SB
250

5234

Alaska State Legislature

Interim: (May - Dec.)
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Senator_Bettye_Davis@legis.state.ak.us
http://www.akdemocrats.org

Senate Health and Social Services Committee

CS for Senate Bill No. 250( )

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

Sponsor Statement

SB 250 requires that health insurers in Alaska provide 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 incremental societal cost of not treating an individual with autism has been estimated by Harvard economist Michael L. Ganz, MS, Ph.D. to be approximately $3.2 million. The cost savings alone in special education to age 22 for each autistic child has been estimated at $187,000-$203,000 or $1.1 million to age 55 relative to three years Early Intensive Behavioral Treatment. The cost to policy holders to implement such coverage is estimated at less than a 1% increase in premiums, or $3.60 per member per month. (See "The Lifetime Distribution of the Incremental Societal Costs of Autism," *Archives of Pediatrics and Adolescent Medicine*, April 2007, Vol. 161, cited in *"Actuarial Cost Estimate: Alaska House Bill 187, an Act Requiring Insurance Coverage for Autism Spectrum Disorders, February 9, 2010").*

SB 250 only mandates coverage for autism spectrum disorders for about the 40% of Alaskans who are covered by insurers or insurance company plans. Self-funded health plans, often sponsored by the largest employers, including the State health care plan, or "Alaska Care" plan, usually are entirely exempt from state regulation because they are preempted by the federal ERISA law. The state historically, however, has complied with state insurance laws including mandated benefit laws, even if it is not legally required to do. The Division of Insurance to date has not enforced insurance laws on the state union health trusts, and its ability to do so is subject to legal debate.

Prevalence of ASDs

The Centers for Disease Control (CDC) reports about 1 in 110 children are affected with ASDs, and is much more prevalent among boys, about 1 in 58. This is a dramatic increase from just a decade ago. It is unclear how much of this increase is due to a broader definition of ASDs, better diagnoses, or a combination of both. Despite being treatable, many children diagnosed with an Autism Spectrum Disorder (ASD) never receive the treatment they need. Families can go bankrupt or mortgage 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. Although some insurers may already cover some types of autism, most insurance plans explicitly exclude the treatment of ASD, even when the service would otherwise be covered by the health plan as a regular medical condition.

What are Autism Spectrum Disorders?

The National Institute of Mental Health reports that Autism Spectrum Disorders (ASD), also known as Pervasive Developmental Disorders (PDDs), cause severe and pervasive impairment in thinking, feeling, language, and the ability to relate to others. These disorders are usually first diagnosed in early childhood and range from a severe form, called autistic disorder, through pervasive development disorder not otherwise specified (PDD-NOS), to a much milder form, Asperger syndrome. They also include two rare disorders, Rett syndrome and childhood disintegrative disorder. All of these can be debilitating to families emotionally, physically, and financially. Societal rewards of early detection and proper treatment include stronger families, healthier children, and savings in health transfer costs later in life.

National and State Coverage

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, mandating the insurance coverage of ASD. Implementing SB 250 while a federal mandate is pending allows insurers and the state needed time to adjust to the requirements of such a law. It also would bring healthcare professionals and jobs to the state.

Since 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, including the 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. On the other hand, families of any state should not be burdened alone with the great cost of treating a disorder they could not prevent or predict. Moreover, they should not find themselves victims of unwarranted discrimination by health insurance companies. Although there is no cure for ASD, SB 250 will help significantly to treat hundreds of Alaskans suffering from these disorders.

26-LS1400\R
Bailey
3/11/10

CS FOR SENATE BILL NO. 250( )

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-SIXTH LEGISLATURE - SECOND SESSION

BY

Offered:
Referred:

Sponsor(s): SENATE HEALTH AND SOCIAL SERVICES COMMITTEE

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 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 required by this subsection must include treatment prescribed by a licensed physician or psychologist, provided by or supervised by an autism service provider, and as identified in a treatment plan developed following a comprehensive evaluation. Covered treatment may include medically necessary pharmacy care, psychiatric care, psychological care, habilitative or rehabilitative care, and therapeutic care. In this subsection,

(1) "habilitative or rehabilitative care" means professional counseling, guidance services, and treatment programs, including applied behavior analysis or other structured behavioral therapies 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 refuse to deliver, execute, issue, amend, or renew coverage to an individual or terminate coverage because the individual is diagnosed with or received treatment for autism spectrum disorders.

(e) In this section,

(1) "autism service provider" means an individual who is licensed, certified, or registered by the applicable state licensing board or by a nationally recognized certifying organization and who provides direct services to an individual with an autism spectrum disorder;

(2) "autism spectrum disorders" means pervasive developmental disorders, or a group of conditions having substantially the same characteristics as pervasive developmental disorders, as defined in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders-IV-TR, as amended or reissued from time to time;

(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 to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and the functional capacity of other persons of the individual's age.

* **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).

FISCAL NOTE

STATE OF ALASKA
2010 LEGISLATIVE SESSION

Fiscal Note Number:
Bill Version: SB 250
() Publish Date:

Identifier (file name): SB250-CED-INS-3-8-10
Title: Ins. Coverage: Autism Spectrum Disorder
Sponsor: Heatlh & Social Services Committee
Requester: Heatlh & Social Services Committee

Dept. Affected: DCCED
RDU: Insurance
Component: Insurance
Component Number: 354

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

	Appropriation Required	Information					
OPERATING EXPENDITURES	**FY 2011**	**FY 2011**	**FY 2012**	**FY 2013**	**FY 2014**	**FY 2015**	**FY 2016**
Personal Services							
Travel							
Contractual							
Supplies							
Equipment							
Land & Structures							
Grants & Claims							
Miscellaneous							
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0	0.0
CAPITAL EXPENDITURES							
CHANGE IN REVENUES ( )							

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts							
1003 GF Match							
1004 GF							
1005 GF/Program Receipts							
1037 GF/Mental Health							
Other Interagency Receipts							
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0	0.0

Estimate of any current year (FY2010) cost:

POSITIONS

Full-time							
Part-time							
Temporary							

ANALYSIS: *(Attach a separate page if necessary)*

This bill mandates coverage for the diagnosis and treatment of autism spectrum disorders in any plan offered by health care insurer.

The department does not expect a fiscal impact as a result of this legislation

Prepared by: Linda Hall, Director
Division: Insurance
Approved by: Emil Notti, Commissioner
Department of Commerce, Community and Economic Development

Phone 907-269-7900
Date/Time 3/8/10 1:50 PM
Date 3/8/2010

(Revised 11/6/2009 OMB)

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
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MEMORANDUM March 11, 2010

SUBJECT: Coverage for autism spectrum disorders; sectional summary (SB 250, 26-LS1400\A; CSSB 250( ), 26-LS1400\R)

TO: Senator Bettye Davis
Chair of the Senate Health and Social Services Committee
Attn: Thomas Obermeyer

FROM: Dennis C. Bailey
Legislative Counsel

You have requested a sectional summary that compares SB 250, ver. A, with CSSB 250( ), ver. R.

