left untreated will result in substantial financial consequences for both public agencies and families with loved ones diagnosed with autism.

Regarding the cost-benefit of intensive ABA services, two analyses, one completed in Pennsylvania and the other in Texas, examined the future cost savings to government units resulting from investment in intensive behavioral interventions for people with autism.

The first such work, completed by John W. Jacobson, James A. Mulick, and Gina Green in 1998, notes that an abundance of research demonstrates the efficacy of early, intensive behaviorally-based interventions to enable substantial numbers of children with autism to "attain intellectual, academic, communication, social, and daily living skills within the normal range" (p. 201).[15] Using representative costs

[14] Ganz, Michael L. (2007). "The Lifetime Incremental Societal Costs of Autism." *Archives of Pediatric and Adolescent Medicine.* Vol. 161, Apr. 2007, pp. 343-349.
[15] Jacobson, John W., James A. Mulick, and Gina Green (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.

from Pennsylvania, including costs for special educational and adult special needs services, they found that, "At varying rates of effectiveness and in constant dollars, this model estimates that cost savings range from $187,000 to $203,000 per child for ages 3-22 years, and from $656,000 to $1,082,000 per child for ages 3-55 years (Jacobson, et al., p. 201).

More recently, Gregory S. Chasson, Gerald E. Harris, and Wendy J. Neely compared the costs of early intensive behavioral intervention ("EIBI") and special education for children with autism (cited above). Alluding to recent comparison studies that strongly suggest that "eclectic" special education programs are materially ineffective for many children with autism, the authors note that the human cost of failing to provide EIBI services is considerable. Consistent with Jacobson's et al.'s findings, Chasson et al. found that "the state of Texas would save $208,500 per child across eighteen years of education with EIBI" (p. 401). Based on their estimate that the average annual cost associated with EIBI is approximately $22,500, and the average duration of service is three years (see p. 402), the return on the health care investment would be 308% in avoided special education costs to the local and state taxpayer during the education years alone. It is important to note that, without treatment, persons with autism will grow to become adults dependent on publicly-funded services for their lifespan. For another third of those receiving such services early, the intensity of publicly-funded services needed in adulthood would be considerably reduced. For just less than half of those children receiving intensive EIBI services early, opportunities to be gainfully employed contributors to the tax base will only increase the return on that initial three-year investment. As Chasson et al. put it, "By implementing EIBI with all children with autism, as a way to prevent the need for special education, the investment not only produces a sizeable savings after 18 years, but it maximizes the likelihood that most of these children will return a profit long after maturation" (p. 410).

Chasson et al. posit that, "For this reason, it would behoove policy makers to reconsider the role of educational services with children with developmental disabilities. Indeed, it may mean a minimization of the education system's role in providing services and a maximization of population-specific treatment implementation by mental health practitioners. Following from this, special education would then have expanded resources to serve children who failed to mainstream into typical education despite implementation of appropriate interventions" (p. 411). "The bottom line," they write, "is that a simple change in policy could drastically improve functioning and quality of life for thousands of children with autism in Texas. As a bonus, the taxpayers could potentially save over $2 billion across 18 years (p. 412).

Applying similar assumptions to the population served by the proposed legislation indicates that Alaska's taxpayers could save millions in avoided special education costs during the school years alone and hundreds of millions in avoided human services costs over the autistic person's lifespan.

Section 4. Other State Cost Estimates Associated with Similar Legislation

While a number of factors unique to individual states can influence the cost effect of legislation that is similar to House Bill 187, a review of cost estimate findings in states where similar legislation has been enacted, offered by proponents, opponents, and neutral sources, can reveal a useful trend to lawmakers in Alaska. During the past two years, several states have enacted legislation similar to House Bill 187, including South Carolina, Arizona, Florida, Louisiana, and Pennsylvania. Additionally, numerous other states with sophisticated mandate review processes have examined the likely cost effect resulting from mandating similar coverage. These states include Maryland, Virginia, and Oklahoma.

Due to differences in coverage criteria (e.g., ages of those covered and annual and lifetime limits), cost estimates in other states would not be directly comparable to Alaska's House Bill 187. The cost analyses completed for Pennsylvania, Maryland, and Virginia would be most instructive due to similar age limitations, amount of annual benefit limitation, and the lack of a lifetime limit, although South Carolina's costs would also be similar to Alaska's due to the relatively low per capita expenditure expected for children with autism age 16 and over. A consistent theme emerging from proponents, opponents, and independent sources, including nationally trusted actuarial firms such as Mercer, Aon, and Oliver Wyman, is that the likely cost of insuring the treatment of children with autism is relatively low, and is consistently reported to be at or below 1%. (See **TABLE 5** and **TABLE 6** below).

TABLE 5: Rate and/or Cost Effect of Similar Mandates Enacted in Other States

State/Party	Eligibility/ Disposition	Annual Cap	Lifetime Limit	Estimated % Premium Increase
Arizona	**Birth to 16 yrs**	**$50,000 to age 9, $25,000 ages 10-16**	**None**	
Key HealthCare Concepts, LLC[16]	Independent			0.33%-0.69%
Florida	**< 18 yrs or 18 yrs & older if in HS & have a DD dx by age 8**	**$36,000**	**$200,000**	
Bouder, James N.[17]	Proponent			0.27%-0.56%
Louisiana	**< 17 yrs**	**$36,000**	**$144,000**	
Bouder, James N.[18]	Proponent			0.27%-0.56%
Louisiana Office of Group Benefits[19]	Independent			0.29%
Pennsylvania	**< 21 yrs**	**$36,000**	**None**	
Abt Associates[20]	Independent			+/- 1%
Blue Cross of Northeastern PA[21]	Opponent			+/- 0.50%
Bouder, JN et al.[22]	Proponent			+/- 1%
Highmark Blue Shield[23]	Opponent			+/- 0.50%
PA Department of Insurance[24]	Independent			+/- 1%
South Carolina	**< 16 yrs & Dx w/ ASD at age 8 or younger**	**$50,000**	**None**	
Governor Sanford (Veto Letter)	Opponent			+/- 1%

[16] Key HealthCare Concepts, LLC (2008), *Actuarial Report Regarding Financial Impacts* [Regarding private insurance coverage for autism treatment], p. 4.
[17] Bouder, JN for Autism Speaks (2008) [Financial Impact Section Only], *Report Under § 624.215(2), Fla. Stat. (2007), Assessing the Social and Financial Impacts of House Bill 1291 and Senate Bill 2654*, retrieved from <http://www.autismvotes.org>
[18] Bouder, JN (2008), *Cost Analysis – HB 958 of 2008 (As Amended 4/30/08)* (2008), pp. 2-7, retrieved from <http://www.autismvotes.org>
[19] *Ibid*, pp. 7-9 and Exhibit "C-2"
[20] Abt Associates, Inc. (2008), *Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150*, Prepared for the Pennsylvania Health Care Cost Containment Council, retrieved from <http://www.phc4.org>
[21] See Mercer (2008), *Annual Mandated Health Insurance Services Evaluation, Section 1, Coverage for Autism Spectrum Disorders*, prepared for the Maryland Health Care Commission, p. 23, evaluating Highmark Blue Shield's cost estimate submitted to the Pennsylvania Health Care Cost Containment Council.
[22] Bouder, JN, Stuart Spielman, David S. Mandell (2009). *Brief Report: Quantifying the Impact of Autism Coverage on Private Insurance Premiums,* Journal of Autism and Developmental Disorders.
[23] See Mercer (2008), *Annual Mandated Health Insurance Services Evaluation, Section 1, Coverage for Autism Spectrum Disorders*, prepared for the Maryland Health Care Commission, p. 23, evaluating Blue Cross of Northeastern Pennsylvania's cost estimate submitted to the Pennsylvania Health Care Cost Containment Council.
[24] Commonwealth of Pennsylvania Insurance Department (2008), regarding the effect of Pennsylvania House Bill 1150 on commercial insurance rates, p. 8.

TABLE 6: Rate and/or Cost Effect of Similar Mandates Proposed in Other States

State/Party	Eligibility/ Disposition	Annual Cap	Lifetime Limit	Estimated % Premium Increase
Georgia	**Not Specified**	**$55,000**	**None**	
Oliver Wyman[25]	Proponent			0.63%
Maryland	**< 21 yrs**	**$50,000**	**None**	
Mercer/Oliver Wyman[26]	Independent			0.52%-1.22%
New Jersey	**Not Specified**	**None**	**None**	
Mandated Benefits Advisory Comm.[27]	Independent			1%
Oklahoma	**< 21 yrs**	**$75,000**	**None**	
Aon (for OSEEGIB)[28]	Independent			0.34%-1.00%
Virginia	**< 21 yrs**	**$36,000**	**None**	
Oliver Wyman[29]	Proponent			0.60%
West Virginia	**< 24 yrs**	**$75,000**	**None**	
Bouder, James N.[30]	Proponent			0.82%
Public Employees Insurance Agency[31]	Independent			1.54%

[25] Oliver Wyman (2009), *Actuarial Cost Estimate: Georgia Senate Bill 161 – An Act Related to Insurance Coverage for Autism*, p. 13.
[26] Mercer (2008), *Annual Mandated Health Insurance Services Evaluation, Section 1, Coverage for Autism Spectrum Disorders*, prepared for the Maryland Health Care Commission, pp. 30-31.
[27] New Jersey Mandated Benefits Advisory Commission (2006), *Evaluation of the Impact of Autism Mandated Benefits contained in Assembly Bill A-999.*
[28] Aon (2009), *Memorandum Regarding the Cost Impact of Oklahoma SB 1 on the Office of State Education Employees Group Insurance Board's Health Plans.*
[29] Oliver Wyman (2009), *Actuarial Cost Estimate: Virginia House Bill 1588 – Coverage for the Diagnosis and Treatment of Autism Spectrum Disorder*, p. 12.
[30] Bouder, JN (2009), *Cost Analysis – House Bill 4091 Pertaining to Private Insurance Coverage for Autism Diagnosis and Treatment.*
[31] West Virginia Public Employee Insurance Agency (2008), *Fiscal Note Summary on Effect HB 4091 will have on Costs and Revenues of State Government.*

Conclusion

Based on my review of House Bill 187, Alaska's commercial premium and claims data and state employees' health benefits data, I believe it is reasonable to conclude that the likely cost impact of mandating coverage for the diagnosis and treatment of autism will be less than 1%, even after a sufficient provider network is established to meet the demands for services. Furthermore, given significant evidence concerning the efficacy of Applied Behavior Analysis in treating the varied symptoms of autism, Alaska can expect significant future savings in avoided special education and human services costs. Lastly, expected premium and cost impacts relating to the Alaska House Bill 187 are consistent with similar legislation enacted or pending in at least 10 other states.

Please note that my cost analysis assumes that a provider network capable of meeting the needs of all children with autism who require and seek treatment is prepared to deliver services during the first year of implementation of House Bill 187. As a practical matter, however, it takes time for providers to recruit, train, and deploy professionals, especially in markets that lack a pre-existing provider base like Florida and Pennsylvania, which the Behavior Analyst Certification Board ("BACB") reports have approximately 1,800 and 300 Board Certified Behavior Analysts ("BCBA"), respectively. By comparison, the BACB reports that the State of Alaska has two (2) BCBAs. The existence of alternative funding streams in the former two states encouraged the aggressive proliferation of Behavior Analysts, and the same can be expected in Alaska once a reliable funding stream is established. Therefore, it could be several years before Alaska experiences the full cost impact associated with House Bill 187.

It is also important to note that other factors may further reduce first year claims. House Bill 187 is currently written to require coverage for plans offered, issued for delivery, delivered, or renewed in Alaska on or after January 1, 2010. Assuming open enrollment trends in Alaska are similar to those in other states, approximately 80% of health plans renew on January 1. This could also translate into a lower claims experience during the first year of implementation.

Exhibit "A"

James N. Bouder, MPA

Forecasted Rate Impact of Alaska House Bill __

	Medical Loss Ratio 85%	$ Cost	% Cost
Low Estimate		1,987,483	0.57%
Mid Estimate		3,189,512	0.92%
High Estimate		5,147,242	1.49%

Total Alaska Premiums Collected (est. 2010)* 345,975,804

% of Population Covered by ERISA Plans *** 54.6%
% Population Covered by Non-ERISA Plans 45.4%

	Avg./Yr.	Avg./Mo.	PMPM $ Rate Impact (Low)	PMPM $ Rate Impact (Mid)	PMPM $ Rate Impact (High)	PMPY $ Rate Impact (Low)	PMPY $ Rate Impact (Mid)	PMPY $ Rate Impact (High)
Average Individual Policy $	4,683	390	$ 2.24	$ 3.60	$ 5.81	26.90	43.17	69.67
Average Family Policy $	12,351	1,029	$ 5.91	$ 9.49	$ 15.31	70.95	113.86	183.75

NOTE: Source of average annual premiums from Kaiser Family Foundation"Employer Health Benefits - 2008 Annual Survey

Population Estimate (2006) **	Total Population by Age Band	Total Insured Population by Age Band 55.9%	Total Full Insured Population by Age Band 45.4%	Age Band % of Population	ASD Treated Prevalence for Age Band Low	ASD Treated Prevalence for Age Band Mid	ASD Treated Prevalence for Age Band High	Cost per Treated Person Low	Cost per Treated Person Mid	Cost per Treated Person High	Total $ Cost Low	Total $ Cost Mid	Total $ Cost High
2 to 4 years	29,863	16,681	7,573	15.64%	0.25%	0.30%	0.45%	30,000	36,000	36,000	567,999	817,918	1,226,877
5 to 9 years	47,169	26,349	11,962	24.70%	0.35%	0.45%	0.67%	19,660	26,200	30,500	823,127	1,410,357	2,444,498
10 to 14 years	50,714	28,329	12,861	26.56%	0.25%	0.30%	0.35%	6,758	9,000	12,000	217,292	347,256	540,176
15 to 19 years	52,627	29,398	13,346	27.56%	0.20%	0.25%	0.30%	2,525	3,500	3,500	67,400	116,782	140,138
20 years	10,575	5,907	2,682	5.54%	0.20%	0.20%	0.25%	2,525	3,500	3,500	13,543	18,773	23,466
TOTAL UNDER 20	190,947	106,664	48,425	100.00%							1,689,361	2,711,085	4,375,156

	Low (1:400)	Mid (1:325)	High (1:250)
Average Treated Prevalence Assumption	0.25%	0.30%	0.40%
Average Per Capita Expenditure	12,294	15,640	17,100

Alaska % Insured

% Children in Alaska with Private Health Insurance (CYSHCN) ****	66.6%
% Children in Alaska with Individual Private Health Insurance	10.7%
% Children in Alaska with Group Private Health Insurance	55.9%

Sources

* Estimate derived from 2008 Report of the Alaska Division of Insurance retrieved from <http://www.commerce.state.ak.us/insurance/>
** United States Census Bureau <http://factfinder.census.gov/>
*** Medical Expenditure Panel Survey Report <http://www.meps.ahrq.gov/mepsweb/data_stats/summ_tables/insr/state/series_2/2005/tiib2b1.pdf>
**** Catalyst Center State-at-a-Glance Chartbook on Coverage and Financing for Children and Youth with Special Health Care Needs, p. 43

Exhibit "B"

James N. Bouder, MPA

State Worker Autism Coverage Claims Impact

Select Benefits

Category	# State Employees	Assumed # Children (State Employees) 0.74	Total Claims Paid (2008)	Total Operating Expenses	% Operating Expenses/Total Claims	Total Increase in Claims $	$ PMPM
State employees	6,000	4,420	62,360,104	4,143,000	6.6%		
Prevalence Rate							
Low (1:400)						133,996	$ 1.86
Mid (1:325)						217,354	$ 3.02
High (1:250)						350,181	$ 4.86

Select Benefits Data (1)

State Workers by Age Band	Age Band %	Estimated # Children by Age Band (State Employees)	ASD Treated Prevalence for Age Band Low	ASD Treated Prevalence for Age Band Mid	ASD Treated Prevalence for Age Band High	Cost per Treated Person Low	Cost per Treated Person Mid	Cost per Treated Person High	Total $ Cost Low	Total $ Cost Mid	Total $ Cost High
2 to 4 years	9.68%	428	0.25%	0.30%	0.45%	30,000	36,000	36,000	32,100	46,224	69,336
5 to 9 years	20.90%	924	0.35%	0.45%	0.67%	19,660	26,200	30,500	63,580	108,940	188,819
10 to 14 years	27.65%	1,222	0.25%	0.30%	0.35%	6,758	9,000	12,000	20,646	32,994	51,324
15 to 19 years	35.34%	1,562	0.20%	0.25%	0.30%	2,525	3,500	3,500	7,888	13,668	16,401
20 years	6.43%	284	0.20%	0.20%	0.25%	2,525	3,500	3,500	1,434	1,986	2,485
TOTAL UNDER 20		4,420							125,648	203,813	328,365

(4) Source: Personal correspondence with State of Alaska - Department of Administration, Division of Retirement and Benefits

% of State Workers Insured by Select Benefits **40.00%**

Total State Worker Assumptions

Category	# State Employees (2)	Assumed # Children (State Employees) 0.74	Total Claims Paid (2008)	Total Operating Expenses (3)	% Operating Expenses/Total Claims	Total Increase in Claims $	$ PMPM
State employees	15,000	11,050	155,900,260	10,357,500	6.6%		
Prevalence Rate							
Low (1:400)						334,990	$ 1.86
Mid (1:325)						543,384	$ 3.02
High (1:250)						875,452	$ 4.86

(2) FTE Alaskan State Employees per 2008 Alaska Comprehensive Annual Financial Report, p. 252

Total State Worker Claims Data Estimate

State Workers by Age Band	Age Band %	Estimated # Children by Age Band (State Employees)	ASD Treated Prevalence for Age Band Low	ASD Treated Prevalence for Age Band Mid	ASD Treated Prevalence for Age Band High	Cost per Treated Person Low	Cost per Treated Person Mid	Cost per Treated Person High	Total $ Cost Low	Total $ Cost Mid	Total $ Cost High
2 to 4 years	9.68%	1,070	0.25%	0.30%	0.45%	30,000	36,000	36,000	80,250	115,560	173,340
5 to 9 years	20.90%	2,310	0.35%	0.45%	0.67%	19,660	26,200	30,500	158,951	272,349	472,049
10 to 14 years	27.65%	3,055	0.25%	0.30%	0.35%	6,758	9,000	12,000	51,614	82,485	128,310
15 to 19 years	35.34%	3,905	0.20%	0.25%	0.30%	2,525	3,500	3,500	19,720	34,169	41,003
20 years	6.43%	710	0.20%	0.20%	0.25%	2,525	3,500	3,500	3,586	4,970	6,213
TOTAL UNDER 20		11,050							314,121	509,533	820,914

Alaska State Legislature

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Fax: 269-0264

Representative Pete Petersen
District 19

MEMORANDUM

DATE: March 30, 2010

FROM: Rep. Pete Petersen

TO: Rep. Wes Keller

RE: Coverage of autism spectrum disorders under new federal health care reform

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According to our research and consultations with health policy experts, the Health Care Education and Affordability Reconciliation Act of 2010 improves accessibility of treatment for autism spectrum disorders, **but not for the majority of families**. As such, HB 187 is still necessary to allow families not affected by the new Act to receive adequate coverage, which would save hard-earned money for themselves *and* the State.

Here are some of the problems the Act has in providing treatment for autism spectrum disorders:

- There is no specific mention of or guidelines for "autism" or "autistic spectrum disorders" or "pervasive developmental disorders" in the Act. Anywhere it says "behavioral health treatment," it is assumed it *may* apply to autism spectrum disorders.
- The pool of insurers obligated to offer the "behavioral health treatments" mandated by the Act is small: it does not cover "large group plans" – that is, families whose insurance plans are provided by employers of 50 or more people.
- Discrimination against treating autism spectrum disorders is not rectified. While discrimination against "pre-existing conditions" may now be addressed, this doesn't matter to the families whose insurance coverage will not cover treatment for autism spectrum disorders and are not required to do so under the new Act.
- Individuals and small-businesses can purchase insurance plans that offer specific coverage for autism which are exchanged over state lines, but this does not take effect until 2014. This is also assuming the appropriate legislation has passed and guidelines have been established to allow Alaskan families and small businesses to participate in these exchanges.
- While some families affected by autism will be able to receive health insurance coverage for behavioral health treatments, the majority of families will remain without this coverage. Those who can receive it may not be able to take advantage of it for several more years and then miss that window of opportunity for early intervention.

Attached are a few of our sources and supplements to this information. Please feel free to contact me or my staff with any additional questions. Thank you for your consideration.

AUTISM VOTES
AN AUTISM SPEAKS INITIATIVE

It's time for lawmakers to listen.

AUTISM SPEAKS
It's time to listen.

News Center

Health Care Reform: What does it mean for the Autism Community?

Families caring for a child with autism often have health insurance, but most of these plans explicitly exclude coverage of the treatments their child needs. Since 2007, Autism Speaks has been working with grassroots partners on autism insurance reform in states across the country with the goal of enacting legislation that would end marketplace discrimination on the basis of an autism diagnosis. To date, 15 states have passed reform measures that specifically require insurers to provide coverage of evidence-based, medically necessary treatments including behavioral therapies, such as Applied Behavioral Analysis (ABA). Similar legislation is pending in about two dozen additional states.

From the beginning we knew that passage of state laws was only a first step – albeit a critical one – and that true autism insurance reform would demand a federal law requiring all types of health plans to cover autism treatments. President Obama even made a campaign pledge during the 2008 election that he would support a federal mandate requiring coverage of autism treatments.

With today's historic signing of health care reform legislation by President Obama, people are asking "What does this mean for autism insurance reform?" As many know, Autism Speaks, the autism grassroots community, and our supporters in Congress, especially Congressman Mike Doyle (PA) in the House and Senators Robert Menendez (NJ) and Chris Dodd (CT) in the Senate, worked very hard during the past year to include in health care reform legislation language that would address the insurance inequities many families have endured for decades. This language makes behavioral health treatments a part of the essential health benefits that must be included in certain health plans.

There are many questions about what health care reform WILL and WON'T do to help your family cover the cost of the medically necessary, evidence-based behavioral therapies. Let's consider where things stand.

Will health care reform directly benefit the autism community?

The new health care reform law will curb abusive practices like pre-existing condition exclusions, excessive waiting periods for coverage, and rescissions of coverage. Some insurers will be limited in their ability to set lifetime or annual limits on the dollar value of benefits. This may affect caps on autism insurance benefits in some states.

Does it apply to all insurers?

While the new health care reform law will extend autism insurance reform to some families, not all insurance plans will be required to cover behavioral health treatment. That's because only certain types of health plans will be required, beginning in 2014, to cover the list of essential benefits, including behavioral health treatment. The types of plans included under this provision are: (1) plans offered by state-based exchanges, through which individuals and small businesses can purchase coverage; and (2) plans offered in the individual and small group markets outside the exchange. Existing coverage, plans offered in the large group market outside exchanges, and self-insured plans (plans under which an employer assumes direct financial responsibility for the costs of enrollees' medical claims, or sometimes referred to as "ERISA plans") will not be required to provide the essential benefits package. This last exception is especially significant because 57% of workers who are currently covered by their employers' health benefits are enrolled in a plan self-insured by the employer.

How does health care reform impact the state autism insurance reform effort?

Autism Speaks is committed to autism insurance reform that includes coverage of all medically necessary, evidence-based treatments for all people living with autism spectrum disorders. While passage of health care reform will bring some relief to families caring for a child with autism, there is still much work to be done in state legislatures and in Congress to make effective health care coverage a reality for the autism community and to bring about an end to discrimination of individuals with autism by the insurance industry.

We all know families who have gone to extreme measures, including mortgaging their homes and the futures of other children, in order to provide the best possible services for their child with autism. According to research, families living with autism have far greater medical expenditures and out-of-pocket costs and are far less likely to report that health insurance meets their child's needs when compared to families living without autism. Health care reform will not end these problems, but it may lessen their severity. That's why Autism Speaks will continue its efforts to make autism insurance reform a reality for all Americans living with autism.

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TAKE ACTION IN CONGRESS!

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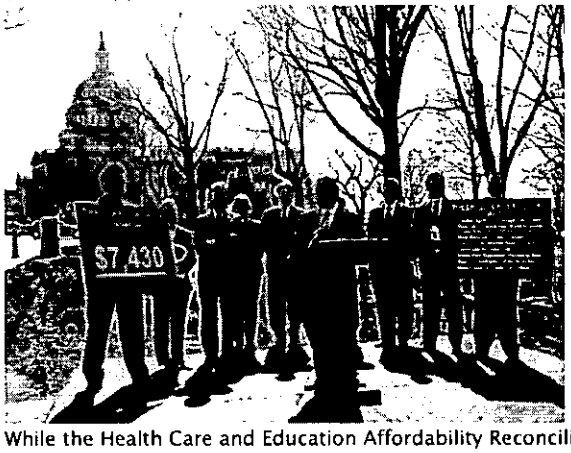
U.S. HOUSE PASSES HEALTH CARE REFORM BILL CONTAINING PROVISION FOR AUTISM INSURANCE

25 March , *by Christine Kennedy*

Autism Speaks, the nation's largest autism science and advocacy organization, today pledged to continue the battle to end insurers' discrimination against individuals with autism at both the state and federal levels. While praising elements of the Health Care Education and Affordability Reconciliation Act of 2010 - passed over the weekend by the U.S. House - that could result in improved access to care for individuals with autism and their families, the bill still falls short of eliminating marketplace discrimination for coverage of medically necessary autism treatments. The reconciliation bill will now move to the Senate for consideration.