As a preliminary matter, note that a sectional summary of a bill should not be considered an authoritative interpretation of the bill and the bill itself is the best statement of its contents.

VERSION A.

Section 1, ver. A.

Sec. 21.42.397(a) requires a health care insurer to provide coverage for the cost of diagnosis and treatment of autism spectrum disorder, including treatment prescribed by a physician or psychologist and provided by an autism service provider under a treatment plan that must identify pharmacy, psychiatric, psychological care, rehabilitative care, and therapeutic care; defines "rehabilitative care" and "therapeutic care".

Sec. 21.42.397(b) requires that coverage (1) only applies for individuals under 21 years of age; (2) is limited to $36,000 per year; (3) may not limit the number of visits for treatment; (4) is subject to copayment, deducible, coinsurance, general exclusions or limitations to the same extent as other health care services covered under the policy; (5) must cover treatment coordinated with an education program but may not be contingent on coordination of treatment with an education program.

Sec. 21.42.397(c) states that the section does not limit benefits otherwise available to an individual under a health care insurance plan.

Sec. 21.42.397(d) prohibits an insurer from refusing to provide coverage or terminating coverage because an individual is diagnosed with autism spectrum disorders.

Sec. 21.42.397(e)(1) defines an "autism service provider" as a licensed, certified or registered individual with (A) a doctoral degree with a specialty in psychiatry, medicine, clinical psychology, and behavioral or health science with one year of experience with people with autism spectrum disorder, (B) with a master's degree and board certification as a behavior analyst, (C) and (D) with a master's degree or higher in behavior or health science, licensed as a physical therapist, occupational therapist, or speech language pathologist, and with one year of directly supervised experience in behavioral therapies for people with autism spectrum disorder, (E) with a baccalaureate degree or higher and is a board certified associate behavior analyst.

Sec. 21.42.397(e)(2) defines "autism spectrum disorder" using the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders including autistic disorder, Asperger's disorder, and pervasive developmental disorders not otherwise specified.

Sec. 21.42.397(3) defines a "health care insurance plan."

Sec. 21. 42.397(4) defines a "health care insurer."

Sec. 21.42.397(5) defines "medically necessary" to mean care, treatment, intervention, service or item prescribed by a physician or psychologist in accordance with accepted standards of practice that will, or is expected to (A) prevent the onset of an illness, condition, injury, or disability, (B) reduce the physical, mental, or developmental effects of an illness, condition, injury or disability, or (C) assists in achieving or maintaining maximum functional capacity in performing daily activities.

Section 2, ver. A. Makes the changes in the Act applicable to policies issued after January 1, 2011.

Section 3, ver. A. Sets an immediate effective date.

VERSION R.

Section 1, ver. R.
Sec. 21.42.397(a) requires a health care insurer to provide coverage for the cost of diagnosis and treatment of autism spectrum disorder, including treatment prescribed by a physician or psychologist and provided by or supervised by an autism service provider under a treatment plan that must identify pharmacy, psychiatric, psychological care, habilitative or rehabilitative care, and therapeutic care; defines "habilitative or rehabilitative care" and "therapeutic care".

Sec. 21.42.397(b) requires that coverage (1) only applies for individuals under 21 years of age; (2) is limited to $36,000 per year; (3) may not limit the number of visits for treatment; (4) is subject to copayment, deducible, coinsurance, general exclusions or limitations to the same extent as other health care services covered under the policy; (5)

must cover treatment coordinated with an education program but may not be contingent on coordination of treatment with an education program.

Sec. 21.42.397(c) states that the section does not limit benefits otherwise available to an individual under a health care insurance plan.

Sec. 21.42.397(d) prohibits an insurer from refusing to provide coverage or terminating coverage because an individual is diagnosed with autism spectrum disorders.

Sec. 21.42.397(e)(1) defines an "autism service provider" as a licensed, certified, or registered individual who provides direct services to an individual with an autism spectrum disorder.

Sec. 21.42.397(e)(2) defines "autism spectrum disorder" using the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders including autistic disorder, Asperger's disorder, and pervasive developmental disorders not otherwise specified.

Sec. 21.42.397(3) defines a "health care insurance plan."

Sec. 21.42.397(4) defines a "health care insurer."

Sec. 21.42.397(5) defines "medically necessary" to mean care, treatment, intervention, service or item prescribed by a physician or psychologist in accordance with accepted standards of practice that will, or is expected to (A) prevent the onset of an illness, condition, injury, or disability, (B) reduce the physical, mental, or developmental effects of an illness, condition, injury or disability, or (C) assists in achieving or maintaining maximum functional capacity in performing daily activities.

Section 2, ver. R. Makes the changes in the Act applicable to policies issued after January 1, 2011.

Section 3, ver. R. Sets an immediate effective date.

If I may be of further assistance, please advise.

DCB:ljw
10-162.ljw

Alaska State Legislature

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Senator_Bettye_Davis@legis.state.ak.us
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Senate Health and Social Services Committee

CS for Senate Bill No. 250( )

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

BULLET POINTS

- 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.