Through the efforts of Autism Speaks, the autism grassroots community and supporters in Congress, especially Congressman Mike Doyle (PA) in the House and Senators Robert Menendez (NJ) and Chris Dodd (CT) in the Senate, behavioral health treatment is included as part of the essential health benefits package required in certain health plans. Behavioral health treatments were added to ensure that people with autism are provided with insurance coverage of medically necessary, evidence -based behavioral treatments, such as applied behavior analysis (ABA) therapy.



While the Health Care and Education Affordability Reconciliation Act will extend autism insurance reform to some families, not all health plans will be required by the bill to cover behavioral health treatment. The reconciliation bill will require the following health plans to offer at least the essential benefits package: (1) plans offered by state-based exchanges, through which individuals and small businesses can purchase coverage; and (2) plans offered in the individual and small group markets outside the exchange.

Therefore, while some families affected by autism will be able to receive health insurance coverage for behavioral health treatments, the majority of families will remain without this crucial coverage.

"We are grateful to our supporters in Congress who fought so hard to make sure that families dealing with autism are a part of larger

health care reform," said Peter Bell, Autism Speaks executive vice president for programs and services. "Though passage of this bill does not end autism insurance discrimination for all families, Autism Speaks will continue to work for autism insurance reform in state legislatures and in Congress until all those touched by autism no longer face discrimination from the insurance industry."

March 24, 2010

Recent healthcare reform dictates that we intensify state mandate efforts for ABA therapy

Filed under: Obama Initiative — admin @ 6:59 pm

The following is a message from Autism Speaks...

Families caring for a child with autism often have health insurance, but most of these plans explicitly exclude coverage of the treatments their child needs. Since 2007, Autism Speaks has been working with grassroots partners on autism insurance reform in states across the country with the goal of enacting legislation that would end marketplace discrimination on the basis of an autism diagnosis. To date, 15 states have passed reform measures that specifically require insurers to provide coverage of evidence-based, medically necessary treatments including behavioral therapies, such as Applied Behavioral Analysis (ABA). Similar legislation is pending in about two dozen additional states.

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futures of other children, in order to provide the best possible services for their child with autism. According to research, families living with autism have far greater medical expenditures and out-of-pocket costs and are far less likely to report that health insurance meets their child's needs when compared to families living without autism. Health care reform will not end these problems, but it may lessen their severity. That's why Autism Speaks will continue its efforts to make autism insurance reform a reality for all Americans living with autism.

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Representative Pete Petersen
District 19

Sponsor Statement

HB 187
INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS

Autism is a devastating disorder affecting at least 1 in 100 children, accounting for 1% of America's youth and 1 in 58 boys, according to the most recent study by the Center for Disease Control and Prevention. Despite being treatable, many children diagnosed with an Autism Spectrum Disorder (ASD) never receive the treatment they need. Families go bankrupt mortgaging their future, trying to provide their children with the treatment to ameliorate their condition. Families are forced to dig into their savings, retirement funds, and their other children's college savings because ASD is not covered by insurance plans. In fact, most insurance plans explicitly exclude the treatment of ASD, even when the service is otherwise covered by the health plan.

HB 187 would require insurance coverage for autism spectrum disorders, including the behavior therapies that after 30 years of study have shown to be the only effective treatment of these disorders. Treatment has been shown to improve the symptoms of ASD and in some cases even eliminate the need for special education services for a child with ASD. The cost savings in special education alone would amount to approximately $208,500 per capita during the school years. This number rises to over $1.08 million over the autistic person's lifespan.

The incremental societal cost of not treating autism has been estimated by Michael Ganz, a Harvard economist, to be approximately $3.2 million per capita. The cost to policy holders to implement such coverage is minimal: estimated at less than a 1% increase in their premiums, or $3.60 per member per month.

Furthermore, President Obama has stated the coverage of treatment and other types of funding for ASD would be a priority of his administration. Sens. Durbin, Casey and Menendez introduced the Autism Treatment Acceleration Act of 2009 in April, mandating the insurance coverage of ASD. While the federal legislation is currently pending, HB 187 allows Alaska to start this process on our own terms, and gives the state the needed time to meet the demands created in HB 187.

Implementing this legislation in Alaska before a federal mandate is enacted would bring well-paying healthcare jobs to the state and bring those interested in this field to Alaska. It is in the best interest of Alaska and autistic Alaskans to have this implemented as soon as possible.

Since HB 187 was introduced in March of 2009, 11 states have passed legislation regarding mandatory insurance coverage of treatment for ASD, with 8 states having enacted legislation prior to March of 2009. The District of Columbia, Puerto Rico and 19 additional states currently have similar legislation pending. These enacted and pending bills and the pending Autism Treatment Acceleration Act demonstrate the nationwide need for relief for families of autistic individuals. Autism is not a state- or region-specific condition. Families burdened with the costs of autism are unlikely to relocate to one of those 11 states that require insurance companies to cover the cost of ASD treatment. Families of any state should not be burdened with the great cost of treating a disorder they could not prevent or predict; they should not find themselves a victim of discrimination by health insurance companies.

Insurance coverage of ASD would not only provide a much needed service to those families burdened with the effects of a child with autism, but also save the state and taxpayers exponentially over the lifespan of those diagnosed with autism. Though there is no cure for ASD, this legislation would help significantly to treat those suffering from these disorders. In addition, a state that covers ASD treatment will be desirable to those in the field and will bring jobs and professionals in the field to Alaska. It will also allow more flexibility for families with autistic children who wish to move to Alaska to do so. Prompt passage of this legislation would allow the state to reap the health and economic benefits that would result from being among the first states to cover ASD.

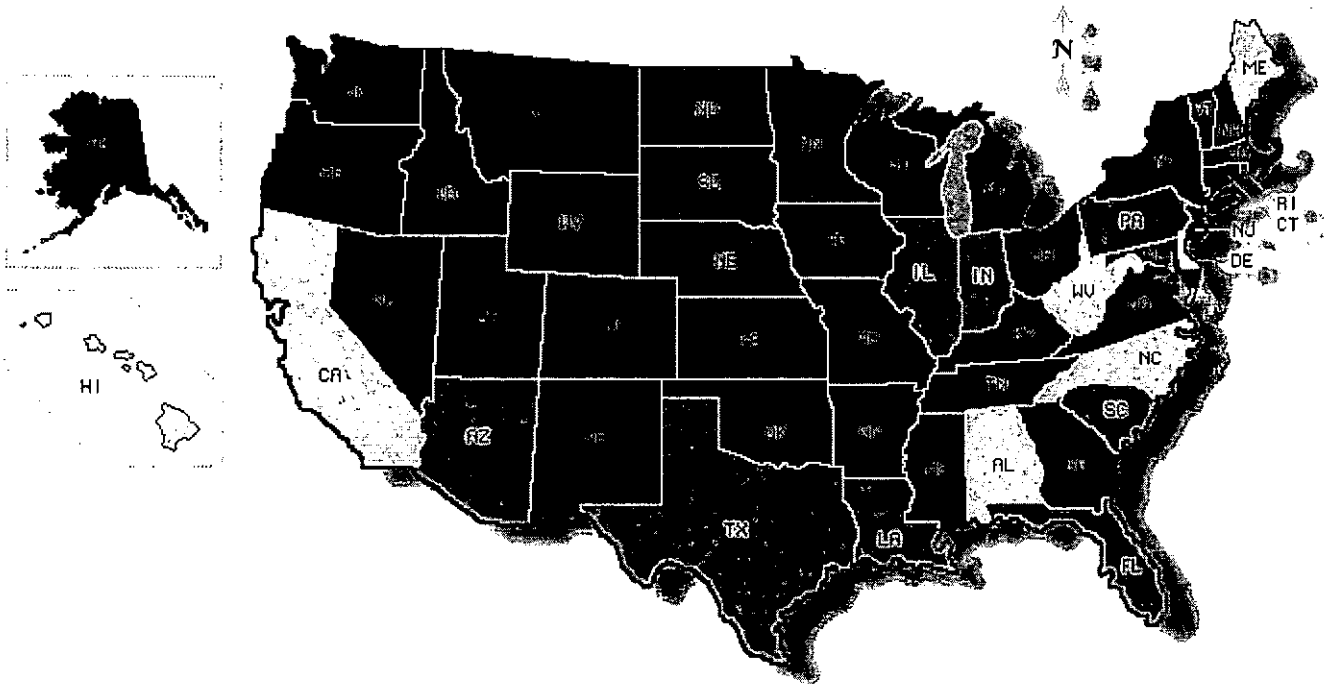
I respectfully ask for your careful consideration and support of HB 187.

Autism Speaks
Government Relations Department

3/18/2009

Autism Speaks 2009 State Initiatives

UPDATED



[illegible]	[illegible]	[illegible]	[illegible]	Bill Under Development	
Arizona	Alaska	Mississippi	New Hampshire	Alabama	Idaho
Florida	Arkansas	Missouri	Oklahoma	California	Nebraska
Illinois	Connecticut	Montana	Oregon	Delaware	North Dakota
Indiana	Colorado	Nevada	Tennessee	Hawaii	Rhode Island
Louisiana	Georgia	New Jersey		Maine	South Dakota
Pennsylvania	Iowa	New Mexico		North Carolina	Vermont
South Carolina	Kansas	New York		Wash., DC	Wyoming
Texas	Kentucky	Ohio		West Virginia	
	Maryland	Utah			
	Massachusetts	Virginia			
	Michigan	Washington			
	Minnesota	Wisconsin			

Autism Speaks

Arguments in Support of Private Insurance Coverage of Autism-Related Services

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It's time to listen.

AUTISM VOTES
AN AUTISM SPEAKS INITIATIVE
It's time for lawmakers to listen.

Eight arguments defining the justification for autism insurance reform legislation

February 2009

1990 K Street NW, Washington, DC 20006 Tel 202.955.3114 Fax 202.955.3115 WWW.AUTISMVOTES.ORG

Contents

Executive Summary

Autism is a complex neurobiological disorder and is the fastest-growing serious developmental disability in the U.S. The Centers for Disease Control estimates that 1 in 150 children have autism. These children require extensive services from medical professionals. Early intervention is critical to gain maximum benefit from existing therapies. Most private health insurance plans do not provide coverage for Applied Behavioral Analysis (ABA) and other autism-related services.

This document contains eight arguments in favor of requiring private health insurance policies to cover the diagnosis and treatment of autism spectrum disorders for individuals under the age of 21. These arguments are based on epidemiological, social, and economic studies of the children and families affected by autism and prove the significant long-term financial and public health benefits of this requirement.

We first point out that children with autism have substantial medical needs and have a difficult time accessing necessary treatments through Medicaid and private health insurance. Most insurance policies contain specific exclusions for autism. This is a hardship for many families, who are often forced to cope with delayed, inadequate, and fragmented care through the Medicaid system. Often, families must pay for costly treatments out-of pocket or forego them.

We then review some of the many studies and reports that document the effectiveness of intensive behavioral therapies in the treatment of autism. An autism insurance mandate should specifically target coverage of Applied Behavior Analysis (ABA) and other structured behavioral therapies, which are the most effective forms of treatment and have the best outcomes, both in human costs and in long-term economic benefits.

We then comment on the experiences of several states with insurance reform. Their experiences show that the policy holder costs resulting from the passage of legislation requiring comprehensive autism services have been relatively small.

Finally, we point out that the mandate offers hope that children with autism will need less intensive care in the future. They will, in short, have a better chance at a normal life.

What is Autism Speaks?

Autism Speaks is an organization dedicated to increasing awareness of autism spectrum disorders, to funding research into the causes, prevention, treatments, and cure for autism, and to advocating for the needs of affected families. The organization was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Bob Wright is Vice Chairman, General Electric, and served as chief executive officer of NBC for more than twenty years. Autism Speaks has merged with both the National Alliance for Autism Research (NAAR) and Cure Autism Now (CAN), bringing together the nation's three leading autism advocacy organizations.

What is Autism?

Autism is a complex neurobiological disorder that typically lasts throughout a person's lifetime. It is part of a group of disorders known as autism spectrum disorders (ASD). Today, 1 in 150 individuals is diagnosed with ASD, making it more common than pediatric cancer, diabetes, and AIDS combined. It occurs in all racial, ethnic, and social groups and is four times more likely to strike boys than girls. Autism impairs a person's ability to communicate and relate to others. It is also associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Symptoms can range from very mild to quite severe.

***Argument 1*: Mandated private health insurance coverage will provide services that are desperately needed by children with autism, who have greater health care needs than children without autism.**

Children with autism have a tremendous need for services from trained medical professionals. These children are at risk for a range of other medical conditions, including behavioral or conduct problems, attention-deficit disorder or attention-deficit/hyperactivity disorder, stuttering, stammering, and other speech problems, depression and anxiety problems, bone, joint, or muscle problems, ear infections, hearing and vision problems, allergies (especially food allergies), and frequent and severe headaches. These problems greatly affect their overall health and their need for and use of health care services.

A recent study by James G. Guerney and others[1] highlights the broad medical needs of children with autism. Using data from the National Survey of Children's Health, Guerney showed that relative to children without autism, children with autism require more services for physical, occupational, and speech therapy. Children with autism are also much more likely to have poor health, to require medically necessary care for behavioral problems, and to be using medications. As evidenced in the chart below taken from the study, parents of children with autism were more likely to report the presence of a variety of concurrent medical conditions and the need for more visits to a range of medical service providers than parents of children without autism.

Table 2. Parental Description of Health Status and Therapy and Services Use, From the National Survey of Children's Health

Variable	Children With Autism (n = 324 000)*	Children Without Autism (n = 11 100 000)*	OR (95% CI)†
Would you say your child's health is			
Excellent	33.7	60.2	1.0
Very good	22.8	23.5	1.9 (1.2-2.7)
Good	32.7	12.0	5.0 (3.0-8.1)
Fair	7.4	2.0	7.7 (4.2-13.8)
Poor	3.5	0.4	21.1 (10.2-47.0)
Does the child use more medical care, mental health or educational services than is usual for most children of the same age?	30.6	11.9	52.8 (24.7-60.4)
Is the child limited or prevented in the ability to do the things most children the same age can do?	68.5	5.7	35.2 (24.9-52.6)
Does the child get special therapy, such as physical, occupational, or speech therapy?	76.0	6.3	44.4 (31.9-61.9)
Does the child have any emotional, developmental, or behavioral problem for which she needs treatment or counseling?	75.4	7.0	35.9 (25.7-53.1)
Does the child currently need or use medicine prescribed by a doctor, other than vitamins?	54.7	21.1	3.5 (2.6-4.7)
If yes, is this for a condition expected to last 12 mo or longer?	51.4	14.5	11.0 (1.6-76.0)

Abbreviations: CI, confidence interval; OR, odds ratio.
*Data are given as the percentage of each group and are based on sampling fractions and weighted extrapolation from parent report of 453 children with autism and 84 789 children without autism.
†Data are adjusted for sex, primary language, age, insurance, and household educational attainment.

This reform of private health insurance coverage will address the broad medical needs of children with autism. It will ensure that these children will receive the full range of therapies necessary to ameliorate their condition.

***Argument 2*: Treatments for autism are difficult to access, often inadequate, and frequently delayed. Denied coverage by private group health insurance companies, parents are often forced either to pay out-of-pocket or forego the treatments their children need.**

Children with autism face barriers in accessing early intensive behavioral treatments and other therapies. According to the Institute of Medicine, the term "access" is defined as "the timely use of personal health services to achieve the best possible health outcomes."[2] For a child with autism, lack of access to services can be the cause of inconsistent and uncoordinated care. Children with autism often experience barriers to access with even greater frequency than children with other special health care needs. In fact, one study found that "over one-third of the children with autism were reported to have experienced an access problem with respect to specialty care from a medical doctor in the preceding 12 months." [3] A study of the Tennessee Medicaid system, TennCare, found that for children with autism, "the rate of service use was only one tenth what should be expected based on prevalence rates." The chart below illustrates these results and the significantly lower rates of service access for children with autism.

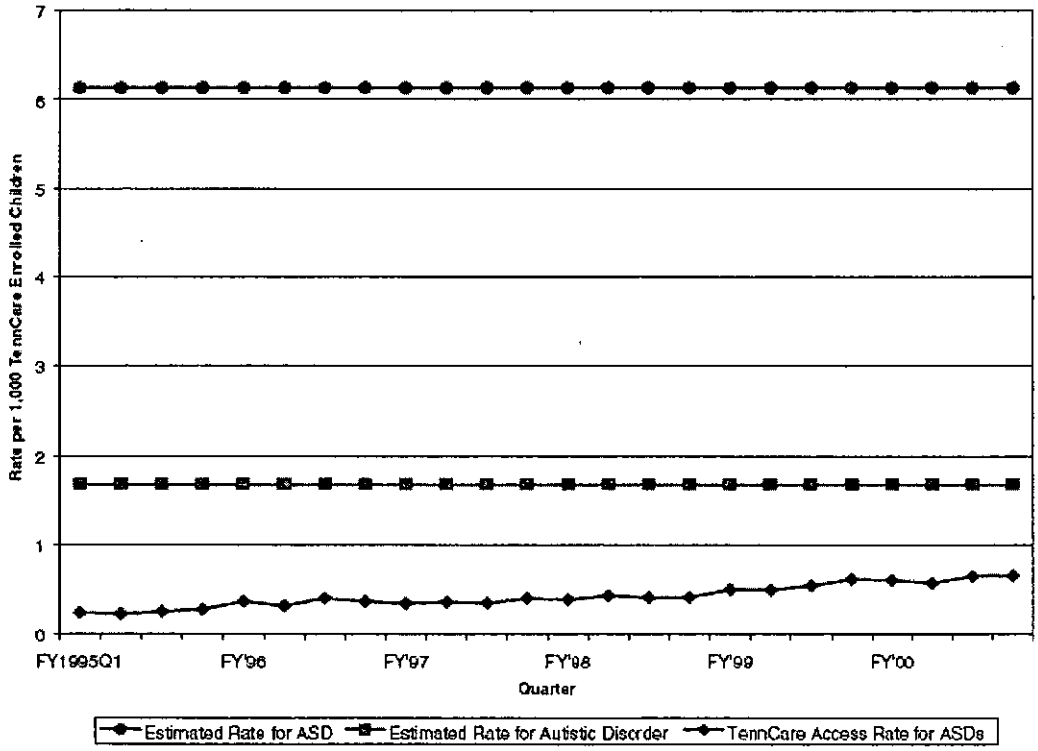

Fig. 1. Estimated incidence rates vs. service rates of autism spectrum disorders (ASDs) in TennCare for children ages 0–17 years, by quarter.

Within the Medicaid system, the amount of public money spent for services for developmental disabilities including autism is now eight times the rate of spending just a few decades ago.[4] Medicaid accounts for 75% of all funding for services for the developmentally disabled, making it the largest single public payer of behavioral health services.[5] Children with disabilities comprise a significant portion (15%) of all Medicaid recipients, and an even more significant portion (31%) of disabled children use the Medicaid system as their primary insurer.

Medicaid suffers from very low reimbursement rates that make it difficult for many locations to retain service providers. Moreover, services that can be accessed through the Medicaid system are often inadequate at meeting the specific needs of a child with autism. The system operates as a short-term service provider, tending to push children through treatment as quickly as possible. The success of the Applied Behavior Analysis, however, depends in part, on the amount of time the child with autism spends with the provider of the therapy.[6]

The failings of Medicaid point to the importance of the private health care system in providing services to children with autism. But nationwide there are very few private insurance companies or other employee benefit plans that cover Applied Behavior Analysis and other behavioral therapies. Most insurance companies designate autism as a diagnostic exclusion, "meaning that any services rendered explicitly for the treatment of autism are not covered by the plan, even if those services would be covered if used to treat a different condition."[7] A 2002 study by Pamela B. Peele and others of 128 behavioral health plans administered by one of two large managed behavioral health organizations found that all the plans had some type of limit on benefits for behavioral therapies – over half of the plans had limits on the number of annual outpatient sessions and 65 percent of the plans imposed limits on the number of inpatient days covered per year. [8]

Families that refuse to allow their children to suffer through the inadequate Medicaid system and are denied coverage by their private health insurance carriers often end up paying for therapies out of their own pockets. For these families, the financial burden is immense. Without the negotiating powers of an insurance company behind them, out-of-pocket prices are extremely high. Parents can often spend upwards of $50,000 per year on autism-related therapies, often being forced to wager their own futures and the futures of their non-autistic children to pay for necessary autism-related therapies. Children whose parents cannot afford to pay for behavioral and other therapies and who cannot access adequate therapies through the Medicaid system simply go without these interventions.

***Argument 3*: Mandated private insurance coverage will bring effective autism services within the reach of the children who need them. The efficacy of Applied Behavior Analysis (ABA), the centerpiece of this legislative mandate's benefits, has been established repeatedly.**

Private health insurance coverage of autism services will allow children with autism to access Applied Behavior Analysis (ABA), a proven treatment for their condition. Several studies have shown that as many as 47 percent of the children that undergo early intensive behavioral therapies achieve higher education placement and increased IQ levels. A significant portion of children who receive ABA are placed into mainstream educational settings. Children who begin their treatment with minimal IQ levels end treatment with substantially higher levels of intellectual functioning. These results have been shown to last well beyond the end of treatment. As such, the effectiveness of ABA therapy has allowed many children to forego costly intensive special education in the future.

Lovaas:

The most famous study of the effectiveness of behavioral modification treatments was conducted in 1987 by O. Ivar Lovaas.[9] Lovaas's study showed that when compared with other treatment programs that provide minimal therapy, Applied Behavior Analysis is extremely effective in helping many children struggling with autism, providing gained capacity for intellectual functioning and allowing a child to progress educationally.

Lovaas conducted his study of the effectiveness of behavioral modification treatments on very young children affected by autism. For his study, Lovaas split his 38 subjects into two groups: 19 subjects were put into an intensive-treatment experimental group that received more than 40 hours of one-to-one treatment per week, and 19 subjects were place in a minimal-treatment control group that received 10 hours or less of one-to-one treatment per week. Both groups were identical at intake in terms of intellectual functioning abilities, and both received their assigned treatment for 2 or more years.

Upon follow-up at age 7, the experimental group attained significantly higher results on education placement and IQ levels than the control group. According to the results of Lovaas's study, the 19-subject experimental group showed nine children (47%) who successfully passed through normal first grade in a public school and obtained an average or above average score on IQ tests.

McEachin:

Lovaas's landmark 1987 study was followed in 1993 by another study of these same 38 subjects. The objective of John J. McEachin's study was to discover the long-term effects of Lovaas's early intensive behavioral treatment and to find out if the results of the experimental group were preserved over time.[10]

For this study, Lovaas's original subjects were evaluated at a mean age of eleven-and-a-half years. The study was presented in two parts: the first examined whether the experimental group had maintained its treatment gains, the second part focused on the nine subjects who had achieved the greatest gain in the original study and examined the extent to which they "could be considered free of autistic symptomology."

McEachin's follow-up resulted in findings in three different categories: school placement, intellectual functioning, and presence of adaptive and maladaptive behaviors. In terms of class placement, the study found that "the proportion of experimental subjects in regular classes did not change from the age 7 evaluation (9 of 19, or 47%). In the control group, none of the 19 children were in a regular class, as had been true at the age 7 evaluation." (McEachin, *supra* note 10) In terms of intellectual functioning, the study found that "the experimental group at follow-up had a significantly higher mean IQ than did the control group... indicating that the experimental group had maintained its gains in intellectual functioning between age 7 and the time of the current evaluation." Finally, in terms of presence of adaptive and maladaptive behaviors, "the findings indicate that the experimental group showed more adaptive behaviors and fewer maladaptive behaviors than did the control group." (McEachin, *supra* note 10)

Based on these findings, the effectiveness of ABA and other structured behavioral programs, as provided by the proposed benefit, would be experienced in the short-term as well as the long-term.

Argument 4: **Government and scientific organizations have endorsed Applied Behavior Analysis (ABA) and other structured behavioral therapies.**

ABA is the treatment of choice for autism. Its efficacy has been recognized in a number of prominent reports, including the following:

- **The 2001 U.S. Surgeon General's Report on Mental Health**, which states, "Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior." [11]

- **The New York State Department of Health** assessed interventions for children ages 0-3 with autism, and recommended that "behavioral interventions for reducing maladaptive behaviors be used for young children with autism when such behaviors interfere with the child's learning or socialization or present a hazard to the child or others." [12]

- **The Maine Administrators of Services for Children with Disabilities** notes in their report that "There is a wealth of validated and peer-reviewed studies supporting the efficacy of ABA methods to improve and sustain socially significant behaviors in every domain, in individuals with autism. Importantly, results reported include 'meaningful' outcomes such as increased social skills, communication skills academic performance, and overall cognitive functioning. These reflect clinically-significant quality of life improvements. While studies varied as to the magnitude of gains, all have demonstrated long term retention of gains made." [13]

- **The National Institute of Mental Health** reports, "The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles, calling for an intensive, one-on-one child-teacher interaction for 40 hours a week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential. The goal of behavioral management is to reinforce desirable behaviors and reduce undesirable ones." [14]

- **The National Institute of Child Health and Human Development** lists Applied Behavior Analysis among the recommended treatment methods for Autism Spectrum Disorders. [15]

- **The National Research Council's** 2001 report on Educating Children with Autism acknowledged, "There is now a large body of empirical support for more contemporary behavioral approaches using naturalistic teaching methods that demonstrate efficacy for teaching not only speech and language, but also communication." [16]

- **The Association for Science in Autism Treatment** recommends ABA-based therapies, stating, "ABA is an effective intervention for many individuals with autism spectrum disorders." [17]

Argument 5: **To combat the difficulty many families face in accessing Applied Behavior Analysis (ABA) and other structured behavioral treatments through public insurance, three states have passed autism insurance mandates that specifically require private insurance companies to provide coverage of these therapies, thus creating a public-private partnership for the provision of care.**

While there are several states that have passed autism specific private insurance mandates, very few states specifically mandate coverage for ABA and other structured behavioral therapy programs. Without coverage of these crucial, medically necessary, evidence based therapies, the effectiveness of most mandates is severely diminished. For this reason, we have concluded that only the following states have passed autism insurance legislation:

South Carolina:

Senate Bill 20, better known as Ryan's Law, was passed by both the South Carolina House of Representatives and Senate on May 31, 2007. [18] The bill was then vetoed by Governor Mark Sanford on June 6. On June 7, the bill was brought back to the House and Senate floors, and unanimous votes in both chambers overrode the Governor's veto. This law goes into effect in July 2008.

Coverage Includes: Treatments, including behavioral therapies, which are prescribed by the individual's treating medical doctor in accordance with a treatment plan.

Age Range: An individual must be diagnosed with autistic spectrum disorder at age eight or younger. The coverage must be provided to any eligible person less than sixteen years of age.

Dollar Cap: Coverage for behavioral therapy is subject to a $50,000 maximum benefit per year.

Texas:

On June 15, 2007, Texas enacted House Bill 1919, effective September 1, 2007. [19] While the Texas bill limits the ages for children who can benefit from coverage, it goes further than some other states in spelling out exactly what kinds of services are covered. The bill's text specifically cites which kinds of autism-related services are examples of treatments that must be covered.

Coverage Includes: Evaluation and assessment services, A BA, behavior training and behavior management, speech therapy, occupational therapy, physical therapy, medication or nutritional supplements used to address symptoms of autism spectrum disorder.

Age Range: An individual must be between ages three and five to receive this

coverage.

Dollar Cap: Same as afforded to physical illnesses

Indiana:

In 2001, the Indiana enacted House Bill 1122, requiring insurers that issue accident and sickness insurance policies on an individual basis to provide coverage for the treatment of autism spectrum disorders. [20]

Coverage Includes: Treatment that is prescribed by the insured's treating physician in accordance with a treatment plan. The statute thus allows many different professionally accepted therapies, such as ABA, speech therapy, occupational therapy, physical therapy, and medications to address symptoms of autism.

Age Range: All ages are allowed coverage

Dollar Cap: Same as afforded to physical illnesses

Argument 6: **The costs of the proposed benefit are small and will have very little impact on the cost of health insurance premiums for the individual consumer.**

Earlier this year, The Council for Affordable Health Insurance, a research and advocacy association of insurance carriers, released its annual report on state health insurance mandates, *Health Insurance Mandates in the States 2007.* [21] The report defined a mandate as "a requirement that an insurance company or health plan cover (or offer coverage for) common – but sometimes not so common – health care providers, benefits and patient populations." (Bunce, *supra* note 21) Using this definition, the report identified legislative mandates for autism benefits in ten states: Colorado, Delaware, Georgia, Iowa, Indiana (which, as we have noted, provides comprehensive benefits), Kentucky, Maryland, New Jersey, New York, and Tennessee. The report assessed the incremental cost of state mandated benefits for autism in these ten states *as less than one percent.*

The Council's modest estimate of incremental premium costs is consistent with state government estimates across the country. Prior to enactment of Indiana's sweeping legislation, the Indiana Legislative Services Agency estimated additional premium costs as ranging from $.44 per contract per month to $1.67 per contract per month. [22] In vetoing Ryan's Law in South Carolina, Governor Mark Sanford estimated that the bill, with its $50,000 maximum yearly benefit for behavioral therapy, would add $48 annually to insurance policies.[23] And in Wisconsin, where pending Assembly Bill 417 would provide the same broad coverage Indiana's statute mandates, the Department of Administration estimates policy increments of between $3.45 and $4.10 per month – about the same as Governor Sanford's estimate for Ryan's Law. [24]

The cost estimates for Indiana, South Carolina, and Wisconsin – all states whose legislation allows a maximum benefit that can be considered high – suggest that an average autism insurance coverage mandate will cost approximately $50 annually per policy holder. For only a modest effect on premium cost, this insurance reform holds the promise of significantly improving the lives of thousands of children.

Argument 7: **By improving outcomes for children with autism, mandated private insurance coverage will decrease the lifetime costs of treating and providing services and will actually result in an overall cost savings in the long-run.**

A 1998 study by John W. Jacobson and others titled, *Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case,* examined the cost/benefit relationship of early intensive behavioral intervention treatment at varying levels of treatment success.[25] The study used estimates of costs for early intensive behavioral interventions (EIBI) from childhood (age three) through adulthood (age 55) based on prices in the Commonwealth of Pennsylvania and compared these costs with the expected amount of income the child would earn later in life to arrive at an estimated cost savings.

With a success rate of 47 percent for early intensive behavioral intervention therapy (as determined by Lovaas), Jacobson's study found that cost savings per child served are estimated to be from $2,439,710 to $2,816,535 to age 55.

Table 6. Financial benefits at different levels of effectiveness, age 3–55 years, per 100 children served and per child served—Pennsylvania model

	Inflated total	*1996 $ total*	*Inflated/ student*	*1996 $/ student*
At 20% normal range				
20 norm range vs. partial effect	96,085,200	36,654,400	4,804,260	1,832,720
70 partial vs. minimal effect	72,520,910	28,984,130	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	168,606,110	65,638,530	1,686,061	656,385
At 30% normal range				
30 norm range vs. partial effect	144,127,800	54,981,600	4,804,260	1,832,720
60 partial vs minimal effect	62,160,780	24,843,540	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	206,288,580	79,825,140	2,062,886	798,251
At 40% normal range				
40 norm range vs. partial effect	192,170,400	73,308,800	4,804,260	1,832,720
50 partial vs. minimal effect	51,800,650	20,702,950	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	243,971,050	94,011,750	2,439,710	940,118
At 50% normal range				
50 norm range vs. partial effect	240,213,000	91,636,000	4,804,260	1,832,720
40 partial vs. minimal effect	41,440,520	16,562,360	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	281,653,520	108,198,360	2,816,535	1,081,984

Note: This table presents a comparison of financial benefits at different levels or rates of achievement of normal skills or functioning achieved by EIBI, for people ages 3–55 years, ranging from 20% of children achieving normal range skills or functioning (an assumed minimal rate) to 50% of children. At each level of effectiveness, differing rates of normal range functioning, as well as partial benefit are estimated. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars.

The study also accounts for the initial investment in early intervention by concluding that, with an initial annual cost of $32,820, the total cost-benefit savings of EIBI services per

child with autism or PDD for ages 3-55 years averages from $1,686,061 to $2,816,535 with inflation.

According to a 2005 Government Accounting Office (GAO) report, "the average per pupil expenditure for educating a child with autism was more than $18,000 in the 1999-2000 school year. This amount was almost three times the average per pupil expenditure of educating a child who does not receive any special education services."[26] With this insurance reform in place, more children would be able to access the early intervention services they need. That investment will, in the long run pay benefits, both economic and social, to the greater population.

Argument 8: **Without passage of legislation requiring private health insurance coverage for autism, the costs associated with autism will continue not only to affect families, but will have far reaching social effects as well.**

The cost of autism is borne by everyone. Michael L. Ganz's study of the societal costs of autism, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, examined how the large financial burdens of autism affect not only families with an autistic child but society in general. [27]

Ganz broke down the costs associated with autism into two distinct categories, direct costs and indirect costs. Direct costs include direct medical costs, such as physician, outpatient, clinic services, dental care, prescription medications, complementary and alternative therapies, behavioral therapies, hospital and emergency services, allied health, equipment and supplies, home health, and medically related travel, as well as direct nonmedical costs, such as child care, adult care, respite and family care, home and care modification, special education, and supported employment. Indirect costs include productivity losses for people with autism (calculated by combining standard average work-life expectancies for all men and women with average income and benefits and estimated age and sex specific labor force participation rates).

According to Ganz's study, direct medical costs reach their maximum during the first five years of life, averaging around $35,000. As the child ages, direct medical costs begin to decline substantially and continue to decline through the end of life to around $1,000. Ganz goes on to report, "The large direct medical costs early in life are driven primarily by behavioral therapies that cost around $32,000 during the first 5-year age group and decline from about $4,000 in the 8-to 12-year age group to around $1,250 for the 18- to 22-year age group." (Ganz, *supra* note 27)

In terms of direct medical costs "the typical American spends about $317,000 over his or her lifetime in direct medical costs, incurring 60% of those costs after the age of 65 years. In contrast, people with autism incur about $306,000 in incremental direct medical costs, which suggests that people with autism spend twice as much as the typical American over their lifetimes and spend 60% of those incremental direct medical costs after age 21 years." (Ganz, *supra* note 27)[27]

The study also found the indirect costs of autism to be significant as well. While in the first 22 years of life, indirect costs are mostly associated with lost productivity for the parents of a child with autism, the costs from age 23 on are associated with lost productivity of the actual individual with autism as depicted in the chart below taken from the study. The impact of this lost productivity can have enormous ramifications for the tax base of an entire society and the future of the older generation as their children with autism transition into adult care.

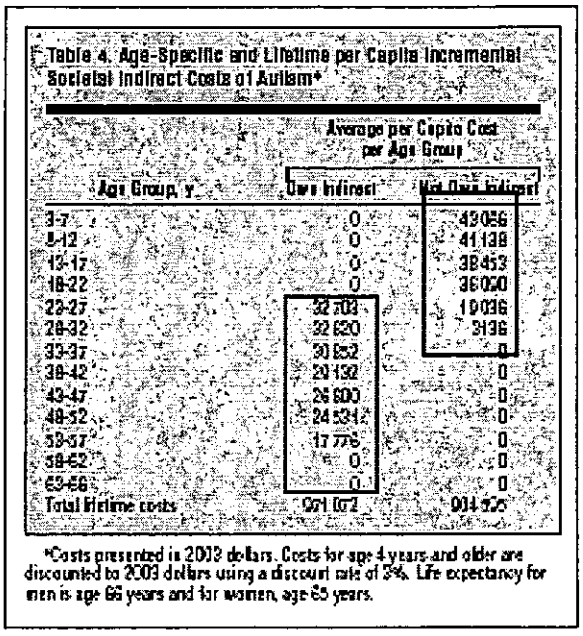

Table 4. Age-Specific and Lifetime per Capita Incremental Societal Indirect Costs of Autism*

Age Group, y	Average per Capita Cost per Age Group: Own Indirect	Average per Capita Cost per Age Group: Non-Own Indirect
3-7	0	43056
8-12	0	41138
13-17	0	38453
18-22	0	36050
23-27	32703	19036
28-32	32620	3136
33-37	30852	0
38-42	29132	0
43-47	26800	0
48-52	24534	0
53-57	17776	0
58-62	0	0
63-66	0	0
Total lifetime costs	971 072	904 926

*Costs presented in 2008 dollars. Costs for age 4 years and older are discounted to 2009 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 85 years.

Ganz posited that direct medical costs "combined with very limited to non-existent income for their adult children with autism combined with potentially lower levels of savings because of decreased income and benefits while employed, may create a large financial burden affecting not only those families but potentially society in general."(Ganz, *supra* note 27)

Without the help of private insurance coverage, families affected by autism may never be able to pull their heads above water and provide their children with the medically necessary, evidence- based treatments that they need. It is to the advantage of these families, to the 1 in 150 children affected by autism, and to all of society that private health insurance coverage is provided for these services.

Conclusion

A legislative mandate for coverage of autism asks private insurance companies to make a limited, but significant, contribution to help pay for medically necessary, evidence- based treatments that have been established to be of the greatest impact in fighting this terrible disorder.

Unbelievably, it is not uncommon for insurance carriers to have line- item exclusions for treatment of individuals diagnosed with autism. Across the nation, children with autism are routinely denied insurance benefits for treatment of their disorder. We believe that private insurance companies must contribute their fair share and partner in the financial burdens with these families.

With every new child diagnosed with autism costing an estimated $3 million over his or her lifetime, the current practices are both unfair and not cost effective in the long run for states and their citizens. Autism Speaks is confident that many more state governments will recognize the significant long-term cost benefits found in these legislative measures, will do what is right for their constituents, and will pass legislation requiring private health insurance coverage of autism services.

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DSM-IV Definitions.

Pervasive Development Disorders (PDD)

The term "PDD" is widely used by professionals to refer to children with autism and related disorders; however, there is a great deal of disagreement and confusion among professionals concerning the PDD label. Diagnosis of PDD, including autism or any other developmental disability, is based upon the *Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV)*, published by the American Psychiatric Association (Washington, DC, 1994), and is the main diagnostic reference of mental health professionals in the U.S.

According to the *DSM-IV*, the term "PDD" is not a specific diagnosis, but an umbrella term under which the specific diagnoses are defined.

Diagnostic labels are used to indicate commonalities among individuals. The key defining symptom of autism that differentiates it from other syndromes and/or conditions is substantial impairment in social interaction (Frith, 1989). The diagnosis of autism indicates that qualitative impairments in communication, social skills, and range of interests and activities exist. As no medical tests can be performed to indicate the presence of autism or any other PDD, the diagnosis is based upon the presence or absence of specific behaviors. For example, a child may be diagnosed as having PDD-NOS if he or she has some behaviors that are seen in autism, but does not meet the full criteria for having autism. **Most importantly, whether a child is diagnosed with a PDD (like autism) or a PDD-NOS, his/her treatment will be similar.**

Autism is a spectrum disorder, with symptoms ranging from mild to severe. As a spectrum disorder, the level of developmental delay is unique to each individual. If a diagnosis of PDD-NOS is made, rather than autism, the diagnosticians should clearly specify the behaviors present. Evaluation reports are more useful if they are specific and become more helpful for parents and professionals in later years when reevaluations are conducted.

Ideally, a multidisciplinary team of professionals should evaluate a child suspected of having autism. The team may include, but may not be limited to, a psychologist or psychiatrist, a speech pathologist and other medical professionals, including a developmental pediatrician and/or neurologist. Parents and teachers should also be included, as they have important information to share when determining a child's diagnosis.

In the end, parents should be more concerned that their child find the appropriate educational treatment based on their needs, rather than spending too much effort to find the perfect diagnostic label. Most often, programs designed specifically for children with autism will produce greater benefits, while the use of the general PDD label can prevent children from obtaining services relative to their needs.

Also within each diagnosis is the ASA Panel of Professional Advisors' recommended definition of the autism spectrum and related syndromes and conditions, which is not to be used for research purposes but rather for defining the demographics of the ASA's membership. The ASA is not attempting to represent individuals with related syndromes or conditions who do not also have autism, but rather those where autism is present in related syndromes and conditions, and where autism is the defining syndrome (e.g., autism-Asperger's). The rationale for this position is due to the unique service needs that are imperative for individuals with autism that may not

be required of the cohort disability. (See also "General Standards of Care for Individuals with Autism Throughout the Lifespan.")

- Autistic Disorder (299.00 DSM-IV)
- Asperger's Disorder (299.80 DSM-IV)
- Rett's Disorder (299.80 DSM-IV)
- Childhood Disintegrative Disorder (299.10 DSM-IV)
- PDD-NOS (299.80 DSM-IV)

Autistic Disorder (299.00 DSM-IV)

The central features of Autistic Disorder are the presence of markedly abnormal or impaired development in social interaction and communication, and a markedly restricted repertoire of activity and interest. The manifestations of this disorder vary greatly depending on the developmental level and chronological age of the individual. Autistic Disorder is sometimes referred to as Early Infantile Autism, Childhood Autism, or Kanner's Autism (page 66).

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. Qualitative impairment in social interaction, as manifested by at least two of the following:
   - Marked impairment in the use of multiple nonverbal behaviors such as eye to-eye gaze, facial expression, body postures, and gestures to regulate social interaction .
   - Failure to develop peer relationships appropriate to developmental level
   - A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
   - Lack of social or emotional reciprocity
2. Qualitative impairments in communication as manifested by at least one of the following:
   - Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
   - In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   - Stereotyped and repetitive use of language or idiosyncratic language
   - Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
   - Encompassing preoccupation with one or more stereotyped patterns of interest that is abnormal either in intensity or focus
   - Apparently inflexible adherence to specific, nonfunctional routines or rituals
   - Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
   - Persistent preoccupation with parts of object

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

- Social interaction
- Language as used in social communication

- Symbolic or imaginative play

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

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Asperger's Disorder (299.80 DSM-IV)

The essential features of Asperger's Disorder are severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interest, and activity. The disturbance must clinically show significant impairment in social, occupational, and other important areas of functioning. In contrast to Autistic Disorder, there are no clinically significant delays in language. In addition there are no clinically significant delays in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior, and curiosity about the environment in childhood.

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

- Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- Failure to develop peer relationships appropriate to developmental level
- A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
- Lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- Apparently inflexible adherence to specific, non-functional routines or rituals
- Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
- Persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

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Rett's Disorder (299.80 DSM-IV)

The essential feature of Rett's Disorder is the development of multiple specific deficits following a period of normal functioning after birth. There is a loss of previously acquired purposeful hand skills before subsequent development of characteristic hand movement resembling hand wringing or hand washing. Interest in the social environment diminishes in the first few years after the onset of the disorder. There is also significant impairment in expressive and receptive language development with severe psychomotor retardation. (Page 71)

A. All of the following:

- Apparently normal prenatal and prenatal development
- Apparently normal psychomotor development through the first 5 months after birth
- Normal head circumference at birth

B. Onset of all of the following after the period of normal development:

- Deceleration of head growth between ages 5 and 48 months
- Loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
- Loss of social engagement early in the course (although often social interaction develops later)
- Appearance of poorly coordinated gait or trunk movements
- Severely impaired expressive and receptive language development with severe psychomotor retardation

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Childhood Disintegrative Disorder (299.10 DSM-IV)

The central feature of Childhood Disintegrative Disorder is a marked regression in multiple areas of functioning following a period of at least two years of apparently normal development. After the first two years of life, the child has a clinically significant loss of previously acquired skills in at least two of the following areas: expressive or receptive language; social skills or adaptive behavior; bowel or bladder control; or play or motor skills. Individuals with this disorder exhibit the social and communicative deficits and behavioral features generally observed in Autistic Disorder, as there is qualitative impairment in social interaction, communication, and restrictive, repetitive and stereotyped patterns of behavior, interests, and activities. (Page 73)

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:

- Expressive or receptive language
- Social skills or adaptive behavior

- Bowel or bladder control
- Play
- Motor skills

C. Abnormalities of functioning in at least two of the following areas:

- Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
- Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
- Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms

D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

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PDD-NOS (299.80 DSM-IV)

The essential features of PDD-NOS are severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills; and stereotyped behaviors, interests, and activities. The criteria for Autistic Disorder are not met because of late age onset; atypical and/or sub- threshold symptomotology are present. (Page 77-78)

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

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Last updated: 30 January 2008

Biosketch

Gina Green received a PhD in Psychology (Analysis of Behavior) from Utah State University in 1986 following undergraduate and master's degree studies at Michigan State University. She has been a faculty member in Behavior Analysis and Therapy at Southern Illinois University; Director of Research at the New England Center for Children in Southborough, Massachusetts; Associate Scientist at the E.K. Shriver Center for Mental Retardation in Waltham, Massachusetts; and Research Associate Professor of Psychiatry and Pediatrics, University of Massachusetts Medical School. Dr. Green is currently the Executive Director of the Association of Professional Behavior Analysts, a consultant in private practice in San Diego, a lecturer in Special Education at San Diego State University, and an Adjunct Professor in the Department of Behavior Analysis, University of North Texas. She has authored numerous publications on the treatment of individuals with developmental disabilities and brain injuries, as well as the experimental analysis of behavior. Dr. Green co-edited the books *Behavioral Intervention for Young Children with Autism* and *Making a Difference: Behavioral Intervention for Autism*. She serves or has served on the editorial boards of several professional journals in developmental disabilities and behavior analysis. Dr. Green also serves on the Autism Advisory Group of the Cambridge Center for Behavioral Studies and the advisory boards of several autism programs and organizations. She is a Board Certified Behavior Analyst, former president of the Association for Behavior Analysis and the California Association for Behavior Analysis, a former member of the Board of Directors of the Behavior Analyst Certification Board, a founding Director of the Association of Professional Behavior Analysts, and a Fellow of the American Psychological Association and the Council for Scientific Medicine and Mental Health. *Psychology Today* named her "Mental Health Professional of the Year" in 2000. In 2005 she received an honorary Doctor of Science degree from The Queen's University of Belfast, Northern Ireland for her work in autism. Dr. Green lectures and consults widely on autism and related disorders, behavioral research, and effective interventions for people with disabilities.

Gina Green, PhD
Board Certified Behavior Analyst
6977 Navajo Rd., PMB 176
San Diego, CA 92119

September 2, 2008

The Honorable S. Ward Casscells, MD
Assistant Secretary of Defense for Health Affairs
1200 Defense Pentagon, Room 3E1082
Washington, DC 20301-1200
Via FAX: 703-697-4197

Dear Dr. Casscells:

As a long-time autism researcher and practitioner, I am writing to offer some information in support of your efforts to make effective treatment more widely and easily accessible to military children with autism spectrum disorders (ASD). In addition to having worked in this field for more than three decades, it has been my privilege over the past couple of years to work with some extraordinary military families who are advocating for coverage of effective treatment for ASD by TRICARE. They have taught me a great deal and have won my everlasting admiration, so I am grateful to have this opportunity to help them by providing expert opinion on the efficacy and medical necessity of applied behavior analysis (ABA) treatment for ASD.

As you know, ASDs are neurodevelopmental conditions that affect virtually all aspects of everyday functioning to some degree. Difficulties are typically seen in communication, social interaction, intellectual functioning, play and leisure skills, academics, and self-care skills. Many individuals with ASD also exhibit behavior disorders that interfere with their acquisition of useful skills and put them and others at risk of physical harm. Without effective intervention to help them build the skills required for everyday living and to reduce problem behaviors, many people with ASD suffer needless injuries and illnesses, and require extensive – and expensive – specialized services throughout the lifespan. That takes an enormous toll on their families, on healthcare and human service systems, and on society as a whole. Fortunately, research has shown that much of that toll can be alleviated for people with ASD who receive competently delivered applied behavior analysis (ABA) intervention.

Behavior analysis is a natural science approach to understanding how behavior interacts with environmental variables. In this scientific discipline, "behavior" means anything done by living organisms (not just misbehavior), and "environment" includes all types of physical and social events that might change or be changed by an individual's behavior. Like many other sciences, behavior

analysis has conceptual, experimental, and applied branches. The basic science focuses on discovering principles (that is, general laws) about how behavior works, or how learning takes place. For example, one principle of behavior analysis is positive reinforcement: When a behavior is followed by a consequence that is valued by the individual, that behavior is likely to be repeated in the future. Applied behavior analysis (ABA) is the use of the principles and methods derived from research to bring about meaningful changes in socially important behaviors. The applied component of the field was originally created by blending the experimental analysis of behavior – the basic science – with research on human development. Through nearly five decades of laboratory and field research, the discipline of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may be harmful or that interfere with learning. Some of the many areas in which this science has been applied fruitfully include developmental disabilities, education, brain and spinal cord injury rehabilitation, communication disorders, public health, substance abuse, business and industry, safety, child abuse and neglect, parenting, gerontology, and of course, ASD.

Numerous reviews of scientific research have identified ABA as a proven, safe, and effective approach to ASD intervention. Several of those reviews have cited the hundreds of published studies documenting the efficacy of a variety of ABA techniques for increasing a wide array of specific skills and decreasing a wide array of problem behaviors in people with ASD of all ages. In addition to those focused interventions, comprehensive, intensive early intervention programs using combinations of many ABA techniques have been shown to produce large improvements in multiple skill domains in many young children with ASD, more modest but still clinically important improvements in many other children. Those effects have been obtained when ABA intervention was designed and overseen by qualified professional behavior analysts. Among those who have recognized competently delivered ABA as an evidence-based approach to ASD intervention are the U.S. Surgeon General, New York State Department of Health, U.S. Department of Defense, American Academy of Pediatrics, Association for Science in Autism Treatment, and Autism Speaks.

I understand that in the course of deliberations about TRICARE policies, questions have arisen about the medical necessity of ABA intervention for ASD and whether that intervention is special education. I hope the following points of information will help ease concerns you and others may have about those issues.