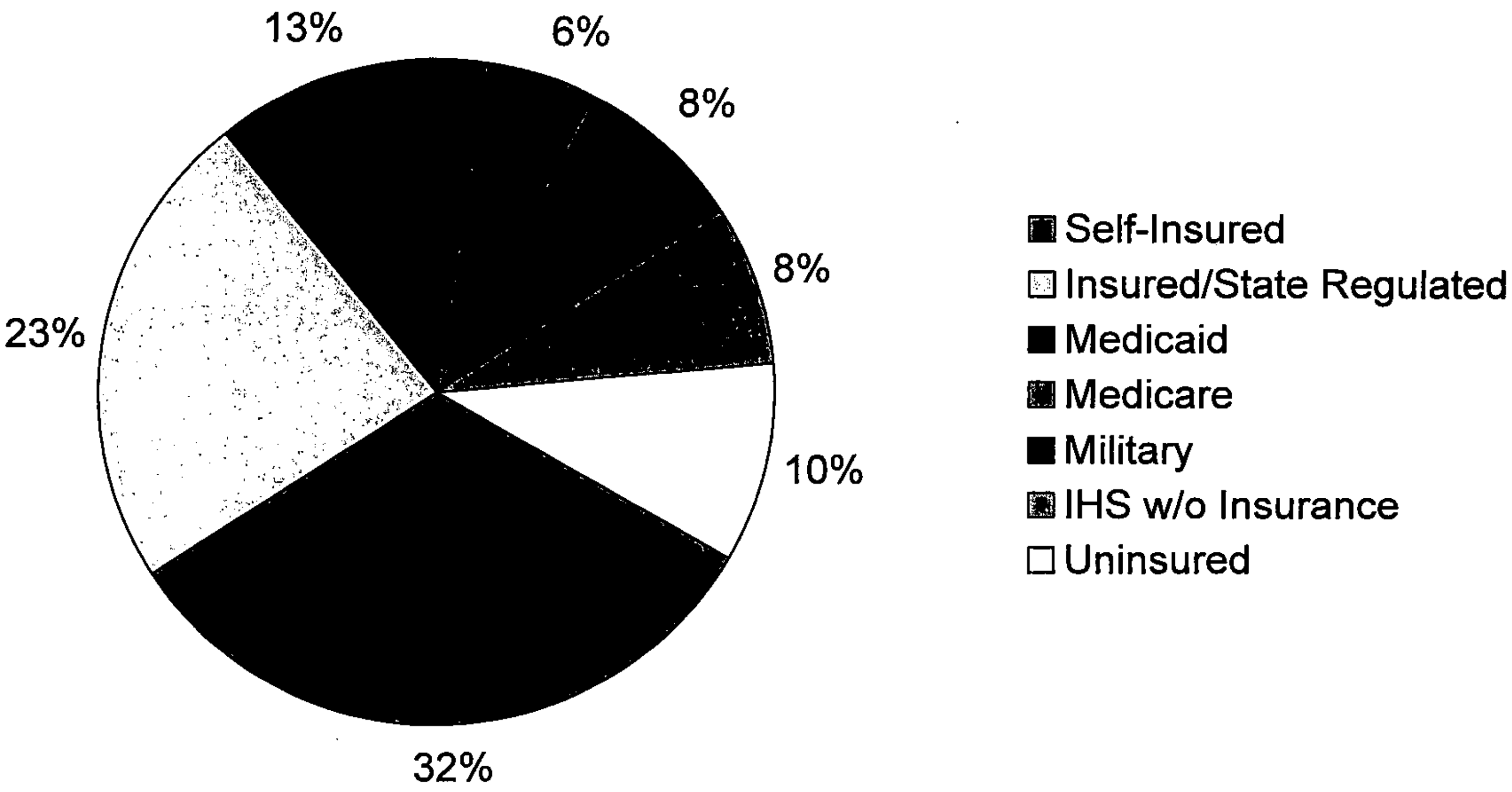
- Since the House version of this bill, HB 187, was introduced in March of 2009, 11 states have passed legislation regarding mandatory insurance coverage of treatment for ASD, with 8 states having enacted legislation prior to March of 2009. The District of Columbia, Puerto Rico and 19 additional states currently have similar legislation pending

- 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.

- The potential pool of beneficiaries between ages 2 and 20 is 48,425, which includes the 54.6% of private sector enrollees working in Alaska who are enrolled in self-insured plans, and after excluding the uninsured and those federal employees in Alaska covered by the ERISA preemption.

- 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. WITHOUT treatment, estimated cost to the state of $3.2 million per capita in state funds.
- SB 250 would affect approximately 23% of all insurance plans in Alaska, providing a maximum annual coverage of $36,000 for diagnosis and treatment of ASD, including, <u>but not limited to,</u> applied behavior analysis.

Health Coverage of Alaska Population



[redacted]

SB 250 Autism Insurance Coverage
Used in (S)HSS hearing 3/15/2010

PREMERA | BLUE CROSS BLUE SHIELD OF ALASKA

Jack C. McRae
Senior Vice President

January 25, 2010

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

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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The Voice of Small Business®
ALASKA

February 1, 2010

RECEIVED
FEB 02 2010

The Honorable Bettye Davis, Chair
Senate Health and Social Services Committee
State Capitol Building
Juneau, Alaska 99801-1182

Dear Senator Davis:

RE: SB 250

On behalf of the National Federation of Independent Business/Alaska, I wish to respectfully share our opposition to Senate Bill 250. The National Federation of Independent Business is the largest small-business advocacy group in Alaska.

Senate Bill 250 proposes to lay an expensive new burden on small businesses already struggling to provide health care. SB 250 mandates coverage for Autism Spectrum Disorder and requires small businesses to cover the costs. The bill does not include the state or most local governmental agencies. Federal law already exempts most large firms and union health plans from the state mandate.

It is understandable that legislators consider the autism mandate too expensive for the state, but it is puzzling that, at a time when the ranks of the uninsured swell, they expect Alaska's small businesses to shoulder a burden that government itself is unwilling to address.

The unfairness of SB 250 is compounded by federal law, which prohibits states, including Alaska, from placing such mandates on large employers who self-insure such as major oil companies and most big box stores. So if you are a larger business, you can operate under one lower-cost, lower-mandate set of federal rules; however, if you are an Alaska small business, you must comply with 28 mandates (29 if SB 250 becomes law) that drive up the costs.

In addition to the economic implications, lawmakers are also sending a highly contradictory message to their constituents. If this legislation is important, why shouldn't state workers and the thousands employees covered by ERISA plans and union health plans have access to this benefit.

American small businesses, which employ 80 percent of the nation's workers, are at the dead center of the health-care crisis in the country. Whereas 99 percent of big companies and corporations provide health care for their employees, less than half (47 percent) of small business owners can afford to do so, according to studies by the National Association of Insurance Commissioners and the Kaiser Family Foundation. Small business that do struggle to provide health care for their employees also pay 18 percent more in premiums than the largest firms do --

for the same benefits -- according to a Commonwealth Fund-supported study.

If Senate Bill 250 becomes law, its first and most lasting effect will be to increase the cost of health insurance and contribute to driving more Alaska workers into the ranks of the uninsured. No one should get trapped into an argument over whether or not it is important to include Autism Spectrum Disorder in health coverage. What small businesses have been asking for is the ability to work with health insurers to individually tailor health plans that fit the needs of their particular businesses and their employees -- which might or might not include autism coverage -- rather than be forced to operate under the one-size-fits-all, legal straightjacket of mandates.

If the legislature intends that it is public policy that Autism Spectrum Disorder be insured, it should make payment also a public responsibility. Since the savings identified by proponents are found in state funded programs, logic would suggest that the state should fund the benefit. Making Autism Spectrum Disorder a diagnosis eligible benefit for the state's Medicaid program could accomplish that goal.

Sincerely yours,

Dennis L. DeWitt
Alaska State Director

Cc: NFIB/AK Leadership Council

SB 250 Autism Insurance Coverage
Used in (S)HSS hearing 3/15/2010

Mercedes Theuer

From: Hall, Linda S (CED) [linda.hall@alaska.gov]
ent: Wednesday, January 27, 2010 5:38 PM
o: Mercedes Theuer; Rep. Pete Petersen
Subject: FW: Mental Health Parity

Following is the information from the Division Life & Health supervisor and actuary regarding the questions we discussed yesterday. My apologies for getting this to you so late. Please do not hesitate to contact me should you have any questions.