ABA is medically necessary treatment for ASD

- Unfortunately, many people with ASD engage in behaviors that jeopardize their safety and health, such as self-injury, pica (ingesting inedible items), elopement (running away), flopping (throwing themselves on the ground), aggression, sleep disorders, and severely restricted eating. Several studies have found that such behaviors lead to disproportionate numbers of emergency room visits, hospitalizations, and prescriptions of psychotropic drugs for people with ASD, with the associated high costs. Extensive

research by behavior analysts has shown that those behaviors are often learned, and are triggered and reinforced by environmental events. Behavior analysis methods have proved effective not only for identifying those environmental events, but also for reducing problem behaviors and developing appropriate alternative behaviors, such as requesting help with a task instead of eloping or aggressing, eating a healthy diet, and sleeping through the night.

- Although some drugs can reduce some of the problem behaviors just mentioned, relatively few psychotropic medications have been tested adequately with children with ASD. Further, as the American Academy of Pediatrics noted recently, no drugs ameliorate the core symptoms of ASD, and many drugs that are prescribed for problem behaviors have negative side effects. For example, the only drug that has been approved by the FDA to date for the treatment of ASD – risperidone -- has been shown to reduce irritable and agitated behavior. But risperidone is not 100% effective, and its negative side effects include incontinence and weight gain, which increases the risk of diabetes and other health problems. ABA methods, on the other hand, can effectively reduce problem behaviors without adverse physical side effects.

- The behavioral excesses and deficits exhibited by people with ASD often hamper the delivery of health care services to this population. Communication difficulties and fearful responses to unfamiliar situations, for example, can make routine medical and dental checkups major ordeals for people with ASD and their families. Studies have shown that with ABA intervention, people with ASD can learn to communicate and cooperate with health care professionals, to comply with medical and dental care routines, and to undergo medical procedures like scans and EEGs.

- In a related vein, a variety of ABA techniques have proved effective for building self-care, hygiene, and personal safety skills in people with ASD, thus enhancing their health and reducing their risk of injury.

- Many people with ASD have difficulty recognizing and responding appropriately to situations that put them at risk of harm. Research has shown that ABA methods are effective for teaching people with ASD to be aware of and to avoid potentially hazardous situations, to seek help when necessary, and to communicate essential information to individuals who can assist them.

- In sum, ABA intervention for ASD is similar to certain treatments that are commonly provided to children and adults with other neurological disorders to develop or restore independent functioning. Those treatments are covered under many health insurance plans. With competently delivered ABA intervention, many people with ASD can enjoy safe and healthy lives. The earlier a child with ASD receives effective intervention, the more likely she is

to achieve large improvements in multiple skill areas, and the less likely it is that health-threatening problem behaviors will develop. Adolescents and adults with ASD can also benefit from ABA intervention. TRICARE insurance coverage to make this medically necessary treatment available to military children with ASD and their families will not only enhance the lives of those individuals, it will also reduce their need for health care services and the associated costs.

ABA is not special education

- Although ABA intervention methods are effective for building academic and other skills, and certainly could be used by properly trained teachers and other school personnel serving students with ASD, applied behavior analysis is increasingly recognized as a unique and distinct professional practice. In fact, in its 2007 report on autism, the U.S. Department of Defense described applied behavior analysis as an "emerging profession." There is an accredited international certification program for practitioners, managed by the Behavior Analyst Certification Board (see www.BACB.com). Some Board Certified Behavior Analysts and Board Certified Assistant Behavior Analysts work in special education, but the BACB certification is not an education credential per se. University training in behavior analysis is provided in a wide range of academic departments (e.g., behavior analysis, psychology, human development, public health, criminal justice, education, special education). Unfortunately, however, most special education teacher certification programs provide little, if any, training in ABA; very few provide all of the didactic training and supervised practical experience that the discipline deems necessary to practice ABA at even a rudimentary level.

- ASDs affect multiple areas of functioning, not just the skill domains that are typically addressed by the education system. Further, schools typically serve students with ASD for just a few hours each weekday for 9 months of the year. As noted previously, many people with ASD have difficulties with eating, sleeping, self-care, and personal safety. Those difficulties are most salient – and are best addressed – in home and community settings. Indeed, the need for intervention to build crucial skills of all kinds and to reduce problem behaviors does not stop with the end of the school day, the school week, or the school year. Abundant research shows that in order to generalize learned skills, people with ASD need carefully planned, consistently delivered behavior analytic intervention throughout each day, 7 days a week, year around, in multiple environments. Behavior analysts have developed specific techniques for promoting skill generalization. Importantly, those techniques include training family members to prompt and reinforce functional skills and to manage problem behaviors in a variety of everyday settings. The education system unfortunately lacks the resources to provide that kind of intervention. Therefore, if the responsibility for treating ASD is placed entirely on the schools, most people with ASD will not receive effective treatment so will

require substantial and expensive health care and other services throughout their lives.

- To expand upon a previous point, ABA intervention for ASD parallels the intensive speech, occupational, and physical therapies that are provided to children and youths with other neurological disorders to build or rebuild communication, cognitive, self-care, academic, and other skills. Those therapies are often delivered in schools, yet they are not narrowly construed as "special education." On the contrary, they are deemed medically necessary, and are covered by most health insurance plans. ABA intervention should be granted the same status.

With effective treatment, military children and youths with ASD can lead happier and healthier lives than they would otherwise. ABA is an effective and safe treatment for ASD when it is designed and overseen by qualified professional behavior analysts. If this medically necessary treatment is delayed or is provided at suboptimal levels, the health and wellbeing of the child with ASD and his family will be affected negatively in both the short and the long run. Failure to cover ABA treatment under the basic TRICARE program will not only add to the already heavy burden carried by military families of children with ASD, it will also add to the costs of health care and other services for those military dependents for years to come. I urge you to head off those tragedies by correcting the Code of Federal Regulations and TRICARE policies to include coverage of ABA treatment for ASD.

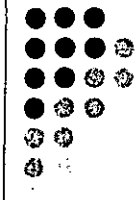
Very respectfully,

Gina Green, PhD, BCBA

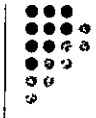
cc: Karen Driscoll (Karen0622@aol.com)
MG Elder Granger, Deputy Director, TRICARE (fax: 703-681-3665)

Applied Behavior Analysis in the Treatment of Autism

Gina Green, PhD, BCBA
Association of Professional Behavior Analysts
San Diego, CA • ggreen3@cox.net



Topics



- Overview of applied behavior analysis (ABA) intervention for autism
  - What ABA is
  - What is known from research on
    - Focused ABA interventions for autism
    - Intensive, comprehensive ABA intervention for young children with autism
- Health insurance coverage of ABA intervention for autism
  - Rationale
  - Self-insured companies
  - TRICARE demonstration program
  - State mandates
  - Proposed federal mandate
- Summary and conclusions

Applied behavior analysis

- Behavior (*not* "behavioral") analysis: a natural science approach to understanding and changing behavior; focus is on relations between behavior and environment
  - A scientific discipline with
    - Conceptual, experimental, and applied components
    - Unique research methodology
    - Professional journals and organizations
    - Professional credentialing program for practitioners
      - Managed by Behavior Analyst Certification Board (see www.BACB.com)
      - Accredited by National Commission for Certifying Agencies
- Applied behavior analysis (ABA): Application of scientific principles of behavior discovered through basic research (e.g., reinforcement) to improve socially significant behavior to a meaningful degree
  - *Many* applications in addition to autism
  - Based on the work of many researchers and practitioners

ABA

- An approach comprising many evidence-based techniques or procedures for changing behavior
- Effective for building skills and reducing problematic behaviors in people of all ages, with and without disabilities
- Stresses positive reinforcement and scientific demonstrations of effectiveness
- Highly individualized
- Flexible and dynamic; intervention is adjusted continuously based on data
- Continuously evolving

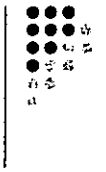
Behavior analysis research methods

- Direct observation and measurement of behavior, and single-case research designs
  - Intensive study of individual behavior interacting with environmental variables over time under control and treatment conditions
- Akin to methods used in other natural sciences, and by some medical researchers
- Focus is on *clinically important changes in individual behavior over time*, not statistical comparisons of group average scores
- Included in several protocols for developing evidence-based practice guidelines for behavioral interventions (e.g., American Psychological Association, National Association of School Psychologists) and for interventions for autism (e.g., New York State Department of Health Early Intervention Program, National Autism Center's National Standards Project, California Department of Developmental Services ASD Guidelines Project).

ABA for autism: Research on focused interventions

- Hundreds of published studies document effectiveness of many ABA techniques for developing many important skills in people with autism *of all ages* (e.g., Matson et al., 1996; New York State Department of Health, 1999; Wolery, Barton, & Hine, 2005; *Journal of Applied Behavior Analysis*):
  - Learning to learn: looking, listening, imitating, following instructions, discriminating and matching stimuli, etc.
  - Communication: verbal and nonverbal; comprehension and production; from simple to complex
  - Social : simple reciprocal exchanges, playing with peers, sharing, expressing emotions, empathizing, dramatic play, etc.
  - Self-care: hygiene, personal safety, community living, dental and healthcare routines, etc.
  - Academics
  - Motor and leisure
  - Vocational
- Hundreds more document effectiveness of ABA methods for reducing problem behaviors (e.g., see Campbell, 2003)

Early intensive ABA for autism: Treatment model



- *Early*: generally, children enter treatment before age 6
- *Intensive*: 25-40 hrs/wk, year around, 1- 4 yrs
- *Comprehensive*:
  - Addresses skills in all domains -- "learning to learn," communication, social, self-care (e.g., safety, hygiene, eating, sleeping), cognitive, preacademic, play -- broken down into small components or steps
  - Many evidence-based ABA techniques used to develop functional skills, reduce problem behaviors
- Usually started in home, but can be done in centers
- Highly individualized to child and family needs and characteristics
- Treatment program designed and overseen by professional behavior analyst with at least a master's degree and specific training in autism

Early intensive ABA (cont'd)

- Each learner's strengths and weaknesses assessed by direct observation and measurement
- Each component skill developed via many carefully planned learning opportunities
  - in both structured and naturalistic situations
  - using written protocols
  - with lots of repetition and positive reinforcement
  - in 1-to1 format initially; gradually changed to small group
- Problem behaviors are not reinforced; appropriate alternative behaviors are
- Where possible, child makes gradual transition to regular preschool or elementary school program

Early intensive ABA (cont'd)

- Behavior analyst
  - Designs treatment program (goals and objectives, intervention methods) in collaboration with parents and other team members
  - Trains parents and "tutors" or "therapists" to deliver most intervention, under close supervision
  - Reviews graphed data on every skill and problem behavior at least weekly, modifies intervention methods as needed
  - Determines when objectives have been obtained or need to be modified
- Treatment goal: help child develop skills that enable safe, successful, independent functioning, both in the short and the long run

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Research on early intensive ABA for autism

- Summaries that follow are drawn from published studies with
  - Treatment group that received ABA intervention *directed by qualified behavior analysts* and one or more comparison groups of similar children
    - Intensive ABA: 25 - 40 hrs/wk
    - Low-intensity ABA: less than 20 hrs/wk
  - Children in *all groups* had autism or PDD-NOS, average developmental rates of about .50 in most skill domains except motor skills pre-treatment
  - ABA intervention provided mainly by tutors, college students, paraprofessionals, and parents trained by the behavior analysts
  - Comparison groups received interventions (e.g., "eclectic" or mixed-method intervention, standard early intervention) from qualified professionals trained in autism

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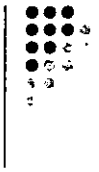
Research on early intensive ABA for autism



- Excluded: studies with other populations; single-group studies (e.g., Weiss, 1999); studies with "ABA" intervention directed by individuals with inadequate or unknown training in behavior analysis (e.g., Magiati, Charman, & Howlin, 2007; Sheinkopf & Siegel, 1998).
- Tables of effectiveness data show average gains [+] and losses [-] on standardized tests of developmental levels/cognitive skills, communication skills, social skills, and adaptive skills administered by independent evaluators in most studies
  - Several researchers also measured academic skills, educational placement, problem behaviors, autism characteristics, parental stress, etc. -- data not shown in tables

Between-groups studies of intensive ABA - UCLA model

Study	Group assignment	Tx Gp (Int ABA)	Comp Gp 1	Comp Gp 2
Lovaas (1987); McEachin, Smith, & Lovaas (1993) [US]	Case control (therapist availability)	N = 19 40 hrs/wk, 2+ yrs In homes	N = 19 ABA 10 hrs/wk + spec ed	N = 21 Standard spec ed
Sallows & Graupner (2005) [US]	Random*	N = 13 38 hrs/wk, 2+ yrs In homes	N = 10 *Parent-managed ABA*, 31 hrs/wk, 2+ yrs	
Cohen, Amerine-Dickens, & Smith (2006) [US]	Case control (IFSP/IEP teams)	N = 21 35-40 hrs/wk, 3+ yrs In homes	N = 21 Standard spec ed	
Eikeseth, Smith, Jahr, & Eldevik (2002, 2007) [Norway]	Case control (supervisor availability)	N = 13 28 hrs/wk 1 yr, 18 hrs/wk 2nd yr In classrooms	N = 12 Int eclectic, 29 hrs/wk 1 yr, 16 hrs/wk 2nd yr	
Smith, Groen, & Wynne (2000) [US]	Random	N = 15 25 hrs/wk, 33m In homes	N = 13 *Parent-managed ABA*, 10 hrs/wk + spec ed, 33m	

*Both groups received intensive ABA

Between-groups studies of intensive ABA - other models

Study	Group assignment	Tx Gp (Int ABA)	Comp Gp 1	Comp Gp 2
Howard, Sparkman, Cohen, Green, & Stanislaw (2005) [US]	Case control (IFSP/IEP teams)	N = 29 25-40 hrs/wk, 14m In homes	N = 16 Int eclectic, 25-30 hrs/wk, 14m	N = 16 Nonint eclectic, 15 hrs/wk, 14m
Zachor, Ben-Itzchak, Rabinovitch, & Lahat (2007) [Israel]	Case control	N = 20 35 hrs/wk, 1 yr In classrooms	N = 19 Eclectic/ developmental 35 hrs/wk, 1 yr	
Remington, Hastings, Kovshoff, Espinosa, Jahr, Brown, Alsford, Lemaic & Ward (in press) [UK]	Case control (parent selected)	N = 23 25 hrs/wk, 2 yrs In homes	N = 21 Standard spec ed 16 hrs/wk, 2 yrs	

Effectiveness: Intensive ABA vs. parent-managed ABA or special ed

Study	Measures	Mean Changes - ABA Tx Gp	Mean Changes - Comp Gp 1	Mean Changes - Comp Gp 2
Lovaas (1987)			Low-int ABA +spec ed	Standard spec ed
	IQ*	+20	0	0
Sallows & Graupner (2005)			*Parent-mgd int ABA*	
	IQ*	+22.2	*+27.5*	
	Nonverbal IQ*	+ 7.0	*+ 6.7*	
	Rec lang*	+17.0	*+27.0*	
	Exp lang*	+ 5.4	*+10.8*	
	Adaptive*	+ 9.5	*+ 5.8*	
Cohen et al (2006)			Standard spec ed	
	IQ*	+25	+14	
	Nonverbal IQ*	+13	+13	
	Rec lang*	+20	+ 9	
	Exp lang*	+25	+15	
	Adaptive*	+ 9	- 4	
Smith, Groen & Wynne (2000)			*Parent-mgd ABA*	
	IQ*	+16.0	*- 01.0*	
	Nonverbal IQ**	+42.7	*+27.3*	
	Rec lang**	+29.4	*+19.3*	
	Exp lang**	+29.4	*+19.9*	
	Adaptive*	- 02.2	*- 06.7*	
Remington et al. (in press)			Standard spec ed	
	IQ*	+12.0	- 2.2	
	Adaptive***	+ 88.1	+ 69.3	

*Standard scores; **age equivalent scores; ***raw scores

Effectiveness: Intensive ABA vs. eclectic intervention

Study	Measures	Mean Changes - ABA Tx Gp	Mean Changes - Comp Gp 1	Mean Changes - Comp Gp 2
Eikeseth et al (2002, 2007)			Intensive eclectic	
	IQ*	+25	+ 7	
	Adaptive*	+11	-10	
Howard et al (2005)			Intensive eclectic	Nonint electic
	IQ*	+29.7	+8.4	+8.9
	Nonverbal IQ*	+20.6	+6.1	+2.3
	Rec lang*	+20.2	+3.9	- 4.8
	Exp lang*	+20.1	+3.8	- 4.5
	Adaptive*	+10.5	- 0.6	- 2.8

*Standard scores

Note: Zachor et al. (2007) not included because authors did not use same standardized tests as in other studies, but they did find that intensive ABA produced greater reductions in autism symptoms than intensive eclectic/developmental intervention, based on the Autism Diagnostic Observation Survey.

Between-groups studies of low-intensity ABA

Study	Group assignment	Tx Gp (Int ABA)	Comp Gp
Birnbrauer & Leach (1993) [Australia]	Case control (supervisor availability)	N = 9 18.7 hrs/wk, 2 yrs In homes	N = 5 Standard special ed, hrs/wk, 2 yrs
Eldevik, Eikeseth, Jahr, & Smith (2006) [Norway]	Case control (education teams)	N = 13 12.5 hrs/wk, 20m In classroom	N = 15 Eclectic, 12 hrs/wk, 21m

Effectiveness: Low-intensity ABA vs. special ed and intensive eclectic intervention

Study	Measures	Mean Changes - ABA Tx Gp	Mean Changes - Comp Gp
Birnbrauer & Leach (1993)			Standard spec ed
	IQ*	+ 7	NT
	Nonverbal IQ*	+ 29	NT
	Lang*	+ 6	- 8
	Adaptive*	- 5	- 7
Eldevik et al (2006)			Nonint eclectic
	IQ*	+ 8.2	- 2.9
	Nonverbal IQ*	+ 8.6	- 10.5
	Rec lang*	+ 6.8	- 7.7
	Exp lang*	+ 11.0	- 6.4
	Adaptive*	- 0.2	- 4.8

*Standard scores; NT = untestable

Main findings

- Professionally directed early intensive ABA (25-40 hrs/wk) produced larger improvements than typical EI/special ed, eclectic interventions, and low-intensity ABA in
  - Cognitive skills (full-scale and nonverbal IQ)
  - Communication skills (receptive and expressive)
  - Social skills
  - Play skills
  - Academic skills
  - Adaptive and self-care skills
  - Problem behaviors
  - Autism characteristics
  - Parental stress
- Just under 50% of children receiving early intensive ABA made large gains in multiple skill domains, achieved normal or near-normal functioning
  - ~ 40% made modest gains and ~10% made small gains as measured on standardized tests

Main findings

- Proportions of children who moved from delayed to normal range on IQ (all between-groups studies combined):
  - Intensive ABA: 61/133 = 46%
  - Typical special ed: 14/79 = 18%
  - Intensive eclectic: 4/28 = 14%
- Largest gains occurred when intervention was most intensive (≥ 30 hrs/wk)
- Parent-managed ABA (with consultation) produced mixed results

Main findings

- Low-intensity ABA produced smaller gains than intensive ABA (not clinically significant), but larger than typical and eclectic intervention
- Other interventions produced negligible gains or losses in most studies
  - Eclectic intervention (mixture of developmental, TEACCH, sensory integration, speech therapy, PECS, and/or ABA methods) was largely ineffective *even when individualized and intensive*
    - *Intensity alone isn't sufficient;* type of intervention matters
- Several uncontrolled studies and case reports with objective measures corroborate effectiveness of early intensive ABA

Health insurance coverage of ABA treatment for autism: Rationale (Autism Speaks)

- Children with autism have greater health care needs than children without autism.
- Treatments are difficult to access, often inadequate and delayed; parents must pay out of pocket or children must go without needed treatment.
- Mandated insurance coverage will bring effective treatment to children who need it. ABA has proved effective.
- Several government and scientific organizations endorse ABA.
- Cost of insurance coverage of ABA is relatively small, will result in savings by improving outcomes for children and reducing lifetime cost of care.

Health insurance coverage of ABA treatment for autism

- At least 20 self-insured companies provide ABA benefit, recognize Board Certified Behavior Analysts (BCBAs) as providers
  - Includes Microsoft, Home Depot, Intel, Cisco Systems, Eli Lilly, Mayo Clinic
- U.S. military's insurance (TRICARE) provides ABA benefit under a "demonstration program"
- Medicaid provides some coverage in some states, but typically inadequate for children to make meaningful improvements

Health insurance coverage of ABA treatment for autism

- 8 states have legislation mandating private health insurance coverage of ABA
  - IN - dollar limits cannot be less favorable than those for physical illnesses
  - SC - up to $50k per year through age 16
  - TX - up to $50k per year, ages 3-6
  - FL - up to $36k per year, $200k lifetime
  - AZ - up to $50k per year through age 8, $25k per year ages 9-16
  - LA - up to $36k per year, $144k lifetime
  - PA - up to $36k per year, no lifetime cap
  - IL - up to $36k per year through age 21
  - Most place no limits on number of visits for ABA
- Bills planned for 26 states this year (see www.autismvotes.org)
- President-elect Obama has proposed federal mandate

Summary and conclusions

- Contemporary ABA intervention for autism rests on more than 40 years of scientific research
  - At present, no other approach to autism intervention has comparable scientific support (Eikeseth, 2008; Myers et al/AAP, 2007; New York State Department of Health, 1999).
- Best available evidence indicates that *competently directed and delivered* early intensive ABA intervention is especially effective (Dawson, 2008; Eikeseth, 2008; Myers et al/AAP, 2007; New York State Department of Health, 1999; Rogers & Vismara, 2008; U.S. Department of Defense, 2007; U.S. Surgeon General, 1999).

Summary and conclusions

- Estimated savings from investment in early intensive ABA:
  - At least $2 million per individual in childhood and adult services costs combined [using 1996 Pennsylvania costs] (Jacobson, Mulick, & Green, 1998)
  - Millions in health care costs over the lifespan (e.g., Leslie & Martin, 2007; Mandell, 2007)
- Focused ABA interventions are also effective for building specific skills and reducing problem behaviors -- thereby reducing health care costs -- for people with autism of all ages

For more information on ABA for autism, please see...

- www.behavior.org/autism (Cambridge Center for Behavioral Studies)
- www.autismspeaks.org/whattodo/what_is_aba.php (Autism Speaks)
- www.apbahome.net (Association of Professional Behavior Analysts)
- www.asatonline.org (Association for Science in Autism Treatment)

For qualifications to practice applied behavior analysis, please see...

- Behavior Analyst Certification Board -- www.BACB.com
- Association of Professional Behavior Analysts -- www.APBAhome.net
- Association for Behavior Analysis Autism Special Interest Group Consumer Guidelines - http://www.autismsig.org
- American Psychological Association Specialty in Behavioral Psychology -- http://www.apa.org/crsppp/archivbehav.html

Mandates don't work against, but for, consumers

By Jeff Raymond
State view

March 13, 2009 04:30 pm

— It's practically an article of faith that mandates to cover specific conditions, drugs and treatments increase costs and lead to a greater number of uninsured.
What's often overlooked is that mandates may, in the long run, save money.
Oklahoma has required insurers to cover the cost of diabetic testing and treatment since 1996. The cost of covering diabetic supplies pales in comparison to the cost of caring for diabetics who haven't managed the condition.
Consider breast cancer: A mammogram costs $50 to $150. The average cost of breast cancer treatment is more than $20,000, according to the National Cancer Institute. Catching tumors early saves considerable money later, not to mention women's lives.
In 2006, according to state Health Department data, 67.7 percent of Oklahoma women over age 40 reported having had a mammogram during the previous two years. In 1996, 59.5 percent reported having had a mammogram during previous two years. In 1988 the number was 42.9 percent.
Required coverage of mammograms has been on the books in Oklahoma since 1988.
The increase in mammography rates has come about because of many factors, including better education and increased availability. But we owe it to ourselves to consider the effect of requiring the procedure to be covered.
Oklahoma's mandate count, 36, falls in the middle. Requirements range from hearing aids to well child care. Interestingly, some states that have far more mandates have more affordable insurance and/or a lower rate of uninsured.
Opponents of mandates focus on their aggregate cost. Yet pinning down the cost of mandates is notoriously difficult. Estimates are unreliable, as the wildly varying estimates of the cost of autism coverage have shown.
We should begin looking at mandates as a reflection on the high cost and disappointing quality of health care rather than their cause. If health insurance companies would serve policyholders rather than block the care they seek, average Oklahomans wouldn't seek redress through the legislative process.
Insurance companies' routine refusal to cover common-sense medical care, especially cost-saving preventative care, has led to mandates. It's time for Oklahomans to look at mandates as a way to improve health care for much less cost than ultimately caring for the sick.
The huge shift in political support for mental health parity illustrates this. Many researchers now accept that it's cheaper to treat someone for mental illness than suffer lost work and productivity.
The National Association of Health Underwriters claims the more groups demand specialized mandates, the more "the train gets a full head of steam" and can't be stopped. Disease- and condition-specific lobbies will queue up and demand coverage as well.
The organization slips into old scare tactics. With health care premiums for an Oklahoma family increasing by 62 percent from 2000-2007, requiring more in return isn't asking too much.
Because coming up quickly with tens of thousands of dollars is impossible for most of us, the end result of requiring insurance companies to do less is to shift the cost to taxpayers.
Opponents of mandates argue that nothing is free. They're right: Someone pays for health care. It's just a question of whom — taxpayers or insurance companies.
Jeff Raymond is executive director of OKWatchdog in Oklahoma City. Call it at (405) 824-2382.