Thanks

Linda S Hall
Director
Alaska Division of Insurance
907-269-7900

From: Campbell, Katie S (CED)
Sent: Wednesday, January 27, 2010 8:57 AM
To: Hall, Linda S (CED)
Subject: Mental Health Parity

Mental health parity only applies to employer groups with 50+ employees.

ental health is defined as "benefits with respect to services for mental health conditions, as defined under the terms f the plan and in accordance with applicable Federal and State law. Our definition is "benefits provided for mental health services as defined under the terms of the health care insurance plan; but does not include benefits for the treatment of substance abuse or chemical dependency".

Financial requirements may not be more restrictive than for medical and surgical benefits. Financial requirements are defined to include deductibles, copays, coinsurance and out of pocket expenses. I don't believe travel benefits were intended to be covered by this definition but I suppose one could argue that travel is an out of pocket expense and if it is covered for medical and surgical it must be covered for mental health as well. If the desire is to cover travel it should be specifically required.

Because the law doesn't mandate benefits it doesn't address the offer of mental health benefits in terms of whether an insurer can offer coverage only for specific types of mental health conditions. The law allows the plan to define what constitutes mental health benefits.

SB 250 Autism Insurance Coverage
Used in (S)HSS hearing 3/15/2010

From: **AUTISM SPEAKS**

AUTISM SPEAKS

Rebecca Shaffer Stelzner -- 202.955.3114; rshaffer@autismspeaks.org

Rubenstein Communications, Inc.
Adam Pockriss – 212.843.8286; apockriss@rubenstein.com

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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SB 250 Autism Insurance Coverage
Used in (S)HSS hearing 3/15/2010

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 <u>**Autism Specialists**</u>, (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) <u>**Certified direct service personnel**</u>, 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.

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

GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

HB 187 – Autism Insurance Reform

[redacted]

SB 250 Autism Insurance Coverage
Used in (S)HSS hearing 3/15/2010

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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GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

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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Autism Issues and Needs

The Governor's Council on Disabilities & Special Education

SB 250 Autism Insurance Coverage
Used in (S)HSS hearing 3/15/2010

Preliminary Report of the Ad Hoc Committee on Autism: Findings and Recommendations

Governor's Council on Disabilities and Special Education

2006

Kathleen Fitzgerald, Chair
Millie Ryan, Executive Director

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Department of Health & Social Services
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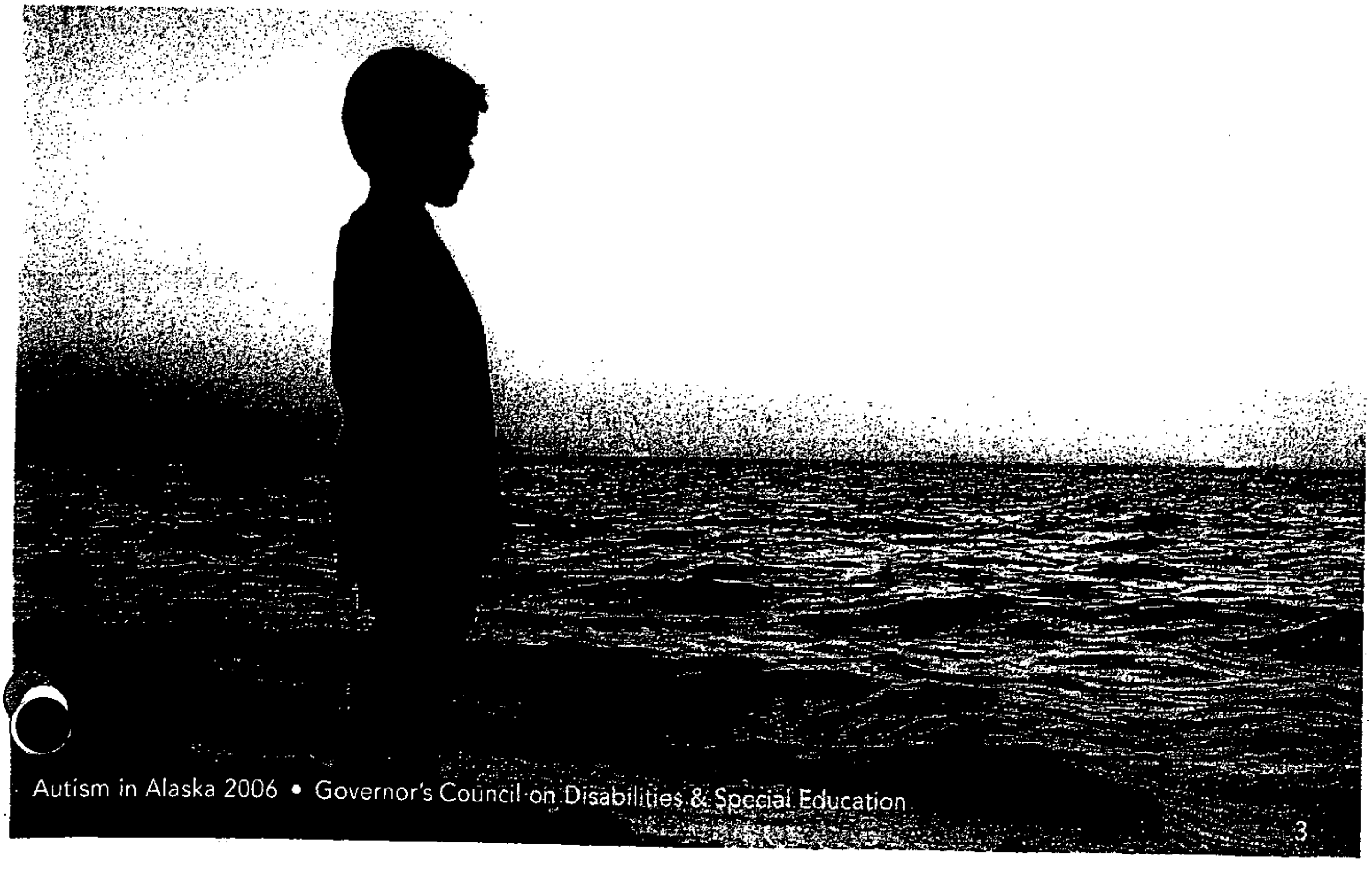

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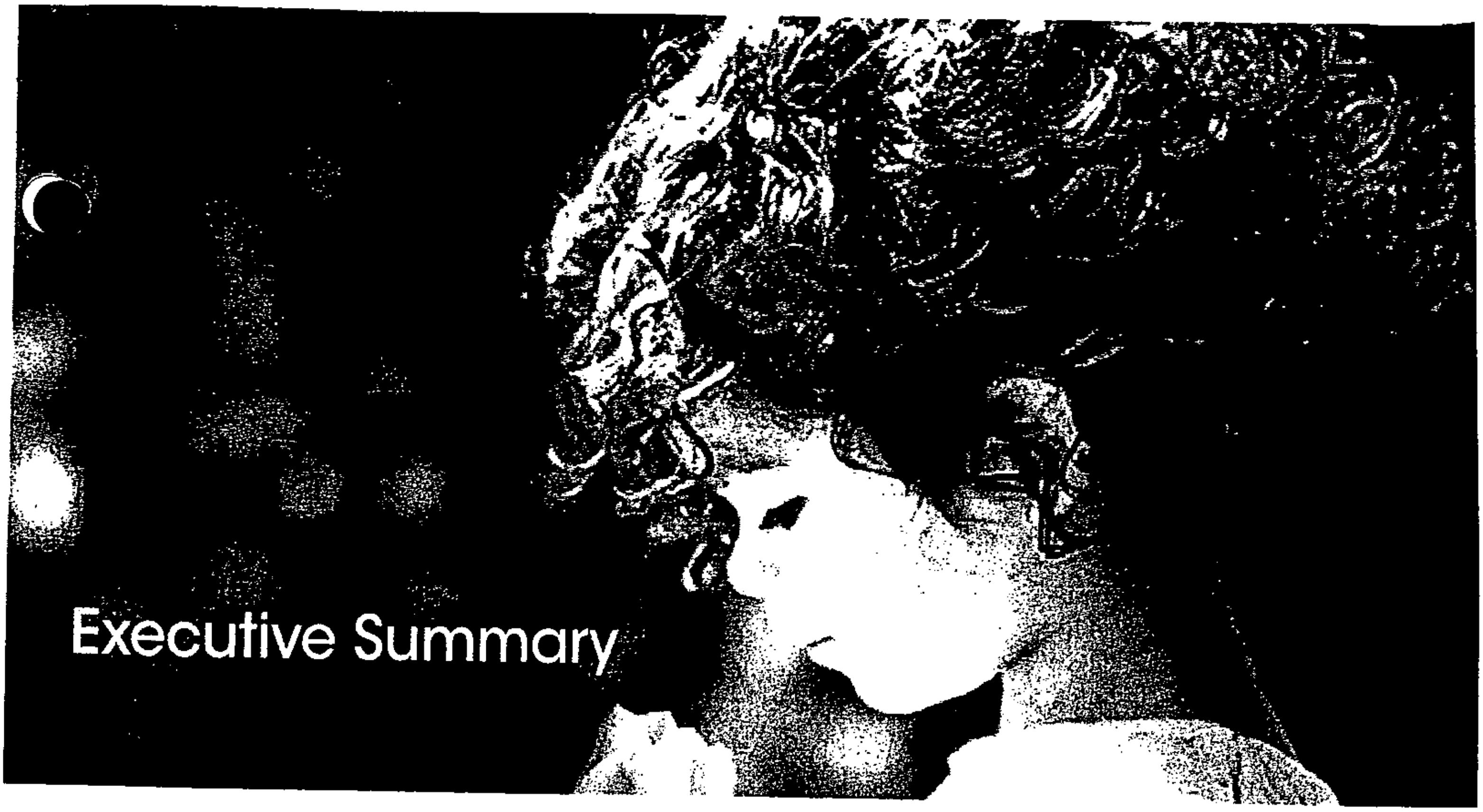


Executive Summary

Although incremental changes have occurred on behalf of children and adults with Autistic Spectrum Disorders (ASD) in Alaska, the pace and amount of change has been inadequate to meet needs. Alaska does not have a system to capture the prevalence of ASD, but as in other states, the educational and service delivery systems have experienced an increased demand for ASD-specific intervention in recent years.

Experts agree that early identification and diagnosis of ASD is important.

Experts agree that early identification and diagnosis of ASD is important. Screening identifies those in need of a comprehensive evaluation and assessment, and a diagnosis leads to appropriate interventions. Research has documented the efficacy of early, intensive intervention (Sheinkopf and Siegel, 1998, Dawson and Osterling, 1997). ASD specific interventions may speed the child's development, ameliorate inappropriate behaviors, and improve functioning over their lifetime. While not all children with ASD experience dramatic improvement with intervention, many do.

The overall cost of caring for a person with autism over his or her lifetime is estimated to be $3.2 million (Ganz, 2006). Applying national prevalence rates of 1/166 to Alaska's 10,000 births annually results in about 60 babies born each year who will likely develop ASD. The lifetime cost for the 60 Alaskan babies born this year would total $192 million, as well as for the 60 babies born every subsequent year.

When children do not receive early intervention, the cost of caring for them over their lifetime exerts a substantial economic burden on society. Behavioral therapies represent only 6.5% of the total cost of caring for an individual with ASD. By contrast, adult care represents 21% and lost productivity is nearly 31% of the total annual expense involved in caring for an individual with ASD.

The Governor's Council on Disabilities and Special Education, with the concurrence of the Alaska Mental Health Trust Authority, convened an Ad Hoc Committee on Autism to develop recommendations to present to the Alaska Legislature and Administration. The group organized their 21 recommendations around identification, diagnosis, and treatment. Recommendations were prioritized by the Committee, and submitted to the Council's Executive Committee for final approval.

The following four recommendations were ranked as the Committee's highest priorities. Although each is a separate recommendation, their interdependent nature requires they be considered as a package. One recommendation is to increase screening of children for ASD. Screening is a quick process used to differentiate children who may experience ASD, and identifies those who need a complete developmental and medical assessment. Without enhancing the capacity for comprehensive assessment and diagnosis, screening would be a disservice, leaving families concerned but experiencing a very lengthy wai before confirming or ruling out a diagnosis of ASD. Similarly, because the value of early diagnosis is in the potential for amelioration; diagnosing more children with ASD will make the existing shortage of services even more critical. To provide an adequate level of services, training for families, teachers, and direct service providers is essential to increase the size and quality of the workforce. Finally, the need for family support will intensify as more children are identified with ASDs.

Research has documented the efficacy of early, intensive intervention (Sheinkopf and Siegel, 1998, Dawson and Osterling, 1997).

1. **Greatly expand autism resources and referral services** so that the program is well funded, independent, and highly visible with a long-range plan for satellite programs throughout the state.

   Several activities are envisioned to expand the functions of an autism resource center. These include:

   - An annual comprehensive fair/institute for families to provide up-to-date medical information, guidance in navigating the system, and other topics. Disseminate the institute through a CD or a webcast for people who cannot attend in person.
   - The establishment of local resource centers across Alaska that are independent in nature, but collaborative with other providers, and state/local/national experts;

- Regional, technical assistance traveling teams with professional oversight; and
- Comprehensive parent training in education, systems and political advocacy, guardianship, medical services, and other topics as needed.