From: **AUTISM SPEAKS**

AUTISM SPEAKS

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FOR IMMEDIATE RELEASE

AUTISM SPEAKS ENDORSES ALASKA AUTISM INSURANCE REFORM BILL

House Bill 187 Would End Health Care Discrimination Against Children with Autism by Requiring Coverage of Diagnosis and Treatment

Juneau, AK (March 19, 2009) – Autism Speaks, the nation's largest autism advocacy organization, today announced its support for House Bill 187, also known as the autism insurance reform bill. The legislation would require private health insurance companies to cover the diagnosis, testing and treatment of autism spectrum disorder (ASD). The maximum benefit would be $36,000 per year.

Sponsored in the Alaska State House of Representatives by State Representative Pete Petersen (D-19) HB 187 includes coverage of Applied Behavior Analysis (ABA), an evidence-based, medically-necessary autism therapy.

"We applaud and thank Representative Petersen for his leadership on this issue of critical concern to thousands of Alaska families," said Elizabeth Emken, Autism Speaks Vice President of Government Relations. "Autism Speaks joins Alaska's autism community in calling on the legislature to pass HB 187 and join the growing number of states that have ended healthcare discrimination against children with autism."

Most states do not require private insurance companies to cover even essential autism treatments and services. In the absence of coverage, families often pay as much as they can out-of-pocket for services that can cost upwards of $50,000 per year. In the process, many risk their homes and the educations of their unaffected children – essentially mortgaging their entire futures.

Eight states – Arizona, Florida, Louisiana, Illinois, Indiana, Pennsylvania, South Carolina and Texas -- have enacted autism insurance reform legislation. Several other state legislatures will vote on similar legislation during the current session.

To learn more about Autism Votes, an initiative of Autism Speaks focused on federal and state legislative advocacy, please visit **www.autismvotes.org**.

About Autism
Autism is a complex brain disorder that inhibits a person's ability to communicate and develop social relationships, and is often accompanied by behavioral challenges. Autism spectrum disorders are diagnosed in one in 150 children in the United States, affecting four times as many boys as girls. The prevalence of autism has increased tenfold in the last decade. The Centers for Disease Control and Prevention have called autism a national public health crisis whose cause and cure remain unknown.

About Autism Speaks
Autism Speaks is dedicated to increasing awareness of autism spectrum disorders, to funding research into the causes, prevention and treatments for autism, and to advocating for the needs of individuals with autism and their families. It was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Bob Wright is Senior Advisor at Lee Equity Partners and served as vice chairman, General Electric, and chief executive officer of NBC and NBC Universal for more than twenty years. Autism Speaks merged with both the National Alliance for Autism Research (NAAR) and Cure Autism Now (CAN), bringing together the nation's three leading autism advocacy organizations. To learn more about Autism Speaks, please visit www.autismspeaks.org

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January 30, 2009

Actuarial Cost Estimate: Virginia House Bill 1588 - Coverage for the Diagnosis and Treatment of Autism Spectrum Disorder

OLIVER WYMAN

Prepared By:

Marc Lambright, FSA, MAAA

MARSH MERCER KROLL
GUY CARPENTER OLIVER WYMAN

Contents

1

Background

Oliver Wyman Actuarial Consulting, Inc. (Oliver Wyman or We) has been engaged by Autism Speaks to develop a cost model in order to analyze and estimate the impact of mandated insurance benefits for Autism Spectrum Disorders (ASD) on insurance premiums. As part of this work, Oliver Wyman has developed a range of independent estimates of the impact on insurance premiums for the benefits mandated by Virginia HB 1588 offered January 14, 2009 which provides coverage for the diagnosis and treatment of autism spectrum disorder in individuals under the age of 21.

Oliver Wyman is a part of the Marsh & McLennan (MMC) family of companies. With over 60 members of the American Academy of Actuaries, Oliver Wyman is one of the largest actuarial practices in North America. Oliver Wyman's health practice, which has twelve credentialed actuaries, advises insurers, regulators, governments, interest groups, and others.

This report, along with its supporting analysis, was developed by Marc Lambright, a Principal and consulting health actuary in Oliver Wyman's Philadelphia office. Marc is a Fellow of the Society of Actuaries and a member of the American Academy of Actuaries and is professionally qualified to analyze the cost impact of HB 1588 and provide the estimates shown in this report. As part of Oliver Wyman's quality assurance process, the underlying analysis and this report were independently peer reviewed by another credentialed Oliver Wyman actuary.

2

Scope and Limitations

The intent of this analysis is to provide a reasonable range of estimates for the insured costs of the mandated ASD benefits provided for in HB 1588 and the associated premium impact on the markets affected by HB 1588. This analysis makes no attempt to quantify potential offsetting cost savings associated with successful ASD treatment, nor does it include the any estimate of the potential reduction in other government expenditures associated with providing ASD services that might overlap with the benefits provided by this mandate. Therefore, the reader is cautioned that this report should only be considered a cost analysis, and not be misconstrued as a cost-benefit analysis when assessing the merit of HB 1588.

We note that cost estimates for autism mandates have varied widely. The JLARC analysis of the impact of Virginia HB 83 showed a range of per member per month (PMPM) group standard premium impact estimates made by 20 Virginia insurers that varied by a factor of 154[1]. This variability of the cost estimates in the JLARC report is not entirely inconsistent with the variance in estimates for similar mandated autism benefits in other states. The reason for this variability is that the largest component of the increase in costs under the HB 1588 mandated ASD benefits is for Applied Behavior Analysis ("ABA"), which is almost universally excluded from health coverage, and therefore essentially no insured data exists for use in developing credible utilization and unit cost estimates for ABA.

[1] *JLARC: Evaluation of House Bill 83: Mandated Coverage of Autism Spectrum Disorders.* September 2008, p. 8.

The reader is cautioned that the ultimate cost of covering ABA benefits is uncertain; however, this analysis attempts to reflect the likely behavior of consumers, providers and insurers of ABA services in developing the assumptions underlying the cost estimates. Likewise, the additional costs for mandated medical services other than ABA are difficult to quantify. Insurance policies often cover some services for children diagnosed with an ASD, although the mandate could cause the costs for certain services to increase because ASD exclusions are common, and certain services that may have been denied or terminated following utilization review might be covered due to the mandate.

3

Description of Key HB 1588 Provisions and their Impact on Covered Benefits

Insurance Markets Covered by Mandate

Section F outlines which markets are excluded from the mandate, of particular note is F(iii) which notes the exclusion of *policies, contracts, or plans issued in the individual market or small group markets to employers with 25 or fewer employees.* In our modeling we are assuming that this means that the individual market would not be subject to this mandate, and that the statutory small group (2-50 employees) market would be covered by the mandate. Therefore, our analysis is based on the commercial insured market, which includes both the small group (2-50 employees) and large group (51+ employees) markets. We note that our estimates of the impact on premium are nearly identical for the large and small group markets.

Covered Benefits

The mandate provides *coverage for the diagnosis and treatment of autism spectrum disorder in individuals under the age of 21.* Treatment includes: *(i) habilitative or rehabilitative care; (ii) pharmacy care; (iii) psychiatric care; (iv) psychological care; and (v) therapeutic care.*

The definition of *habilitative or rehabilitative care* is especially important since it includes applied behavioral analysis (ABA). The coverage of ABA has the most significant impact on cost of any mandated service. ABA programs are marked by intensive therapy that may include 30-40 hours of therapy a week under the most intensive programs, though many programs would not utilize that level of resources. Key assumptions underlying our ABA cost estimates are outlined in Section 5.

Annual Maximum Benefit of $36,000

The annual coverage maximum is important as it has the effect of capping costs for the heaviest users of ASD services. From a practical standpoint, this would generally apply to children whose therapy includes an intensive ABA program.

Medical Necessity and Treatment Review

The bill does allow for *undertaking of usual and customary procedures to determine the appropriateness of, and medical necessity for, treatment of autism spectrum disorder.* This is important as insurers will develop protocols to review treatments and manage care which will limit unnecessary treatments if reviews are done appropriately.

4

Modeling Methodology

The following outlines the general modeling methodology used to develop the cost estimates. Estimates were developed both on a PMPM basis, and as a percentage of average annual premiums as shown in Section 6. Details of key assumptions are discussed in Section 5 and illustrated graphically in the exhibits shown in Appendix 1.

Modeling Perspective

In general, the model was developed to produce costs under the assumption that sufficient providers would be available to meet the demand for autism services, especially with regard to ABA services. It also assumes that there would be sufficient awareness of autism and motivation (primarily by parents) to seek treatment so that the diagnosis and treatment of ASDs would be more in line with the often cited CDC estimated prevalence of ASD of 1 in 150. We would expect that it would take at a minimum several years for both the supply of providers to meet the demand for mandated ASD services and for parents of autistic children to aggressively seek diagnosis and treatment of their children's disorders.

In spite of these real limitations that will likely limit short-term costs associated with mandated autism benefits, we feel that it is appropriate from a public policy perspective to look at the costs from a longer term perspective and assume that both awareness of ASDs will increase and that supply and demand for ASD services would eventually be in balance. We have developed our estimates with this in mind.

In the near term we would note that the supply of ABA service providers, specifically credentialed Board Certified Behavior Analysts (BCBAs) and Board Certified Associated Behavior Analysts (BCaBAs) would not be sufficient to meet the demand for ABA programs if ABA benefits are mandated. There are currently about 122[2] certified BCBAs and BCaBAs in Virginia, which translates to less than one therapist per 100 autistic

[2] BACB Certificant Registry: http://www.bacb.com/cues/frame_about.html, accessed January 2009.

children in Virginia assuming a 1 in 150 prevalence rate for autism. While it is true that not all autistic children will have an ABA program, it is also true that behavioral analysts provide services to individuals other than autistic children. It is reasonable to conclude that demand for ABA services, at least initially, would exceed supply should health care coverage similar to that mandated by HB 1588 become typical.

It is also instructive to look at some of the limited evidence available related to actual costs of ABA mandated benefits in other states. Aetna noted in December 2008 that it had tracked the cost of the autism mandate in Texas for its first year of existence and found that it increased costs for policyholders who filed autism-related claims by $379 a month. A total of 235 policy holders had filed autism claims in the state as of the time the data was released. At that time, the company had not decided whether to pass those costs on to the policyholders because the cost of the mandate might change after the first year.[3] While this is only first year experience for a single insurer, it illustrates that initial mandate costs are likely low. Aetna's Texas block of business is quite large (approximately $1.5 - 2.0 billion in premium[4]), so the statistics provided indicate a mandate cost of less than 0.1% of premium.

General Modeling Process

The modeling process employed to develop our cost estimates was as follows:

1. Prevalence rates were developed so that overall ASD prevalence is equal to the CDC 1 in 150 ASD prevalence estimate for the United States.
2. Prevalence rates by diagnostic subtype (autistic disorder, PDD-NOS, Asperger's Syndrome) were estimated separately as diagnosis patterns and service utilization could reasonably be expected to vary by diagnostic subtype.
3. The percentage of children diagnosed by age for each diagnostic subtype was estimated so that the average age of diagnosis implicit in the modeling is consistent with publicly available age at diagnosis statistics[5].
4. The percentage of diagnosed children who could be expected to have an ABA program was estimated for each age based on assumptions regarding how many children would start a program and typical program continuance.
5. A distribution of the number of annual hours for an ABA program was developed based on ABA provider input and an assumption that utilization review by insurers would impact utilization to some degree.
6. Based on the assumed treatment prevalence, likelihood of having an ABA program, assumed distribution of ABA program hours, and estimated ABA program cost per hour of therapy, ABA cost estimates by age were developed and adjusted to reflect the impact of the annual $36,000 cap.

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[3] Lawmaker: Oklahoma autism bill has momentum. Associated Press. December 4, 2008. http://newsok.com/article/3327594 accessed January 2009.

[4] NAIC Annual Statements for 2007.

[5] IAN database. http://dashboard.ianexchange.org/StateStatsAdvanced.aspx?A1=VA&ADU=T. Accessed January 2009.

7. Non-ABA costs were estimated based upon studies of medical costs for ASD children and judgment regarding the increase in costs that could be expected due to the mandated benefits.
8. Based on Census demographic data and the cost estimates for mandated ASD services by age as outlined in 1-7 above, an annual cost per covered individual was developed.
9. The cost of services was increased to reflect administrative and other insurer costs or profit charges.
10. The estimated size of the covered market was developed based on Census, Medical Expenditure Panel Survey (MEPS) enrollment and premium information for Virginia, and Kaiser Family Foundation coverage data. These assumptions are further documented in the following section.
11. The cost of the mandated services per covered person and as a percentage of premiums were calculated based on the model cost estimates and market data.

5

Summary of Key Assumptions

Key assumptions underlying the cost estimates for the mandated benefits are summarized in this section. Appendix 1 further illustrates these assumptions.

Treated Prevalence and Age at Diagnosis

Overall prevalence is based on a 2007 CDC[6] study, with prevalence by diagnostic subtype estimated based on an academic study published in the American Journal of Psychiatry[7].

As noted in the previous section, the percentage of children diagnosed by age for each diagnostic subtype was estimated so that the average age of diagnosis implicit in the modeling is consistent with publicly available age at diagnosis statistics.

The base model assumptions for Virginia are shown below:

Diagnostic Subtype	Prevalence	Average Age at Diagnosis
Autistic Disorder	1 in 450	3
PDD-NOS	1 in 300	3
Asperger's Syndrome	1 in 900	6
All ASD	**1 in 150**	

[6] Centers for Disease Control. Morbidity and Mortality Weekly Report. February 9, 2007.

[7] Fombonne, E. and S. Chakrabarti. American Journal of Psychiatry. June 2005.

ABA Program Utilization and Cost

ABA Program Utilization by Age

ABA programs require a significant commitment from affected children, as well as their families. It is likely that a significant number of ASD children will not have an ABA program regardless of the availability of a provider. For this reason, we have assumed that two-thirds of diagnosed children will begin an ABA program. ABA programs are generally geared towards addressing deficits in younger children and are generally not intended to be continued indefinitely. For this reason, we have assumed that no programs would terminate prior to school age, that a large percentage of ABA programs would terminate at ages six and seven when an autistic child could be expected to enter elementary school, and thereafter programs would terminate gradually until only a small percentage of children have ABA programs in their teenage years. Programs could be expected to terminate if a child has experienced sufficient progress so that a program is no longer necessary, or if the insurer or family sees no progress, as well as for other reasons.

The assumed percentage of children diagnosed with ASD that have an ABA program is shown in the table below:

	% of Diagnosed Children with an ABA Program by Age
6 and Under	66.7%
6	50.0%
7	33.3%
8	30.0%
9	26.7%
10	23.3%
11	20.0%
12	16.7%
13	13.3%
14	10.0%
15 and Over	6.7%

ABA Program Annual Number of Hours

In developing the assumed annual ABA program hours, we discussed typical ABA programming with ABA providers, and reviewed some benefit materials from one of the few large self-insured employers who offers ABA benefits. For three age bands, we developed a distribution of expected hours that resulted in the annual averages shown in the table below.

Average ABA Program Hours by Age	
Ages Under 8	1,509
Ages 8 to 12	781
Ages 13 to 20	401

The general assumption is that pre-school aged children will have programs for 20 to 40 hours a week, averaging about 30 hours a week. This time will be reduced by roughly half by age eight when children would be expected to be in school and the school system would be required to provide services during the school day, and then would be cut in half again at age 13 as the child ages and ABA programs would be expected to be less time consuming and address a smaller number of behavioral deficits.

Cost per Hour of ABA Service

In developing the costs per hour, we reviewed ABA program staffing information and ABA provider wage and overhead cost assumptions. We developed an average cost for the entire United States and then adjusted this for Virginia, based on Bureau of Labor Statistics[8] health care wage data. The resulting average cost per hour of ABA therapy is $45.45.

Other (than ABA) Medical Costs

Based on several studies[9], we estimated that children with ASDs used approximately three times the non-inpatient medical services (other than ABA) under current benefit programs. It is also clear that the mandate would mean that services that an insurer could currently deny or exclude would now be covered. In our base estimate, we assumed that the mandate would result in additional insured medical costs equal to the current level of covered non-inpatient costs for services to children diagnosed with an ASD.

Administrative Costs

Typically, group medical claims costs could be expected to be 80 to 90% of premiums, meaning 10 to 20% of premiums are available for administration, profit, or other costs, often collectively referred to as "retention." We have estimated the incremental retention charge to be 15% of premium under our base cost assumption.

Virginia Market Data

The MEPS survey provides average premiums, enrollees, offer rates, take-up rates, and self-insured percentages by employer size for healthcare coverage sponsored by privately insured employers. From this data we can estimate the size of the privately insured small group, insured large group, and self-insured markets. State specific premium data for Virginia was available for 2006[10], so we trended this based on average recent employer premium increases provided from the Kaiser Family Foundation HRET[11] survey to estimate the 2009 average annual premium per member necessary to compute the cost of mandated benefits as a percentage of annual premiums.

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[8] BLS wage data. http://www.bls.gov/guide/geography/wages.htm accessed January 2009.

[9] Mandell, Cao, Ittenbach, & Pinto-Martin, 2006. Croen, Najjar, Ray, Lotspeich, & Bernal, 2006. Liptak, Stuart, & Auinger, 2006.

[10] MEPS state survey data. http://www.meps.ahrq.gov/mepsweb/data_stats/state_tables.jsp?regionid=-1&year=-1. Accessed January 2009.

[11] Kaiser Family Foundation and Health Research Educational Trust. Employer Health Benefits- 2008 Annual Survey.

6

Cost Estimates

Base Cost Estimate

The table below summarizes the mandate costs and impact on small and large group premiums under the base assumptions outlined in Section 5. The base estimate is that the long-term cost of the mandated benefits provided by HB 1588 would be about 0.60% of insured premiums, though this cost would likely initially be lower in the years immediately following the passage of the mandate.

	Market		
	Small Group	Large Group	All
Covered Persons	649,000	1,061,000	1,710,000
Average Premium per Person	$3,900	$3,800	$3,838
Annual Mandate Claim Cost per Covered Person	$19.50	$19.50	$19.50
Claim Cost as a Percentage of Premium	0.50%	0.51%	0.51%
Estimated Premium Increase with Admin @ 15%	22.90	22.90	$ 22.90
Premium Increase as a Percentage of Premium	0.59%	0.60%	0.60%

Scenario Estimates

As discussed in Section 1, very little insurance data exists that can be used to directly estimate the costs of ABA benefits mandated by HB 1588. This causes uncertainty in developing actuarial assumptions and cost estimates. Due to this uncertainty, it is useful to develop cost estimates for additional scenarios using more optimistic and pessimistic assumptions. A reasonable range of the long-term impact of the mandated HB 1588 benefits is that premiums would increase 0.45% to 0.75% with a $36,000 annual benefit maximum, or cap. A reasonable estimate of the impact of mandated HB 1588 benefits assuming no annual cap is that premiums would increase 0.90%.

Appendix 1

Cost Assumptions – Illustrative Exhibits

EXHIBIT I - SUMMARY OF HB 1588 ASSUMPTIONS AND COSTS

State	Virginia
Mandate Market	
Individual	No
Small Group	Yes
Large Group	Yes
Self-Insured (ERISA)	No
State and Local Govt	No
Age Limits for Autism Benefits	
Minimum	0
Maximum	20
Annual Maximum	
All Autism Services	$36,000

Annual Limits by Covered Service

	Hours Limit	Max Hours	Dollar Limit	Max $s
ABA	No	-	Yes	$36,000

Key Assumptions:

Diagnostic Subtype	Ultimate Prevalence	Average Age of Diagnosis
Autistic Disorder	1 in 450	3
PDD-NOS	1 in 300	3
Asperger's	1 in 900	6
All ASD	**1 in 150**	

Additional Annual Medical Costs for Non ABA Services

All Ages	$ 3,900

% of Diagnosed Children w/ ABA	
6 and Under	66.7%
6	50.0%
7	33.3%
8	30.0%
9	26.7%
10	23.3%
11	20.0%
12	16.7%
13	13.3%
14	10.0%
15 and Over	6.7%

Average ABA Program Hours	
Ages Under 8	1,509
Ages 8 to 12	781
Ages 13 to 20	401
Cost per ABA Hour:	$45.45

	Coverage Estimates			Costs Excluding Administrative Expense			Premium Increase including Admin @ 15%		
Market	Number of Persons Covered	Premium (Per Person)	Total Premium	Costs	Costs (% of Premium)	Cost (Per Covered Person)	Incremental Premium	Premium Increase %	Annual Increase per Covered Person
Individual									
Small Group	649,000	3,900	2,531,100,000	12,655,500	0.50%	19.50	14,889,000	0.59%	22.90
Large Group	1,061,000	3,800	4,031,800,000	20,689,500	0.51%	19.50	24,341,000	0.60%	22.90
Self-Insured (ERISA)									
State, Local and Federal									
Total	1,710,000	$ 3,838	$ 6,562,900,000	$ 33,345,000	0.51%	$ 19.50	$ 39,229,000	0.60%	$ 22.90

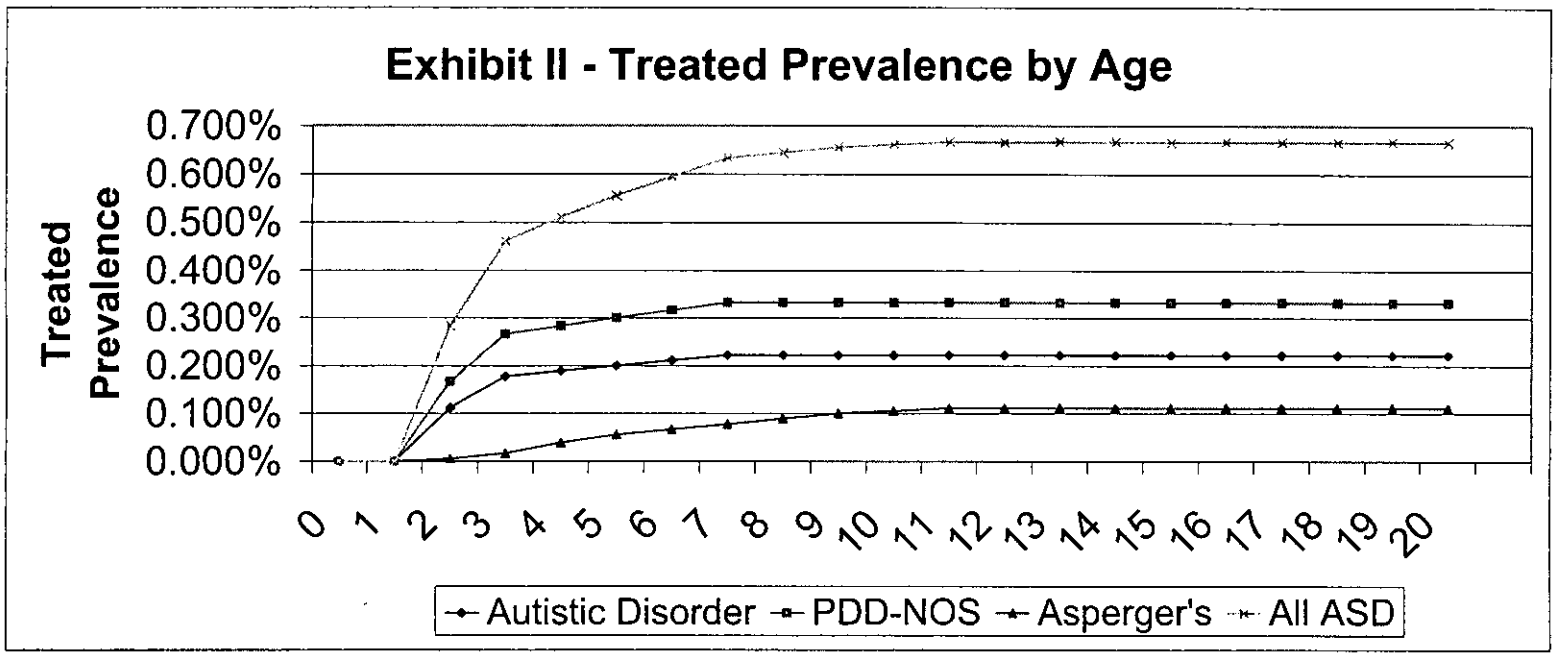
Exhibit II - Treated Prevalence by Age
Treated Prevalence
0.700%
0.600%
0.500%
0.400%
0.300%
0.200%
0.100%
0.000%
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Autistic Disorder
PDD-NOS
Asperger's
All ASD