2. **Establish universal screening for autism spectrum disorders**, using a tool such as the parent-completed Modified Checklist for Autism in Toddlers (M-CHAT), and provide systematic referral for comprehensive assessment for children with risk factors for ASD.

   Screening is a quick, simple and inexpensive process to identify children who have symptoms that could indicate a disorder. Like hearing or vision problems, early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children. Universal screening of children at well-child exams is recommended to ensure that children with ASD are identified as early as possible in life. The M-CHAT is a 23-question, parent-completed survey that can be used at well-child check-ups and is valid for children between the ages of 16 and 36 months.

   Screening does not take the place of a comprehensive assessment; rather it identifies those children who would benefit from a complete evaluation. The next step for children who show possible signs of an ASD is to refer them to early intervention or the school district where the process of a developmental assessment can begin. A protocol for children with risk factors for ASD should be developed to ensure they are referred for further testing and a comprehensive developmental assessment.

Early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children.

3. **Increase the capacity for comprehensive, timely assessments and diagnosis** of Autism Spectrum Disorders using a multidisciplinary team that is embedded with a system for referral to appropriate services (i.e. Early Intervention/Infant Learning Program, school districts, medical and other clinical providers).

   Screening for ASD will identify those children who require a comprehensive assessment across developmental and physical domains. Professionals from multiple disciplines are needed to conduct a complete assessment (i.e. neurodevelopmental pediatrics, psychology, speech, occupational and physical therapy, opthamology, audiology). For young children it is especially critical to perform a differential diagnosis to rule out any other possible genetic or medical disorders.

Executive Summary Cont...

Assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family.

Currently few clinicians and specialists are skilled and trained in performing ASD assessments. Investing in training and developing specialists in ASD will reduce the time between screening and a comprehensive assessment, as all testing needs to occur before a definitive diagnosis can be made.

The comprehensive assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family. Families need information and active referral to link up with needed health, educational, financial and family support resources.

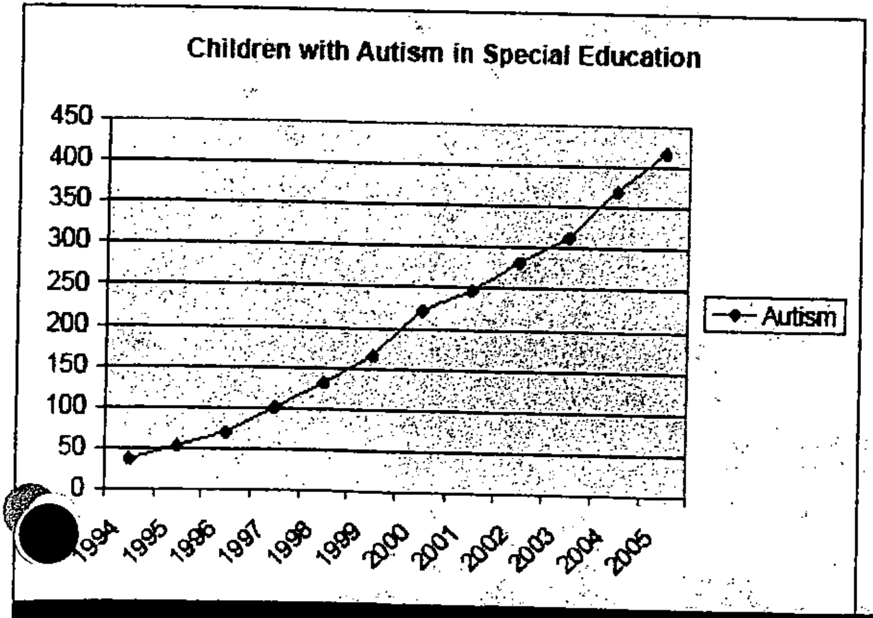
4. **Change Medicaid to ensure that children with ASD are able to receive time-limited, intensive intervention services.**

The Deficit Reduction Act permits flexibility within state Medicaid plans. It is recommended that the Medicaid State Plan be modified to include time-limited autism intervention services. If modifying the Alaska Medicaid Plan is not feasible, the Committee recommends that the state develop an Autism waiver modeled after Minnesota or Wisconsin. A third alternative would be to change eligibility within the Home and Community Based Waiver to ensure children with ASD receive time-limited intensive services.

Introduction

Autism Spectrum Disorder

Autism is a complex developmental disability that is the result of a neurological disorder affecting the functioning of the brain (Autism Society of America). Autism Spectrum Disorders (ASD) includes Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified, and Childhood Disintegrative Disorder. Studies have produced varying prevalence rates, in part due to method of diagnosis and size of the sample; however, 1 in 166 children are thought to have an Autism Spectrum Disorder (Centers for Disease Control and Prevention, n.d.),. Each year about 10,000 babies are born in Alaska, suggesting that 60 of those babies will be identified in their early childhood as having an ASD. Another indicator that Autism is climbing in Alaska comes from the public school system. The number of children with autism in the Alaskan School system has risen each year for the past 13 years. These trends are similar in other states.