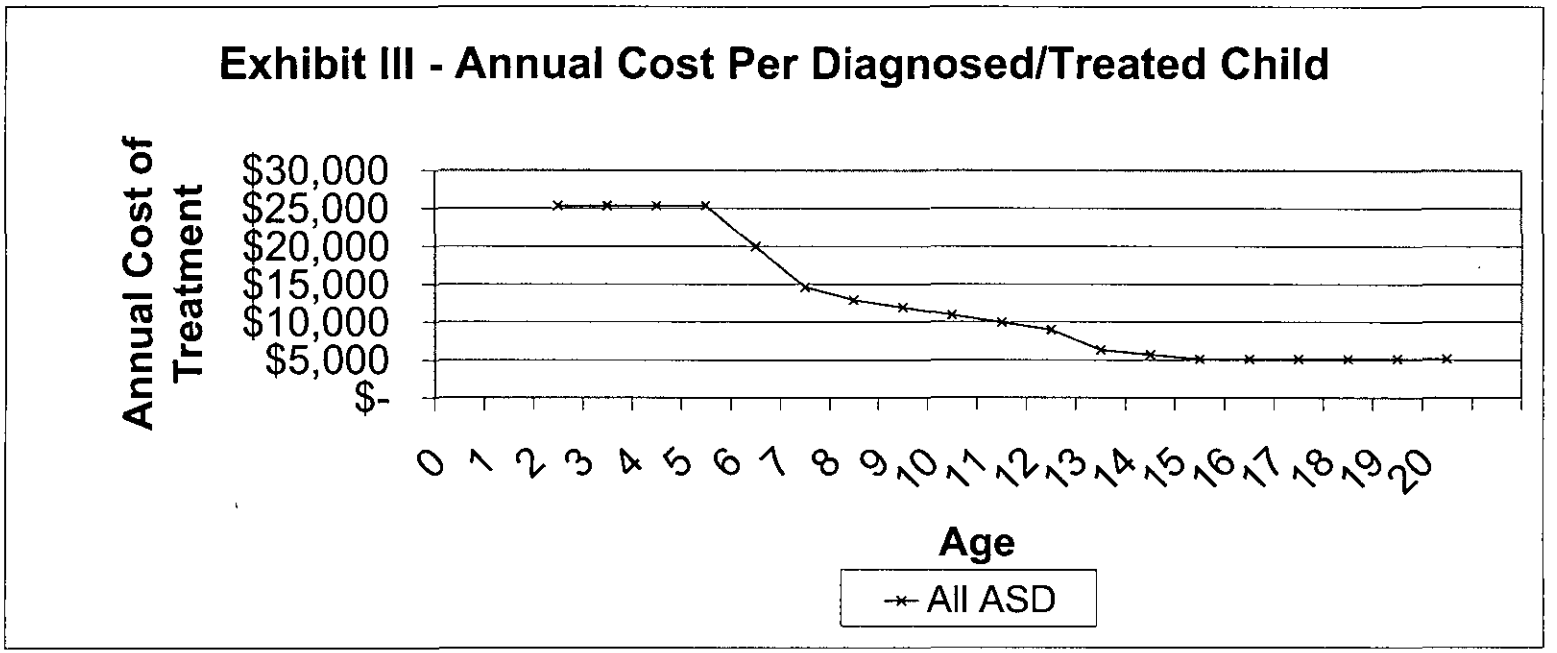
Exhibit III - Annual Cost Per Diagnosed/Treated Child
Annual Cost of Treatment
$30,000
$25,000
$20,000
$15,000
$10,000
$5,000
$-
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
All ASD

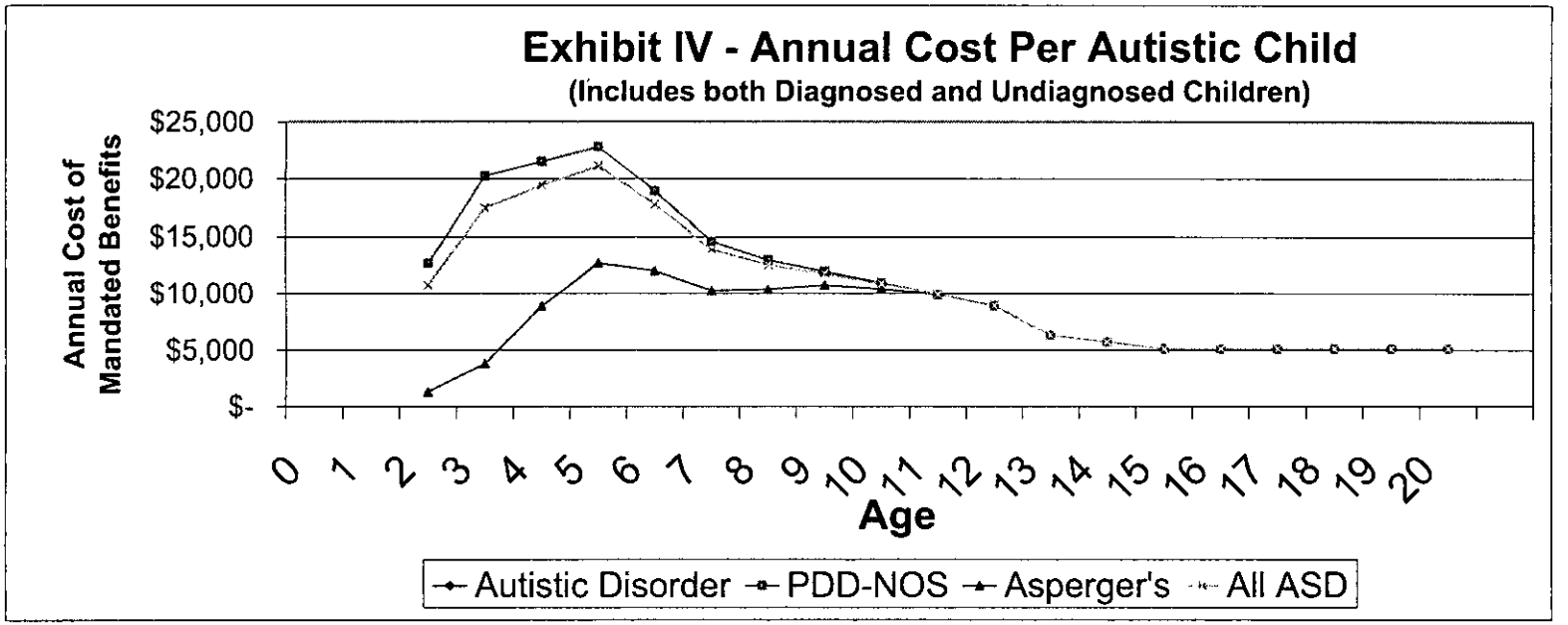
Exhibit IV - Annual Cost Per Autistic Child
(Includes both Diagnosed and Undiagnosed Children)
Annual Cost of Mandated Benefits
$25,000
$20,000
$15,000
$10,000
$5,000
$-
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
Autistic Disorder
PDD-NOS
Asperger's
All ASD

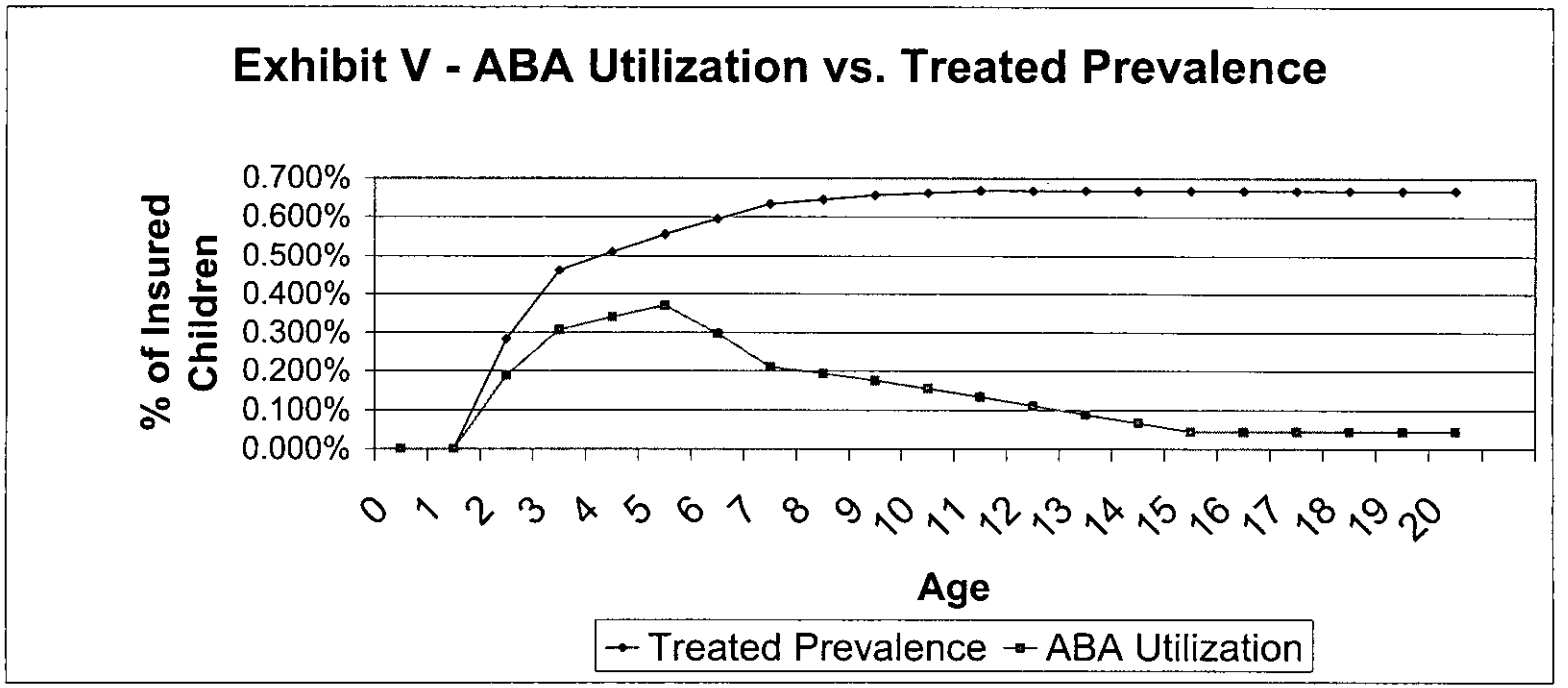
Exhibit V - ABA Utilization vs. Treated Prevalence
% of Insured Children
0.700%
0.600%
0.500%
0.400%
0.300%
0.200%
0.100%
0.000%
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
Treated Prevalence
ABA Utilization

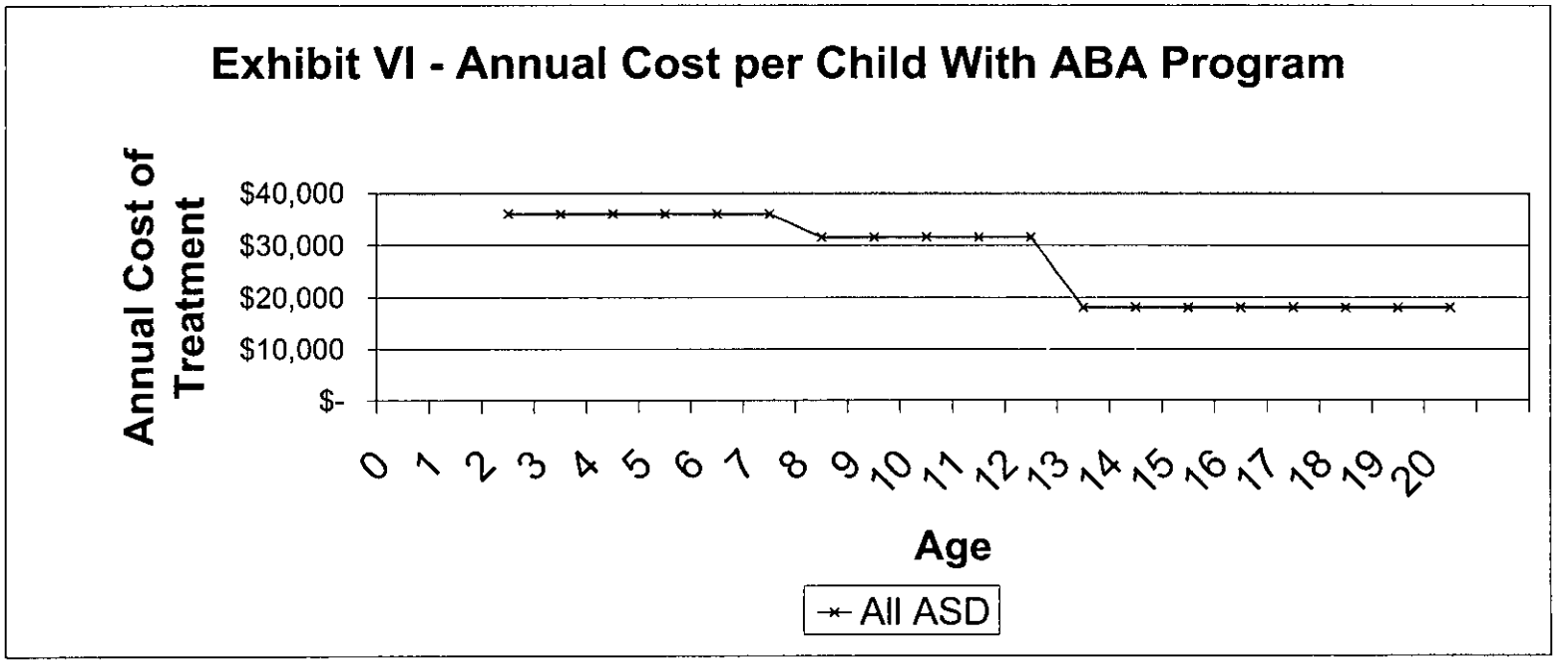
Exhibit VI - Annual Cost per Child With ABA Program
Annual Cost of Treatment
$40,000
$30,000
$20,000
$10,000
$-
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
All ASD

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15 March 2009

The Honorable Pete Petersen
Alaska State Capitol
Juneau, AK 99801

Letter of Endorsement -- HB 187

ASA strongly endorses Alaska House Bill 187 since this legislation offers clear and practical solutions that will enable Alaska families to have equal access to appropriate treatments and services that would be covered by private health insurance if it were not for the diagnosis of an autism spectrum disorder (ASD).

BACKGROUND

Autism is a complex neurodevelopmental disability that typically appears during the first two years of life and affects a person's ability to communicate and interact with others. ASA estimates the lifetime cost of care for an individual with autism at $3.5 to $4 million; with access to early diagnosis and intervention, these costs can be reduced by two-thirds. However, appropriate, effective and evidenced-based interventions are costly – upwards of $50,000 a year – and frequently not covered by private health insurance plans. Many families simply cannot afford to give their children the treatments that could help affected individuals reach their fullest potential and enjoy a happy and productive life.

Although there is no known "cure", autism is treatable. According to the American Academy of Pediatrics (AAP), "early diagnosis resulting in early, appropriate, and consistent intervention" is "associated with improved long-term outcomes."

Autism Spectrum Disorder (ASD) includes three diagnoses as defined in the *Diagnostic and Statistical Manual* (DSM IV) of the American Psychiatric Association:

1. Autism: Difficulty in the developmental areas of communication, socialization and repetitive/restricted interests and behaviors.
2. Asperger's Syndrome: Similar characteristics to autism but do not have a significant delay in language.

3. Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS): This term is used when an individual displays developmental deficits but does not meet diagnostic criteria for the other two ASD diagnoses.

ASD is now the number one childhood developmental disability with 1 of every 150 children in the US being diagnosed (CDC 2007). 26,670 children born in the US this year will eventually be diagnosed with ASD (CDC, 2007), making the diagnoses more common than all types of pediatric cancer, AIDS, and diabetes combined. According to the American Academy of Pediatrics, 44% of primary care physicians reported that at least ten of their patients have ASD.

Males are four (4) times more likely to be diagnosed than females; in contrast, females are more likely to be severely impacted by autism when a diagnosis exists. Females are also more likely than males to have a co-diagnosis of mental retardation (58.2% and 41.8%, respectively [CDC, 2007]). Younger siblings of children diagnosed with an ASD are 20 times more likely to be diagnosed, resulting in families with up to five children known to be on the autism spectrum in the US. A recent study highlights the fact that relative to children without autism, children with autism are much more likely to have poor health, to require medically necessary care for behavioral problems, and to be using medications.

Societal Impact of ASD

ASD results in annual societal costs of $35 billion per year, or over $60,000 per person per year, for services, education and other publicly funded supports. (Ganz, 2006) Over the lifespan, the average societal cost of caring for one person with autism is $3.2 million. (Harvard School of Public Health, 2006) Comprehensive intervention programs for preschool aged children with autism, including behavioral and speech therapies, may cost up to $50,000 per year. (New York Times 2006) Comprehensive intervention programs for young children, including behavioral therapies, may cost up to $100,000 per year.

Autism first became a special education classification under the Individuals with Disabilities Education Act (IDEA) in 1991. Between 1991 and 1999, the number of persons receiving special education services for autism increased 500% (CDC, 2007). In 2005, approximately 224,000 children were served under the autism classification in US schools. To describe the estimates of per pupil expenditures for educating children with autism, we reviewed data collected and analyzed by the Special Education Expenditure Project (SEEP). (GAO-05-220, Special Education Report to Congress 2005)

The average per pupil expenditure for educating a child with autism was estimated by SEEP to be over $18,000 in the 1999-2000 school year, the most recent year for which data were available. This estimate was nearly three times the expenditure for a typical regular education student who did not receive special education services and was among the highest per pupil expenditures for school-age children receiving special

education services in public schools. In contrast, the cost of a typical child's education was $5,000. (Senate Education Committee, 2006) Many, who are employed, tend to be underemployed in dead end or entry level positions. For the population with autism, the number of individuals unemployed has been estimated to be as high as 90% (New Jersey Autism Society). Without effective intervention, that means that of the 560,000 children currently living with autism, 504,000 may be unemployed in adulthood. This would obviously be a human tragedy.

Effective Treatment for ASD

Early Intervention

The CDC reports that "early identification and participation in intervention can improve the long term outcome for children with an ASD" (2007). The Harvard School of Public Health corroborates, writing that "improving behavioral and educational therapies for autistic children may not only lessen these costs but also improve quality of life" (Ganz, 2005).

The National Research Council report offered several key features of successful approaches to the education of children with autism, including early intervention soon after the diagnosis of autism, which can generally occur by the age of 3. The report also offered guidelines regarding educational objectives for children with autism, including the development of social skills and expressive and receptive language and communication skills. (GAO-05-220, Special Education Report to Congress 2005)

Despite the research supporting early intervention, the 2007 CDC study suggests a significant nationwide lag between the first sign of developmental delay and the receipt of an autism diagnosis and subsequent interventions, which may compromise children's potential progress, and increase their likelihood to require publicly funded supports over the lifetime. If such barriers can be eliminated, however, a child's prognosis improves dramatically. In many cases, by a certain age, children with an ASD diagnosis no longer require treatment, thereby reducing or eliminating associated costs to society.

Effective Therapeutic Interventions for ASD

While treatment plans for individuals with ASD are individually tailored to each person's unique needs according to the severity of their deficits and any co-occurring diagnoses, persons with ASD typically require a combination of medical, psychological, psychiatric, physical therapy (PT), occupational therapy (OT), speech therapy (ST), behavioral therapies (ABA) and other developmentally-based interventions. Individuals with ASDs should be engaged in functional and appropriate activities as much as possible. In 2001, the National Research Council Report recommended a minimum of 25 hours per week and the American Academy of Pediatrics recommends 20 hours or more of active engagement in evidence-based interventions. Behavioral therapy typically comprises the largest proportion of therapeutic hours, with children receiving between 10-35 hours per week in most cases. Other therapies, such as speech, PT, and OT, are generally

required for 1-2 hours per week per child. Michael L. Ganz's study of the societal costs of autism supports the fact that ASD treatment costs decline over time. According to Ganz, direct medical costs reach their maximum during the first five (5) years of life.

As the child ages, direct medical costs begin to decline substantially and continue to decline through the end of life. Ganz goes on to report, "The large direct medical costs early in life are driven primarily by behavioral therapies that cost [an average of] $32,000 during the first 5-year age group and decline from about $4,000 in the 8-to 12-year age group to around $1,250 for the 18- to 22-year age group."

Behavioral Therapy

Behavioral therapies for ASD are derived from behavioral science, which is the examination of human and animal behavior using the principles of science, including observation, reproduction, testing, objectivity, etc. Behavioral therapy is also commonly known as, or otherwise includes, Lovaas therapy, early intensive behavioral intervention, applied behavior analysis (ABA), pivotal response treatment, or other similar terms.

ABA is the application of behavioral science in order to improve socially important behaviors and establish new skills. ABA-based procedures apply behavioral principles of skill development to increase or decrease a particular behavior, improve the quality of a behavior, stop an old behavior, or teach a new behavior.

Effective behavioral-based programs include intervention that is:

1. Implemented early (ideally, before school age)
2. Intensive with respect to the number of hours children are actively engaged
3. Provided in natural environments (i.e. home, school, community)
4. Actively involving of families.

Evidence Supporting Behavioral Therapy's Effectiveness with ASDs

Behavioral-based interventions are based upon decades of scientific investigation with individuals affected by a wide range of behavioral and developmental disorders, including autism. Specifically for children with autism, research demonstrates the efficacy of ABA in teaching complex communication, social, play, and self-help skills, and in reducing disruptive behaviors. The seminal article on this type of intervention was published by Ivar Lovaas at UCLA in 1987. This controlled, long-term study found that 47% of children with autism achieved normal intellectual educational functioning after treatment intensive behavioral treatment, compared to only 2% in the control group.

Since the Lovaas article was published, 20 years of research and over 500 studies continues to support the effectiveness of behavioral therapy for autism.

Lovaas's landmark 1987 study was followed in 1993 by another study of these same 38 subjects. The objective of John J. McEachin's study was to discover the long-term effects of Lovaas's early intensive behavioral treatment and to find out if the results of the experimental group were preserved over time. In terms of intellectual functioning, the study found that "the experimental group at follow-up had a significantly higher mean IQ than did the control group... indicating that the experimental group had maintained its gains in intellectual functioning between age 7 and the time of the current evaluation... [and] ... the experimental group showed more adaptive behaviors and fewer maladaptive behaviors than did the control group."

In another study, more than 50% of children with autism who participated in comprehensive treatment programs using ABA were successfully integrated into typical classrooms, with many requiring little ongoing treatment. (Harris and Handleman, 1994) Only four behavioral interventions are scientifically validated for the treatment of ASD, and all of these are derived from the principles of ABA, according to Simpson (2005).

Scientifically validated behavioral-based interventions for autism include:

1. Applied Behavior Analysis (ABA)
2. Discrete Trial Teaching (DTT)
3. Pivotal Response Treatment (PRT), and
4. Learning Experiences: An Alternative Program for Preschoolers & Parents (LEAP).

Reasons to support private health insurance coverage for ASD:

HB 187--Update of Coverage – less of a mandate

- It wasn't long ago that the medical community erroneously believed autism was untreatable. Today, research has proven otherwise. We are asking insurers to simply update their coverage to reflect the widely held belief in the scientific community that autism is treatable.

Reducing the financial burden on Alaskan Families

- Since insurance coverage is not available, families incur significant financial burdens to pay for necessary and appropriate services, sometimes as much as $50,000 a year, if not more. No family can support this burden.

- In addition to the crushing financial burden placed on families affected by autism, the time, energy, stress and emotional commitment can become absolutely overwhelming and, if left unchecked, can adversely impact employment, health and the marriage.

Cost/Benefit Analysis

- Actuarial and economic studies done in Alaska and other State's indicate adding coverage would increase policy premium costs less than 1%

- A 1998 study by John W. Jacobson and others titled, *Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case,* examined the cost/benefit relationship of early intensive behavioral intervention treatment at varying levels of treatment success. The study used estimates of costs for early intensive behavioral interventions (EIBI) from childhood (age 3) through adulthood (age 55) based on prices in the Commonwealth of Pennsylvania and compared these costs with the expected amount of income the child would earn later in life to arrive at an estimated cost savings. The Jacobson's study found that cost savings per child served are estimated to be from $2,439,710 to $2,816,535 to age 55.

- The benefit to Alaskan taxpayers, families and the school system is clear—spend a little now or, spend a lot later.

Consequences for the Status Quo

Without treatment, the taxpayers of Alaska will certainly bear the enormous financial burden of a life-time of care for children who live a normal life span and often need round the clock care. In contrast, many children who receive effective, intensive and evidenced-based treatments require less support in school and go on to lead productive lives as taxpayers.

President Obama and Federal Policy

Autism is a National health care crisis. President Obama is committed to supporting Americans with ASDs, their families, and their communities. There are a few key elements to their support, which are as follows:

1. President Obama supports increased funding for autism research, treatment, screenings, public awareness, and support services. There must be research of the treatments for, and the causes of, ASD.
2. The Obama administration supports improving life-long services for people with ASD for treatments, interventions and services for both children and adults with ASD.
3. The Obama administration supports comprehensive autism services legislation, funding of the Combating Autism Act and working in a bi-partisan fashion with Congress, parents and ASD experts to determine how to further improve federal and state programs for ASD.
4. The Obama administration supports universal screening of all infants and re-screening for all two-year-olds, the age at which some conditions, including ASD, begin to appear. These screenings will be safe and secure, and available for

every American that wants them. Screening is essential so that disabilities can be identified early enough for those children and families to get the support and services they need.

Other States

- Ten (10) states specifically require insurers to provide coverage for the treatment of autism. Eight (8) states enacted such legislation during the 2007-2008 legislative sessions: Arizona, Connecticut, Florida, Illinois, Louisiana, Pennsylvania, South Carolina and Texas. Thirty-four (34) others have reform measures pending.

Thank you for your strong leadership. If I can be of further assistance, please feel free to contact me.

Sincerely,

Jeff Sell, Esq.
Vice President of Advocacy & Public Policy

American Academy of Pediatrics (2001). Policy Statement: The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children (RE060018) Pediatrics, 107, 1221-1226. Committee on Children With Disabilities (2001). Technical Report: The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children. Pediatrics, 107, e85.

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James G. Gurney, Melissa L. McPheeters, Matthew M. Davis, Parental Report of Health Conditions and Health Care Use Among Children With and Without Autism, 160 Archives of Pediatric and Adolescent Medicine, 825-30 (2006).

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J. J. McEachin, T. Smith, O. Ivar Lovaas, Long-term Outcome for Children with Autism Who Received Early Intensive Behavioral Treatment, 97 American Journal on Mental Retardation, 359-72 (1993).

Douglas L. Leslie, Andres Martin, Health Care Expenditures Associated with Autism Spectrum Disorders, 161 Archives of Pediatric and Adolescent Medicine, 350-55 (2007).

ALTCS eligibility is determined according to a subjective determination of whether an individual is "at-risk for institutionalization." For autism, this criterion is not appropriate. The "PAS" tool, which ALTCS

administers during the screening process, is weighted to provide more emphasis on items such as feeding tubes; in fact, the tool provides ZERO points for a diagnosis of autism.

Approximately 50% of personal bankruptcy cases are due at least in part to medical costs. See "Too Great a Burden: Arizona's Families at Risk." Publication No. 07-112AZ. Families USA, December 2007.

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Sarah Palin, Governor
State of Alaska

GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

P.O. Box 240249 • Anchorage, Alaska 99524-0249 • Phone: 907-269-8990 • Fax: 907-269-8995 • Toll Free 888-269-8990

20 March 2009

The Honorable Pete Petersen
State Capitol Room 422
Juneau AK 99801-1182

Re: HB 187 Private Autism Insurance Coverage

Dear Representative Petersen,

The Governor's Council on Disabilities and Special Education appreciates your efforts to ensuring that children in Alaska who experience autism receive the supports they need to live productive lives. We wholeheartedly support HB 187, which mandates that private insurance companies cover autism spectrum disorders.

In Alaska today 1,512 children and young people have autism, of whom approximately 454 need significant clinical treatment. Thirty years of research demonstrates that with intensive early intervention, these children could gain a significant number of IQ points, and half of them could achieve normal functioning. With treatment, Alaska will see a savings of $208,500 per capita in avoided special education costs and lifetime savings of $1.08 million per capita. According to Michael Ganz, a Harvard economist, without treatment it is estimated it will cost the state $3.2 million per capita. By requiring that private insurance policies include coverage for treating autism, we can help many children access the services they need and live more productive lives.

We appreciate your advocacy on behalf of Alaskan children with autism and look forward to continuing to work with you on this issue.

Respectfully,

Stacey Messerschmidt, Chair
Governor's Council on Disabilities and Special Education

Ashley Rousson

From: Jon Lyon [jlyon@LatouchePediatrics.net]
Sent: Tuesday, March 24, 2009 12:26 PM
To: Ashley Rousson
Subject: HB187

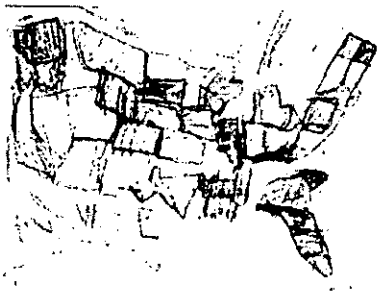
This letter is in support of HB 187.

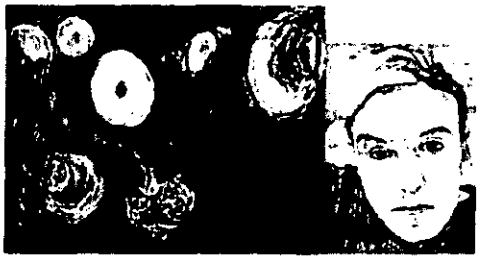
As a pediatrician practicing in Anchorage for the past 33 years, I treat many children with Autism and I recognize the tremendous energy expended by these childrens' parents and the increased cost of medical care.
I see HB 187 as a positive and needed approach and should facilitate the care for these children with very special needs.

W Jon Lyon MD, FAAP

BIOSKETCH

James N. Bouder graduated from The Pennsylvania State University with a Master of Public Administration, with course concentrations in budgeting, finance, and accounting. He is currently the Chief Operating Officer of The Vista School® and The Vista Foundation®, and serves as the Director of Collaboration and Development for the Central Pennsylvania Autism Regional Center. In 2004, he served as the Chairman of the Pennsylvania Autism Task Force's Funding Streams Subcommittee and was the principal author of the Subcommittee's *Final Recommendations*. He is also a principal author of Pennsylvania Act 62 of 2008 (House Bill 1150 of 2007) pertaining to private health insurance coverage for children with Autism Spectrum Disorders, which has become a national model for autism coverage across the United States. In 2007, Mr. Bouder developed an accurate cost model for estimating premium increases associated with mandating private insurance coverage for treating Autism Spectrum Disorders, which contributed to the Pennsylvania Health Care Cost Containment Council's finding that autism insurance coverage in Pennsylvania is cost effective. Since that time, he has completed cost analyses for autism insurance coverage legislation enacted in Pennsylvania, Louisiana, and Florida, has presented cost analysis testimony before legislative bodies in three states, and has also provided volunteer cost analysis services for autism insurance legislation pending in five other states. Mr. Bouder's work regarding the cost and benefit of private insurance coverage for autism diagnosis and treatment is published in the *Journal of Autism and Developmental Disorders* and the *Speaker's Journal* of the Pennsylvania House of Representatives.





Benefit-Cost Analysis of Alaska Insurance Coverage – H.B. 187

Jon Hockenyos
Resources for Hope

January 2010

Note: Pictures shown above were produced by children with autism, and are taken from the Autism Society website at http://www.autism-society.org

Executive Summary

- Although the Centers for Disease Control recently lowered the estimate of community prevalence of autism at 1 in 110 people, the actual rate of individuals who are treated is much lower. The assumption in this analysis relies on a midpoint estimate from an analysis conducted by Jim Bouder in March 2009 (Bouder analysis) of approximately 1 in 500 of the entire population (the equivalent 1 in 250 for eligible individuals covered by group insurance plans).

- Increased insurance premium costs associated with greater coverage under H.B. 187 were estimated at the midpoint by the Bouder analysis at 0.92 percent, the equivalent of $3.60 per member per month.

- The majority of children with autism who receive appropriate intervention and treatment experience marked improvement – 47% recover "typical" function, 40% make significant improvement, and the remaining 13% make little progress.

- There are significant lifetime costs associated with autism related to direct medical expenses, direct non-medical expenses, and indirect expenses (lost productivity). These children and their lifetime costs can be divided into four distinct groups ("cohorts"):

    - Cohort 1: Children who receive treatment and recover to "typical" function = $603,448
    - Cohort 2: Children who receive treatment and make significant improvement = $1,926,790
    - Cohort 3: Children who receive treatment and make little progress = $3,697,979
    - Cohort 4: Children who receive no treatment = $3,439,065

- The blended weighted average cost of Cohorts 1, 2, and 3 (children who receive treatment) is $1,535,074. This blended cost compared with the cost of Cohort 4 (children who receive no treatment) results in an overall benefit-cost ratio of 2.24.

- Under the midpoint assumptions, the Bouder analysis indicates that a total of 351 individuals will be covered by H.B. 187. The difference between the lifetime costs of children who receive no intervention (Cohort 4) and the blended weighted average of Cohorts 1-3 is $1,903,991 per child. Multiplying these two figures together creates total social benefits in Alaska of $667.7 million.

Benefit – Cost Analysis

Aside from moral and emotional concerns, policymakers are justified in asking what are the measurable longer-term costs and benefits associated with appropriate intervention to treat autism. Perhaps the most fundamental issue is related to outcomes – i.e., do children who receive appropriate treatment get better, and, if so, what does "getting better" actually entail? The results summarized in Chasson, et al. suggest that "getting better" is not only possible but likely and that the vast majority of children who receive appropriate intervention experience marked improvement.[1] In particular, the findings of Chasson and others indicate that approximately 47% of the children recover "typical" function; an additional 40% make "significant" improvement, although do not they do not reach "typical" function, and the remaining 13% make little progress. Clearly, this work provides strong justification for intervening as soon as possible.

A second question concerns the lifetime costs associated with autism. In April 2007, Ganz set forth his findings in describing "the age-specific and lifetime incremental societal costs of autism in the United States" (p. 343).[2] Ganz determined that the "lifetime per capita incremental societal cost of autism is $3.2 million" and that "[l]ost productivity and adult care are the largest components of costs" (p. 343). These figures were expressed in $2003; using the national Consumer Price Index, the figure rises to $3.7 million in $2008.

Based on the extant literature demonstrating the efficacy of behavioral interventions, we believe that the "lifetime per capita incremental societal cost of autism" can be mitigated substantially by services included in H.B. 187 pending before the Alaska State Legislature. In short, autism left untreated will result in unwelcome financial consequences for families with loved ones diagnosed with autism, public agencies, and society as a whole. The following outlines a methodology and findings that substantiate this claim.

Overall Cost-Benefit

Chasson and Ganz's work can be adapted to calculate the overall cost benefit of appropriate intervention to treat autism. Ganz grouped costs into three broad categories: Direct Medical, Direct NonMedical, and Indirect. The items included in each category are as follows, along with the lifetime breakdown. Details as to the timing and level of annual costs are included in the Appendix.

Direct Medical:

- Physicians/dentists
- Pharmaceuticals
- Alternative therapies
- Behavioral interventions
- Emergency room/Hospital
- Home healthcare
- Travel

[1] Chasson, Gregory S., Harris, Gerald E., & Neely, Wendy J. (2007). "Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism." *Journal of Child and Family Studies*. Vol 16, pp. 401-413.

[2] Ganz, Michael L. (2007). "The Lifetime Incremental Societal Costs of Autism." *Archives of Pediatric and Adolescent Medicine*. Vol. 161, Apr. 2007, pp. 343-349.

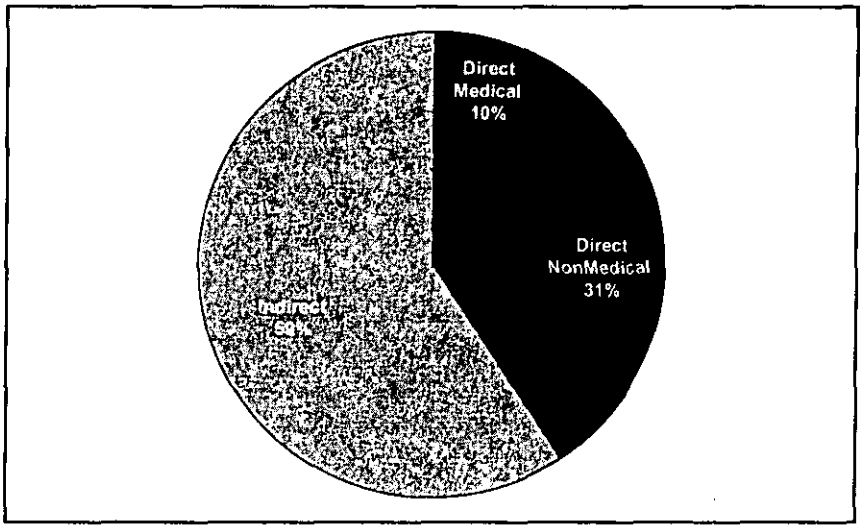
Direct Non-Medical:

- Childcare
- Adultcare
- Respite Care
- Home Improvement
- Special Education
- Supported Work
- Other

Indirect:

- Own lost productivity (wages)
- Caregiver/family lost productivity (wages)

Figure 1: Distribution of Lifetime Costs Associated With Autism



Source: Ganz, et al. and Hockenyos, et al.

The results from Chasson, et al. can be used to identify four cohorts within the overall autism designation: 1) those who recover to "Typical" status; 2) those who recover to "Improved" status; 3) those who see "Little Change" as a result of intervention; and 4) those who receive "No Intervention." The data from Ganz can be compared to the lifetime costs for each of these cohorts in turn. In essence, the cost of the direct medical interventions is the same for cohorts 1-3, although several interventions (such as behavioral) have been removed for cohort 4. The figure below shows the specific assumptions for each variable. A percent figure is shown in relation to the data outlined from Ganz in the Appendix; a figure of "<22" indicates 100% of Ganz until the age that precedes that figure (in this case, age 21). The impact is most pronounced in the timing, duration, and level of nonmedical and productivity (i.e., earnings) estimates, both for the child and his/her parents.

Table 1: Variable Adjustment Factors

	Typical	*Improved*	*Little Change*	*No Intervention*
Direct Medical	**Cohort 1**	**Cohort 2**	**Cohort 3**	**Cohort 4**
Physician/Dental	<22	<22	100%	100%
Drugs	<22	<22	100%	100%
Alt Therapies	<22	<22	100%	0%
Behavioral Therapies	100%	100%	100%	0%
Emergency/Hospital	<22	<22	100%	100%
Home Health	<22	<22	100%	0%
Travel	<22	<22	100%	0%
Direct Non-Medical				
Childcare	<8	<13	100%	100%
Adultcare	0%	0%	100%	100%
Respite Care	<8	<13	100%	100%
Home Improvement	<8	<13	100%	100%
Special Ed	<8	<13	100%	100%
Supported Work	0%	0%	100%	100%
Other	<8	<13	100%	100%
Indirect				
Own lost productivity	0%	at 50%	100%	100%
Other lost productivity	<8	at 75%	100%	100%

The results of this analysis are compelling. Cohort #1 had lifetime costs of $603,448 ($2008); Cohort #2 $1,926,790; Cohort #3 $3,697,979, and Cohort #4, the control group, $3,439,065. Using the incidence percentages from Chasson, et al., the blended cost of Cohorts #1, #2, and #3 is $1,535,074, creating a benefit-cost ratio of 2.24 as compared to Cohort #4, the control (No Intervention) group.

Table 2: Variation in Lifetime Costs by Cohort

	Typical	*Improved*	*Little Change*	*No Intervention*
	Cohort 1	**Cohort 2**	**Cohort 3**	**Cohort 4**
Lifetime Costs	$603,448	$1,926,790	$3,697,979	$3,439,065
Incidence	47%	40%	13%	
Blended Figure	$283,621	$770,716	$480,737	$1,545,074
Net Gain				**$1,903,991**
Benefit-Cost Ratio				**2.24**

Application to Alaska

Selected information from the Bouder analysis is provided below. As shown, the midpoint estimates indicated that prevalence will vary by age band from 0.20 percent to 0.45 percent. Using these ranges in combination with an assumption of 55.9 percent Alaskan children being covered by group insurance and a specific estimate for state employees results in a mid-point figure of 351 total individuals who will receive coverage under H.B. 187. This yields a net benefit to society of $667,708,307 (351 multiplied by the per capita net gain figure of $1,903,991 above).

Table 3: Treated Prevalence Assumptions Under H.B. 187

Low Estimate				
Age Band	Treated Prevalence Rate	Group Plans	State & Union Plans	Total Children Treated
2 to 4	0.25%	42	1	43
5 to 9	0.35%	93	5	98
10 to 14	0.25%	67	4	71
15 to 19	0.20%	58	4	62
20 years	0.20%	9	1	10
TOTAL		**269**	**15**	**284**
Mid-Point Estimate				
Age Band	Treated Prevalence Rate	Group Plans	State & Union Plans	Total Children Treated
2 to 4	0.30%	50	2	52
5 to 9	0.45%	120	6	126
10 to 14	0.30%	80	5	85
15 to 19	0.25%	72	5	77
20 years	0.20%	9	1	10
TOTAL		**332**	**19**	**351**
High Estimate				
Age Band	Treated Prevalence Rate	Group Plans	State & Union Plans	Total Children Treated
2 to 4	0.45%	76	3	78
5 to 9	0.67%	178	9	187
10 to 14	0.35%	94	6	100
15 to 19	0.30%	86	7	93
20 years	0.25%	12	1	13
TOTAL		**446**	**25**	**470**

Source: Bouder analysis

Focus on Education

Regarding the cost-benefit of intensive ABA services, two analyses, one completed in Pennsylvania and the other in Texas, examined the future cost savings to government units resulting from investment in intensive behavioral interventions for people with autism.

The first such work, completed by John W. Jacobson, James A. Mulick, and Gina Green in 1998, notes that an abundance of research demonstrates the efficacy of early, intensive behaviorally-based interventions to enable substantial numbers of children with autism to "attain intellectual, academic, communication, social, and daily living skills within the normal range" (p. 201).[3] Using representative costs from Pennsylvania, including costs for special educational and adult special

[3] Jacobson, John W., James A. Mulick, and Gina Green (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.

needs services, they found that, "At varying rates of effectiveness and in constant dollars, this model estimates that cost savings range from $187,000 to $203,000 per child for ages 3-22 years, and from $656,000 to $1,082,000 per child for ages 3-55 years" (Jacobson, et al., p. 201).

More recently, Chasson, et al. compared the costs of early intensive behavioral intervention ("EIBI") and special education for children with autism.[4] Alluding to recent comparison studies that strongly suggest that "eclectic" special education programs are materially ineffective for many children with autism, the authors note that the human cost of failing to provide EIBI services is considerable. Consistent with Jacobson's et al.'s findings, Chasson et al. found that "the state of Texas would save $208,500 per child across eighteen years of education with EIBI" (p. 401). It is important to note that, without treatment, persons with autism will grow to become adults dependent on publicly-funded services for their lifespan. As Chasson et al. put it, "By implementing EIBI with all children with autism, as a way to prevent the need for special education, the investment not only produces a sizeable savings after 18 years, but it maximizes the likelihood that most of these children will return a profit long after maturation" (p. 410). "The bottom line," they write, "is that a simple change in policy could drastically improve functioning and quality of life for thousands of children with autism in Texas."

Conclusion

Appropriate interventions with autistic children create measurable results. Based on our analysis of the impact of Alaska H.B. 187, we anticipate that its passage and implementation would contribute to the creation of net social benefits to Alaska of approximately $667.7 million.[5] Separate analysis suggests that these benefits can be supported by an increase in insurance premiums of about 0.92 percent, a rate well in line with other states that will yield cost increases per member of $3.60 monthly. Furthermore, given the abundance of evidence concerning the efficacy of Applied Behavior Analysis in treating the varied symptoms of autism, the State of Alaska can expect significant future savings in avoided special education and human services costs. Lastly, expected premium and cost impacts relating to H.B. 187 are consistent with similar legislation enacted or pending in at least 10 other states.

[4] Chasson, Gregory S., Harris, Gerald E., & Neely, Wendy J. (2007). "Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism." *Journal of Child and Family Studies, 16,* 401-413.

[5] It should be noted that the expenditures outlined to create the benefits described extend beyond that which likely will be covered entirely by insurance. However, the costs associated with many interventions, especially behavioral interventions, are large enough to be beyond the means of all but the most affluent families absent insurance coverage.

Exhibit A: Expenditures by Cohort

Cohort 1 - "Typical"

Direct Annual Medical Expenditures ($2008)

AGE	Physicians/ Dentists	Drugs	Alternative Therapy	Behavioral Interventions	ER/Hosp	Home Health	Travel	Total
3-7	$1,342	$172	$232	$38,030	$969	$546	$95	$41,386
8-12	$675	$179	$128	$4,719	$899	$355	$82	$7,036
13-17	$509	$153	$59	$4,071	$692	$312	$70	$5,866
18-22	$498	$151	$39	$1,467	$997	$154	$61	$3,368

Direct Annual Non-Medical Expenditures ($2008)

AGE	Childcare	Adultcare	Respite Care	Home Improvement	Special Education	Supported Work	Other	Total
3-7	$5,425	$0	$1,287	$188	$5,365	$0	$378	$12,643

Indirect Annual Losses Due to Reduced/Foregone Income ($2008)

AGE	Own	Parents/Caregiver	Totals
3-7	$0	$50,392	$50,392

Total Costs: $603,448

Cohort 2 - "Improvement"

Direct Annual Medical Expenditures ($2008)

AGE	Physicians/ Dentists	Drugs	Alternative Therapy	Behavioral Interventions	ER/Hosp	Home Health	Travel	Total
3-7	$1,342	$172	$232	$38,030	$969	$546	$95	$41,386
8-12	$675	$179	$128	$4,719	$899	$355	$82	$7,036
13-17	$509	$153	$59	$4,071	$692	$312	$70	$5,866
18-22	$498	$151	$39	$1,467	$997	$154	$61	$3,368
23-27	$580	$145	$33	$0	$906	$124	$53	$1,841
28-32	$593	$133	$29	$0	$798	$102	$46	$1,701
33-37	$640	$115	$25	$0	$700	$109	$39	$1,626
38-42	$632	$98	$21	$0	$611	$105	$34	$1,501
43-47	$882	$84	$19	$0	$498	$160	$29	$1,683
48-52	$989	$71	$16	$0	$412	$180	$25	$1,693
53-57	$996	$61	$14	$0	$342	$76	$21	$1,509
58-62	$948	$51	$12	$0	$378	$16	$19	$1,424
63-66	$740	$40	$11	$0	$352	$46	$16	$1,204

Direct Annual Non-Medical Expenditures ($2008)

AGE	Childcare	Adultcare	Respite Care	Home Improvement	Special Education	Supported Work	Other	Total
3-7	$5,425	$0	$1,287	$188	$5,365	$0	$378	$12,643
8-12	$4,679	$0	$1,109	$163	$12,102	$0	$325	$18,379

Indirect Annual Losses Due to Reduced/Foregone Income ($2008)

AGE	Own	Parents/Caregiver	Totals
3-7	$0	$50,392	$50,392
8-12	$0	$48,136	$48,136
13-17	$0	$33,746	$33,746
18-22	$0	$31,672	$31,672
23-27	$19,133	$16,706	$35,839
28-32	$19,084	$2,752	$21,837
33-37	$18,050	$0	$18,050
38-42	$17,044	$0	$17,044
43-47	$15,562	$0	$15,562
48-52	$14,352	$0	$14,352
53-57	$10,400	$0	$10,400

Total Costs: $1,926,790

Cohort 3 – "No Improvement"

Direct Annual Medical Expenditures ($2008)

AGE	Physicians/ Dentists	Drugs	Alternative Therapy	Behavioral Interventions	ER/Hosp	Home Health	Travel	Total
3-7	$1,342	$172	$232	$38,030	$969	$546	$95	$41,386
8-12	$675	$179	$128	$4,719	$899	$355	$82	$7,036
13-17	$509	$153	$59	$4,071	$692	$312	$70	$5,866
18-22	$498	$151	$39	$1,467	$997	$154	$61	$3,368
23-27	$580	$145	$33	$0	$906	$124	$53	$1,841
28-32	$593	$133	$29	$0	$798	$102	$46	$1,701
33-37	$640	$115	$25	$0	$700	$109	$39	$1,626
38-42	$632	$98	$21	$0	$611	$105	$34	$1,501
43-47	$892	$84	$19	$0	$498	$160	$29	$1,683
48-52	$989	$71	$16	$0	$412	$180	$25	$1,693
53-57	$996	$61	$14	$0	$342	$76	$21	$1,509
58-62	$948	$51	$12	$0	$378	$16	$19	$1,424
63-66	$740	$40	$11	$0	$352	$46	$16	$1,204

Direct Annual Non-Medical Expenditures ($2008)

AGE	Childcare	Adultcare	Respite Care	Home Improvement	Special Education	Supported Work	Other	Total
3-7	$5,425	$0	$1,287	$188	$5,365	$0	$378	$12,643
8-12	$4,679	$0	$1,109	$163	$12,102	$0	$325	$18,379
13-17	$4,037	$0	$957	$140	$10,440	$0	$281	$15,855
18-22	$3,402	$0	$826	$12	$7,310	$0	$996	$12,545
23-27	$0	$29,328	$0	$11	$0	$978	$1,907	$32,224
28-32	$0	$25,298	$0	$9	$0	$844	$1,645	$27,796
33-37	$0	$21,823	$0	$8	$0	$728	$1,419	$23,978
38-42	$0	$18,824	$0	$7	$0	$628	$1,224	$20,683
43-47	$0	$16,238	$0	$6	$0	$542	$1,057	$17,842
48-52	$0	$14,006	$0	$5	$0	$467	$910	$15,388
53-57	$0	$12,083	$0	$5	$0	$341	$786	$13,214
58-62	$0	$10,422	$0	$4	$0	$0	$677	$11,103
63-66	$0	$8,686	$0	$4	$0	$0	$565	$9,254

Indirect Annual Losses Due to Reduced/Foregone Income ($2008)