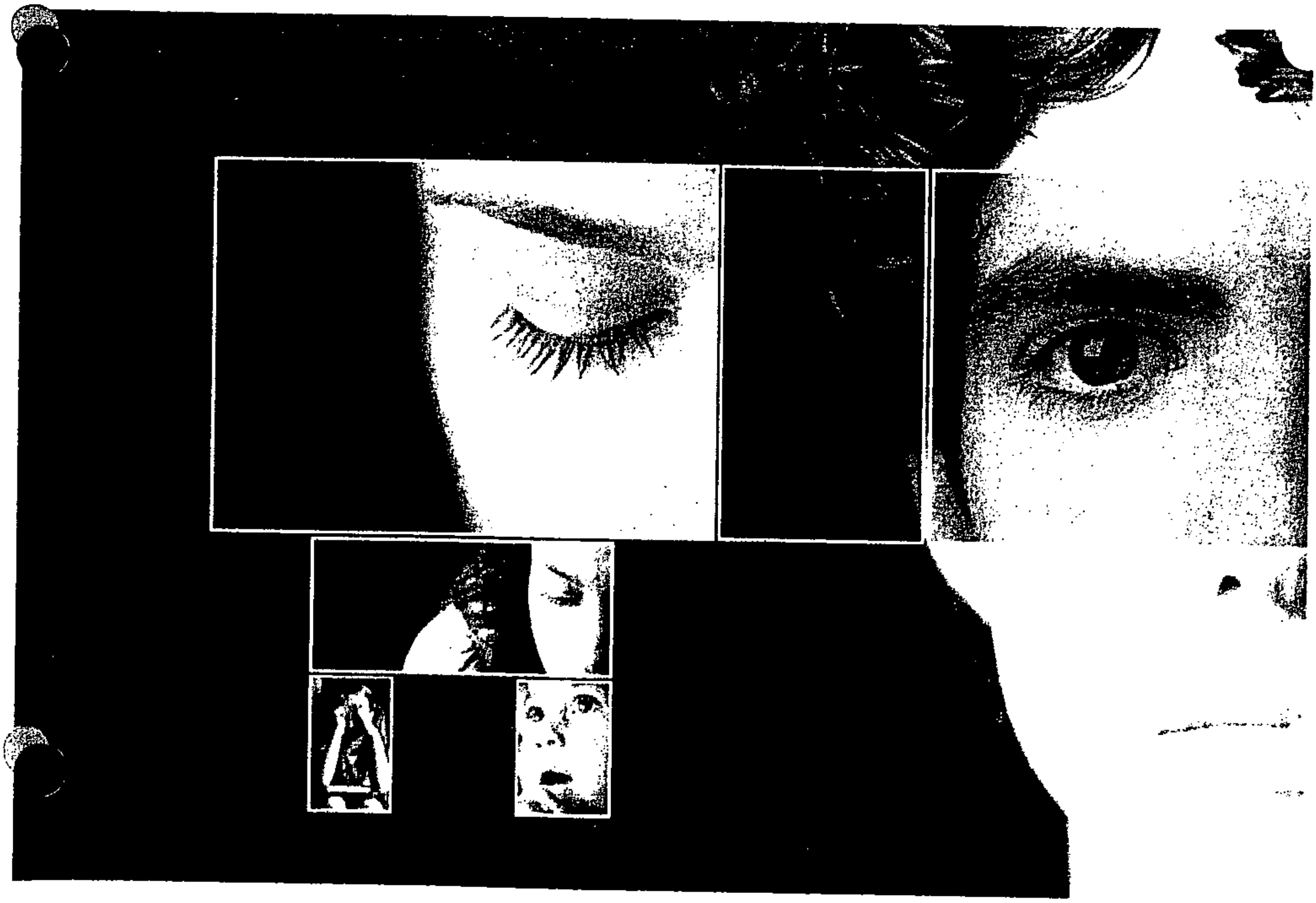


Growth of the Number of Cases of Autism in Alaskan Schools

ASD covers a wide range of symptoms, from very mild to severe. ASD affects social skills, communication, and cognitive development. ASD affects the individuals' ability to convey or interpret others emotions. Children may engage in restricted and/or repetitive play and have

Some individuals with ASD may be nonverbal, while others may not have any difficulty speaking.

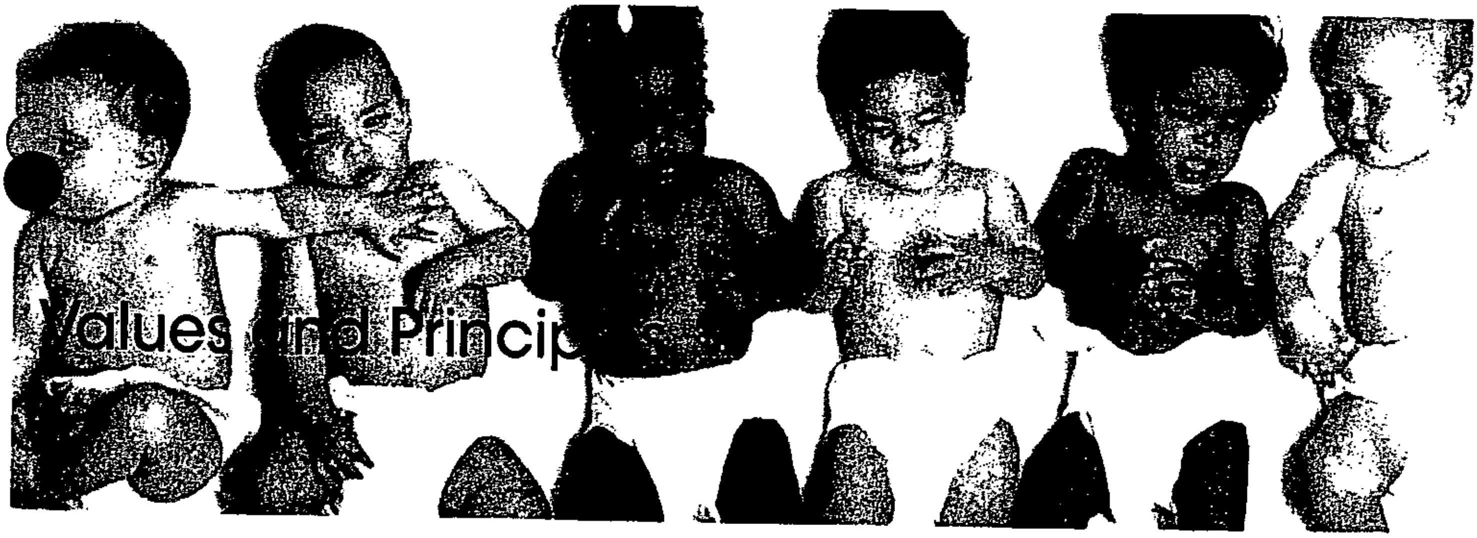
unusual attachments to objects. People with ASD might not seem interested in other people and prefer to be alone. Some children with ASD do not like to be held or cuddled, and many do not make eye contact with others. Individuals with ASD also show varied degrees of impairment in their verbal and nonverbal 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.



Ad hoc Committee on

On December 6th 2005, the Governor's Council on Disabilities and Special Education's convened an Ad Hoc Committee on Autism. The purpose of this group was to examine the current status of services needed by people with ASD and their families and make recommendations to the Legislature and state policymakers. The 17 member committee consists of parents of children with ASD, Governor's Council members, and representatives from the Department of Health & Social Services, Division of Senior and Disability Services, Division of Behavioral Health, Department of Education & Early Intervention, Office of Children Services, and the University of Alaska Anchorage. The Committee met monthly over the course of five months. This report contains the recommendations of the Governor's Council and the Ad hoc Committee on Autism.

The report is organized around the following three major areas: Values and Principles, Identification/Screening/Diagnosis, and Services. Topics are prefaced with a summary of the Committee's evaluation of Alaska's current status and followed by recommendations.



Values and Principles

The following statements articulate the values that guided the Committee's work and recommendations.