AGE	Own	Parents/Caregiver	Totals
3-7	$0	$50,392	$50,392
8-12	$0	$48,136	$48,136
13-17	$0	$44,994	$44,994
18-22	$0	$42,229	$42,229
23-27	$38,266	$22,274	$60,540
28-32	$38,169	$3,669	$41,838
33-37	$36,100	$0	$36,100
38-42	$34,088	$0	$34,088
43-47	$31,125	$0	$31,125
48-52	$28,704	$0	$28,704
53-57	$20,800	$0	$20,800

Total Costs: $3,697,979

Cohort 4 – "No Intervention"

Direct Annual Medical Expenditures ($2008)

AGE	Physicians/ Dentists	Drugs	Alternative Therapy	Behavioral Interventions	ER/Hosp	Home Health	Travel	Total
3-7	$1,342	$172	$0	$0	$969	$546	$0	$2,483
8-12	$675	$179	$0	$0	$899	$355	$0	$1,753
13-17	$509	$153	$0	$0	$692	$312	$0	$1,354
18-22	$498	$151	$0	$0	$997	$154	$0	$1,646
23-27	$580	$145	$0	$0	$906	$124	$0	$1,631
28-32	$593	$133	$0	$0	$798	$102	$0	$1,525
33-37	$640	$115	$0	$0	$700	$109	$0	$1,454
38-42	$632	$98	$0	$0	$611	$105	$0	$1,341
43-47	$892	$84	$0	$0	$498	$160	$0	$1,474
48-52	$989	$71	$0	$0	$412	$180	$0	$1,472
53-57	$996	$61	$0	$0	$342	$76	$0	$1,398
58-62	$948	$51	$0	$0	$378	$16	$0	$1,377
63-66	$740	$40	$0	$0	$352	$46	$0	$1,131

Direct Annual Non-Medical Expenditures ($2008)

AGE	Childcare	Adultcare	Respite Care	Home Improvement	Special Education	Supported Work	Other	Total
3-7	$5,425	$0	$1,287	$188	$5,365	$0	$378	$12,643
8-12	$4,679	$0	$1,109	$163	$12,102	$0	$325	$18,379
13-17	$4,037	$0	$957	$140	$10,440	$0	$281	$15,855
18-22	$3,402	$0	$826	$12	$7,310	$0	$996	$12,545
23-27	$0	$29,328	$0	$11	$0	$978	$1,907	$32,224
28-32	$0	$25,298	$0	$9	$0	$844	$1,645	$27,796
33-37	$0	$21,823	$0	$8	$0	$728	$1,419	$23,978
38-42	$0	$18,824	$0	$7	$0	$628	$1,224	$20,683
43-47	$0	$16,238	$0	$6	$0	$542	$1,057	$17,842
48-52	$0	$14,006	$0	$5	$0	$467	$910	$15,388
53-57	$0	$12,083	$0	$5	$0	$341	$786	$13,214
58-62	$0	$10,422	$0	$4	$0	$0	$677	$11,103
63-66	$0	$8,686	$0	$4	$0	$0	$565	$9,254

Indirect Annual Losses Due to Reduced/Foregone Income ($2008)

AGE	Own	Parents/Caregiver	Totals
3-7	$0	$50,392	$50,392
8-12	$0	$48,136	$48,136
13-17	$0	$44,994	$44,994
18-22	$0	$42,229	$42,229
23-27	$38,266	$22,274	$60,540
28-32	$38,169	$3,669	$41,838
33-37	$36,100	$0	$36,100
38-42	$34,088	$0	$34,088
43-47	$31,125	$0	$31,125
48-52	$28,704	$0	$28,704
53-57	$20,800	$0	$20,800

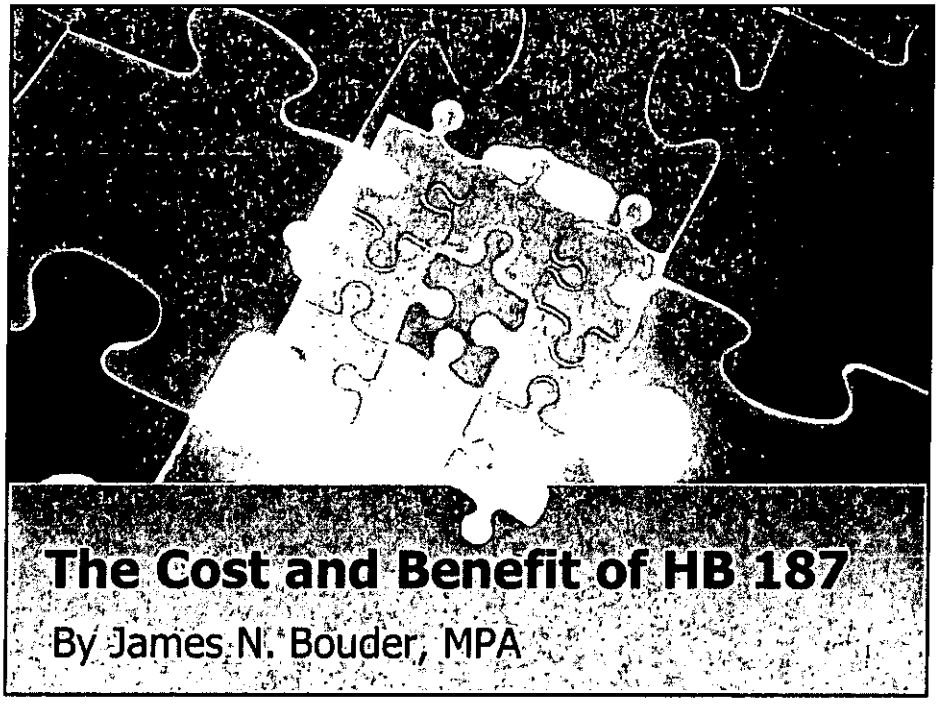
Total Costs: $3,439,065

Biosketch of Author

Jon Hockenyos has had a life-long interest in economics and public policy. Following stints as an aide to a member of the British Parliament and work on a Senatorial campaign in his home state of Illinois, Mr. Hockenyos founded TXP while attending the LBJ School of Public Affairs at the University of Texas at Austin in 1987. Since then, TXP has successfully completed hundreds of projects for a wide variety of clients, with a strong record of on-time, on-budget delivery.

Along with serving as President of the firm, Mr. Hockenyos makes numerous public presentations and speeches, has served as a resource witness on a variety of issues for a large number of city councils, state legislatures, and the U.S. Congress, and is widely quoted by both print and electronic media.

Mr. Hockenyos received a Bachelor of Arts in Philosophy from the University of Illinois and Masters of Public Affairs from the LBJ School of Public Affairs, where he has taught as an Adjunct Professor. He also served on Board of Directors for Capital Metro (the Austin area transit authority), is the current President of the Board of Directors of Hyde Park Theatre in Austin, and is a member of the Advisory Board of American Bank of Commerce. *Resources for Hope* is the recently founded not-for-profit created by Jon Hockenyos and Rebecca Yerly to provide analytical support to autism insurance reform.



Cost Benefit Analysis

Contents:

- Effect on Commercial Insurance Rates
- Effect on State Employee Claims if Legislature Extends Benefits to Dependents of State Workers
- Long-Term Considerations
- Other State Estimates

Summary of HB 187

Bill Summary:

- Requires private insurance coverage for diagnosis and treatment of autism, up to $36,000 annually
- Provides for coverage of medically necessary, evidence-based services
  - Speech, Occupational, and Physical Therapy
  - Psychological and Psychiatric Care
  - Pharmacy Care
  - Rehabilitative Care, including Applied Behavior Analysis

3

Commercial Insurance Cost Estimate

Assumptions:

- Approximately 48,425 Alaskans between the ages of 2 and 20 are insured under plans subject to HB 187, based on census estimates, adjustments for uninsured, and for ERISA preemption
- A treated prevalence rate between 1 in 250 to 1 in 400, to reflect the number of children satisfying the diagnostic criteria for autism who will require and seek treatment once coverage is available
- Highest expenditures experienced during early childhood years, tapering downward as child approaches adulthood

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Commercial Insurance Cost Estimate

Assumptions (cont'd):

- 85% Medical Loss Ratio (Industry Standard) to convert claims increase to premium revenue requirement
- Estimated premium base of $345,975,000 for 2009, based on 2008 Report of the Alaska Division of Insurance
- Average Annual Individual Policy cost of $4,683 and Family Policy cost of $12,351 (Kaiser Family Foundation)
- An adequate provider network will be in place on the legislation's effective date

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How Many?

Eligible Beneficiaries

Total Aged 2-20 Yrs (Census '06 Est.)	190,947
% with Group Health Insurance	55.9%
Total Group Insured Aged 2-20	106,664
% Non-ERISA Plans (MEPS)	45.4%
Total Non-ERISA Aged 2-20	**48,425**

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How Many?

Treated Prevalence Assumptions

- Prevalence children w/ autism seeking and requiring significant levels of treatment
  - Shimabukuru et al. (2008): 1 in 526
  - Leslie et al. (2007): 1 in 520
  - Liptak et al. (2006): 1 in 476
  - Mandell et al. (2006): 1 in 500
- Based on literature, 1 in 500 (0.20%) of children with autism seek and require significant levels of treatment
  - This statistic has remained stable since 1999
- For purposes of this cost analysis, I have assumed a treated prevalence ranging from 1 in 250 to 1 in 400

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How Much?

Low Estimate (Treated Prevalence 1 in 400):

Age Band	# Children	Treated Prevalence	Cost per Person	Total $ Cost
2 to 4	7,573	0.25%	$30,000	$567,999
5 to 9	11,962	0.35%	$19,660	$823,127
10 to 14	12,861	0.25%	$6,758	$217,292
15 to 19	13,346	0.20%	$2,525	$67,400
20 years	2,682	0.20%	$2,525	$13,543
Total	**48,425**			**$1,689,361**
% PMPM (w/ 85% MLR)				**0.57%**
$ PMPM (w/ 85% MLR)				**$2.24**

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How Much?

Mid Estimate (Treated Prevalence 1 in 325):

Age Band	# Children	Treated Prevalence	Cost per Person	Total $ Claims
2 to 4	7,573	0.30%	$36,000	$817,918
5 to 9	11,962	0.45%	$26,200	$1,410,357
10 to 14	12,861	0.30%	$9,000	$347,256
15 to 19	13,346	0.25%	$3,500	$116,782
20 years	2,682	0.20%	$3,500	$18,773
Total	**48,425**			**$2,711,085**
% PMPM (w/ 85% MLR)				**0.92%**
$ PMPM (w/ 85% MLR)				**$3.60**

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How Much?

High Estimate (Treated Prevalence 1 in 250):

Age Band	# Children	Treated Prevalence	Cost per Person	Total $ Claims
2 to 4	7,573	0.45%	$36,000	$1,226,877
5 to 9	11,962	0.67%	$30,500	$2,444,498
10 to 14	12,861	0.35%	$9,000	$540,176
15 to 19	13,346	0.30%	$3,500	$140,138
20 years	2,682	0.25%	$3,500	$23,466
Total	**48,425**			**$4,375,156**
% PMPM (w/ 85% MLR)				**1.49%**
$ PMPM (w/ 85% MLR)				**$5.81**

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Short-Term Cost Estimates

Estimated % and $ PMPM Increase by Year:

Estimated % Increase in Premiums by Year				
Scenario	**Year 1**	**Year 2**	**Year 3**	**Year 4 and Beyond**
Low	0.14%	0.29%	0.43%	0.57%
Mid	0.23%	0.46%	0.69%	0.92%
High	0.37%	0.75%	1.02%	1.49%

Estimated $ Increase PMPM by Year				
Scenario	**Year 1**	**Year 2**	**Year 3**	**Year 4 and Beyond**
Low	$0.55	$1.13	$1.67	$2.24
Mid	$0.90	$1.79	$2.69	$3.60
High	$1.44	$2.92	$3.97	$5.81

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State Fiscal Impact

(Hypothetical)

Fiscal Impact if State Plans Included in HB 187:

Scenario	Annual $ Total	$ Cost Per Employee Per Month
Low	$334,990	$1.86
Mid	$543,384	$3.02
High	$875,452	$4.86

- Assumed same prevalence rates and costs per age band as with Commercial Insurance Estimate
- Based on census and claims data provided by the Division of Retirement and Benefits

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Future Savings

Access to Treatment Reduces Future Costs

- Avoided human service system costs very high
  - Jacobson et al. (1999) – $2 million per person over lifespan
  - Chasson et al. (2007) – $208,500 per capita savings during school years alone
- Ganz (2007) – Incremental societal cost for not treating autism approximately $3.2 million per person
  - Adult care and lost productivity comprise the largest component of this cost
  - Also, lost productivity for primary caregivers a significant contributor to the societal cost

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Other State Findings

Cost Analyses in Other States

SEE ATTACHMENT "A"

14

Conclusion

HB 187 Will Cost Little, But Save Much

- After an adequate provider network is in place, Alaskan insurance ratepayers can expect premium increases ranging from 0.57% to 1.49%
- Alaska can save approx. $208,500 per child in avoided special education costs during the school years alone
- Alaska can save approx. $2.0 million in avoided, lifetime human service costs per child who receives treatment
- **Conclusion**: Based on my review of the data and extant literature, the cost of providing effective treatment to children with autism is low, but the future savings from providing such treatment is significant

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Questions?

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ATTACHMENT "A"

State/Party	Eligibility/ Disposition	Annual Cap	Lifetime Limit	Estimated % Premium Increase
Arizona	**Birth to 16 yrs**	**$50,000 to age 9, $25,000 ages 10-16**	**None**	
Key HealthCare Concepts, LLC[1]	Independent			0.33%-0.69%
Florida	**< 18 yrs or 18 yrs & older if in HS & have a DD dx by age 8**	**$36,000**	**$200,000**	
Bouder, James N.[2]	Proponent			0.37%-0.75%
Louisiana	**< 17 yrs**	**$36,000**	**$144,000**	
Bouder, James N.[3]	Proponent			0.27%-0.56%
Louisiana Office of Group Benefits[4]	Independent			0.29%
Pennsylvania	**< 21 yrs**	**$36,000**	**None**	
Abt Associates[5]	Independent			+/- 1%
Blue Cross of Northeastern PA[6]	Opponent			+/- 0.50%
Bouder, JN et al.[7]	Proponent			+/- 1%
Highmark Blue Shield[8]	Opponent			+/- 0.50%
PA Department of Insurance[9]	Independent			+/- 1%
South Carolina	**< 16 yrs & Dx w/ ASD at age 8 or younger**	**$50,000**	**None**	
Governor Sanford (Veto Letter)	Opponent			+/- 1%

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[1] Key HealthCare Concepts, LLC (2008), *Actuarial Report Regarding Financial Impacts* [Regarding private insurance coverage for autism treatment], p. 4.

[2] Bouder, JN for Autism Speaks (2008) [Financial Impact Section Only], *Report Under § 624.215(2), Fla. Stat. (2007), Assessing the Social and Financial Impacts of House Bill 1291 and Senate Bill 2654*, retrieved from <http://www.autismvotes.org>

[3] Bouder, JN (2008), *Cost Analysis - HB 958 of 2008 (As Amended 4/30/08)* (2008), pp. 2-7, retrieved from <http://www.autismvotes.org>

[4] *Ibid*, pp. 7-9 and Exhibit "C-2"

[5] Abt Associates, Inc. (2008), *Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150*, Prepared for the Pennsylvania Health Care Cost Containment Council, retrieved from <http://www.phc4.org>

[6] See Mercer (2008), *Annual Mandated Health Insurance Services Evaluation, Section 1, Coverage for Autism Spectrum Disorders*, prepared for the Maryland Health Care Commission, p. 23, evaluating Highmark Blue Shield's cost estimate submitted to the Pennsylvania Health Care Cost Containment Council.

[7] Bouder, JN, Stuart Spielman, David S. Mandell (2009). *Brief Report: Quantifying the Impact of Autism Coverage on Private Insurance Premiums*, Journal of Autism and Developmental Disorders.

[8] See Mercer (2008), *Annual Mandated Health Insurance Services Evaluation, Section 1, Coverage for Autism Spectrum Disorders*, prepared for the Maryland Health Care Commission, p. 23, evaluating Blue Cross of Northeastern Pennsylvania's cost estimate submitted to the Pennsylvania Health Care Cost Containment Council.

[9] Commonwealth of Pennsylvania Insurance Department (2008), regarding the effect of Pennsylvania House Bill 1150 on commercial insurance rates, p. 8.

ATTACHMENT "A" (Cont'd)

State/Party	Eligibility/ Disposition	Annual Cap	Lifetime Limit	Estimated % Premium Increase
Connecticut	**< 13 yrs**	**$50,000 < 9 yrs, $35,000 9 to 12 yrs**	**None**	
Oliver Wyman[10]	Proponent			0.19%-0.49%
Georgia	**Not Specified**	**$55,000**	**None**	
Oliver Wyman[11]	Proponent			0.63%
Maryland	**< 21 yrs**	**$50,000**	**None**	
Mercer/Oliver Wyman[12]	Independent			0.52%-1.22%
New Jersey	**Not Specified**	**None**	**None**	
Mandated Benefits Advisory Comm.[13]	Independent			1%
Oklahoma	**< 21 yrs**	**$75,000**	**None**	
Aon (for OSEEGIB)[14]	Independent			0.34%-1.00%
Virginia	**< 21 yrs**	**$36,000**	**None**	
Oliver Wyman[15]	Proponent			0.60%
West Virginia	**< 24 yrs**	**$75,000**	**None**	
Bouder, James N.[16]	Proponent			0.82%
Public Employees Insurance Agency[17]	Independent			1.54%
Council for Affordable Health Insurance[18]	**Not Specified**	**Not Specified**	**None**	
	Opponent			+/- 1.00%

[10] Oliver Wyman (2009), *Actuarial Cost Estimate: Connecticut Senate Bill 301 – An Act Related to Insurance for Coverage for Autism*, p. 14.
[11] Oliver Wyman (2009), *Actuarial Cost Estimate: Georgia Senate Bill 161 – An Act Related to Insurance Coverage for Autism*, p. 13.
[12] Mercer (2008), *Annual Mandated Health Insurance Services Evaluation, Section 1, Coverage for Autism Spectrum Disorders*, prepared for the Maryland Health Care Commission, pp. 30-31.
[13] New Jersey Mandated Benefits Advisory Commission (2006), *Evaluation of the Impact of Autism Mandated Benefits contained in Assembly Bill A-999.*
[14] Aon (2009), *Memorandum Regarding the Cost Impact of Oklahoma SB 1 on the Office of State Education Employees Group Insurance Board's Health Plans.*
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Diagnostic Criteria

The American Psychiatric Association's Diagnostic and Statistical Manual-IV, Text Revision (DSM-IV-TR) 1 provides standardized criteria to help diagnose ASDs.

Diagnostic Criteria for 299.00 Autistic Disorder

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

Diagnostic Criteria for 299.80 Asperger's Disorder

- Qualitative impairment in social interaction, as manifested by at least two of the following:
    - marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction
    - failure to develop peer relationships appropriate to developmental level
    - a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
    - lack of social or emotional reciprocity
- Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:
    - encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus
    - apparently inflexible adherence to specific, nonfunctional routines or rituals
    - stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
    - persistent preoccupation with parts of objects
- The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

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

Diagnostic Criteria for 299.80 Rett's Disorder

- All of the following:
  - apparently normal prenatal and perinatal development
  - apparently normal psychomotor development through the first 5 months after birth
  - normal head circumference at birth
- Onset of all of the following after the period of normal development:
  - deceleration of head growth between ages 5 and 48 months
  - loss of previously acquired purposeful hand skills between 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
  - loss of social engagement early in the course (although often social interaction develops later)
  - appearance of poorly coordinated gait or trunk movements
  - severely impaired expressive and receptive language development with severe psychomotor retardation

Diagnostic Criteria for 299.10 Childhood Disintegrative Disorder

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

HB 187 – Autism Insurance Reform

WHAT:

- **HB 187 will require insurance coverage for autism spectrum disorders.**
- **Autism is a disorder affecting at least 1 in 150 children with approximately 1 in 500 requiring significant clinical treatment.** Alaska currently has 1,512 children and youth under the age of 21 who have autism; approximately 454 need significant clinical treatment.

WHY:

- **Because Alaska law does not require insurance coverage for autism services, families that do not qualify for DHSS services pay out of pocket, often as much as $50,000 per year or more; in some instances, bearing this burden results in divorce or bankruptcy.** Families that cannot afford to do so, go without crucial intervention.
- **Autism is treatable.** 30 years of research shows that with treatment, many children overcome the severe symptoms of their disorder.

  - ✓ About half the children who receive intensive early intervention achieve normal functioning after 2-3 years of treatment.
  - ✓ There is an average gain of 22 IQ points.
  - ✓ 1/3 gained 45 IQ points.
  - ✓ Nearly 50% of those receiving intensive early intervention do not require lifelong services and supports.

- **The earlier the diagnosis, the more effective treatment is.** The diagnostic process involves a comprehensive assessment (neurodevelopmental pediatrics, psychology, speech, occupational and physical therapy, ophthalmology, audiology) by a multidisciplinary team. Only those children who meet specific medical criteria are diagnosed with autism.
- **Treatment equals savings.** With treatment, Alaska will see savings of $208,500 per capita in avoided special education costs and lifetime savings of $1.08 million per capita. Treatment may include the following medically necessary services.

  - ✓ Pharmacy, psychiatric, psychological, rehabilitative and therapeutic care.
  - ✓ Rehabilitative care includes applied behavior analysis (the design, implementation and evaluation of environmental modifications to produce socially significant improvement in human behavior or to prevent the loss of an attained skill or function.

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HB 187 – Autism Insurance Reform

- **Without treatment it is estimated that it will cost the state $3.2 million per capita.** (Michael Ganz, Harvard economist)
- **Coverage of medically necessary autism treatment in Alaska will enable many children to access the services they need and live more productive lives.**
- **Most private insurance policies specifically exclude coverage for treating autism, even when the services are otherwise covered by the health plan.**
- **HB 187 requires private insurance policies (approximately 23% of all insurance plans) to provide a maximum coverage of $36,000 a year for the diagnosis and treatment of autism spectrum disorders, including but not limited to applied behavior analysis.**

  - ✓ Must be prescribed by a licensed physician, psychologist or advanced nurse practitioner.
  - ✓ Must be provided by an autism service provider as identified in a treatment plan developed following a comprehensive evaluation.
  - ✓ Must identify the medically necessary pharmacy care, psychiatric care, psychological care, rehabilitative care and therapeutic care.

- **The maximum likely cost of such coverage to the private insurance ratepayer is approximately 0.92% or $3.60 per policyholder per month.**

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Provided By: Millie Ryan 5 April 2009
The Governor's Council on Disabilities and Special Education

Diagnosis of Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) covers a wide range of symptoms from very mild to severe. ASD affects social skills, communication and cognitive development. ASD affects the individual's ability to convey or interpret others' emotions. Children may engage in restricted and/or repetitive play and have unusual attachments to objects. People with ASD might not seem interested in other people and prefer to be alone. People with ASD might not seem interested in other people and prefer to be alone. Some children with ASD do not like to be held or cuddled, and many do not make eye contact with others. Individuals with ASD also show varied degrees in impairment in their verbal and nonverbal communication. Some individuals with ASD may be nonverbal, while others may not have any difficulty speaking. Some repeat something previously heard or use stock phrases or learned scripts to communicate. Cognitively, individuals with ASD develop differently from others. Many people with ASD have difficulty processing sensory stimuli and verbal input, and this affects their understanding of the world around them.

It is important to note that some people without an ASD might also have some of these symptoms. But for people with an ASD, the impairment is bad enough to make life very challenging in terms of interacting with others, communicating, learning or holding down a job.

The Governor's Council on Disabilities recommended that the state establish universal screening for ASD during well-child exams to identify children who have behaviors that could indicate a disorder. The American Academy of Neurology recommends immediate referral for a diagnostic evaluation for any of the following:

- No babbling by 12 months
- No gesturing by 12 months
- No single words by 16 months
- No 2 work spontaneous phrases by 24 months
- Any loss of any language or social skills at any age

ASD screenings identify those children who require a comprehensive assessment across developmental and physical domains. Professionals from multiple disciplines then conduct a complete assessment (i.e. neurodevelopmental pediatrics, psychology, speech, occupational and physical therapy, ophthalmology, audiology). For young children, it is especially critical to conduct a differential diagnosis to rule out any other possible genetic or medical disorders.

The diagnosis focuses on determining to what extent the child has:

- Irregularities and impairments in communication
- Engagement in repetitive activities and stereotyped movements
- Resistance to environmental change or change in daily routines

- Unusual responses to sensory experiences

In order to receive a diagnosis of ASD, the child must show qualitative impairment in reciprocal social interaction, qualitative impairment in communication and repetitive, stereotypical behaviors that interfere with his or her ability to develop, communicate and learn compared to typically developing peers.

In order to qualify for special education with an ASD, a child must

- exhibit a developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age three, that adversely affects educational performance; and
- require special facilities, equipment, or methods to make the child's educational programs effective; and
- be diagnosed as having an autism spectrum disorder by a psychiatrist, physician, licensed psychologist or advanced nurse practitioner; and
- be certified by a group consisting of qualified professional and a parent of the child as qualifying for and needing special education services