People with Autistic Spectrum Disorders:

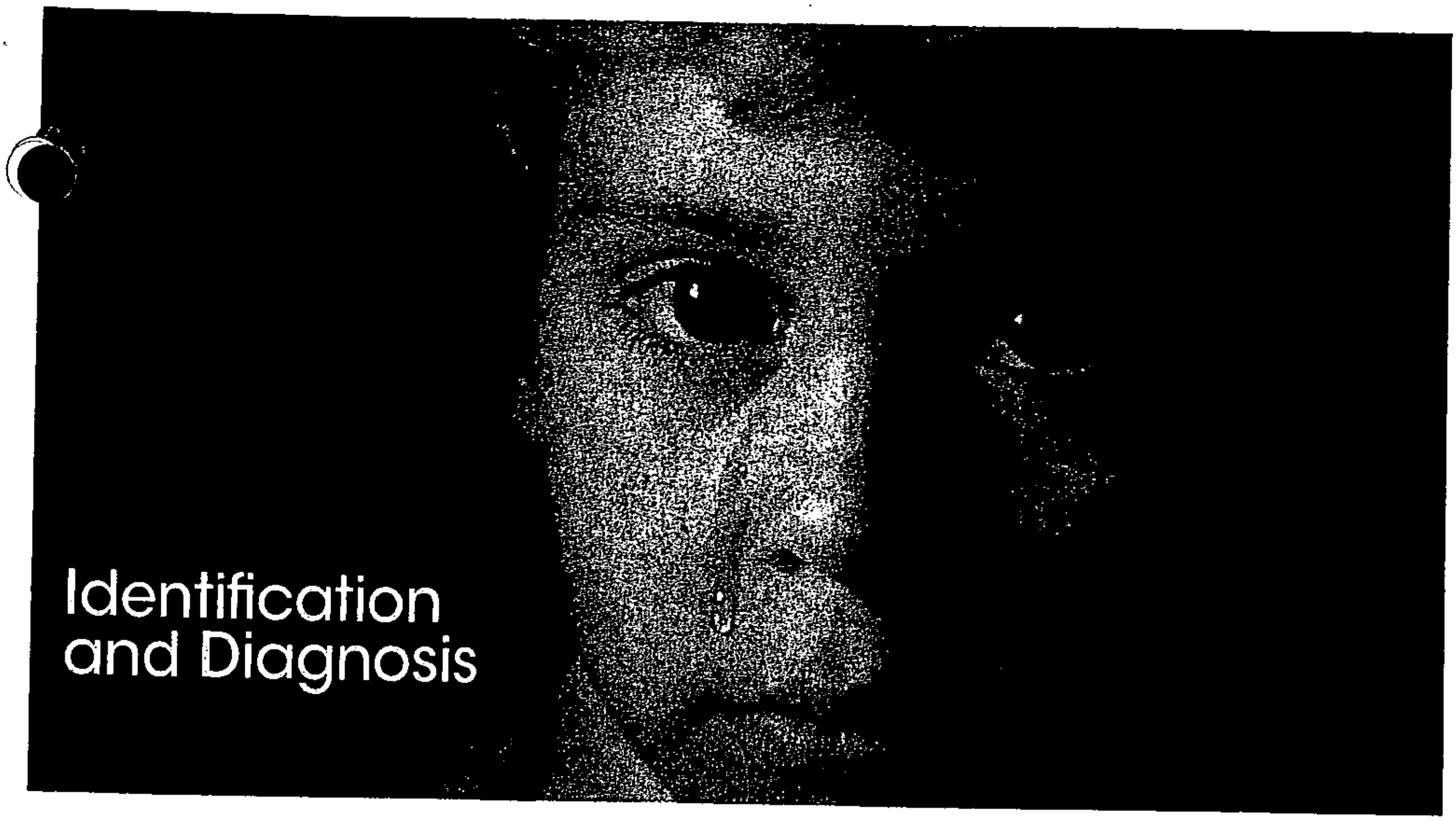
- Have great promise, gifts and potential;
- Deserve the opportunity to engage actively in the community, with friends and family and in work and volunteer positions;
- Contribute to their families, communities, and Alaska;
- Represent ethnic, socioeconomic, racial, and religious groups, speak many languages and live in urban, rural and remote areas of the state; and
- Are people first – ASD is only a part of who they are.

Early intervention works, is cost-effective and fiscally responsible.

Early intervention works, is cost-effective and fiscally responsible.

Services for people with ASD need to be:

- Individualized, based on family choice and need;
- Family directed, and based on principles of self-determination;
- Evidence-based;
- Provided as soon as possible after identification and diagnosis;
- Culturally appropriate and relevant, available in urban and rural areas;
- Coordinated, comprehensive and collaborative across all disciplines and state service systems;
- Available across the lifespan, and the full spectrum of autistic disorders;
- Delivered in a manner that maximizes independence by providing the supports and services needed; and
- Built on and honoring of individual strengths.



Identification and Diagnosis

> The importance of early identification and diagnosis of individuals with autism cannot be overstated.

The importance of early identification and diagnosis of individuals with autism cannot be overstated. Early identification and diagnosis of autism leads to early intervention. Children with autism identified early and enrolled in early intervention programs show significant improvements in their language, cognitive, social, and motor skills, as well as in their future educational placement (National Research Council, 2001). There is also empirical evidence that shows children who enter early intervention at younger ages show greater results than children who enter intervention programs at an older age (Harris & Handleman, 2000; Sheinkopf & Siegal, 1998). There is also a financial incentive for the early identification, diagnosis, and intervention for children with autism. Ninety percent of children with autism who do not receive effective early intervention will require special or custodial care throughout their lives, and this is estimated to cost the United States $35 billion dollars a year (Ganz, 2006).

Where we are now

For the past 14 years, the Children's Hospital at Providence has supported the Center for Children with Special Needs, staffed with a neurodevelopmental pediatrician skilled in the diagnosis of children with ASD and other developmental disabilities. In addition, the State of Alaska sponsors neurodevelopmental screening clinics in locations around the state. However, despite Child Find efforts on the part of early intervention and school districts, not all children with significant developmental delays are referred for a neurodevelopmental evaluation prior to entering school. Children residing in more remote, rural locations may be identified later than children in communities in more urban settings. Accurate identification of the child's pattern of development/learning style and behavior (i.e. autism diagnosis) leads to an appropriate school certification and program as well as an approach to solving behavior problems. Families living outside of Anchorage with children who are suspected of having autism frequently must wait for an appointment and then travel to Anchorage for a medical work-up and diagnosis.

The current definition used by Alaska's Department of Education & Early Development to determine eligibility is also an obstacle for the provision of special education services for students with ASD. This definition includes Autism, but not the other disorders in the spectrum. This committee proposes a definition that includes Pervasive Development Disorder, Asperger's Syndrome, and Childhood Disintegrative Disorder.

Currently there is not an accurate count of persons with ASD in the state. This adds to the difficulty of planning and securing resources for statewide autism services. This affects people with autism, their families, state and local governments, school districts, and federal agencies. Having hard data on autism in the state will provide a comprehensive information resource that can direct state policies and service decisions that will improve the lives of people with ASD and their families. Autism registries have already been shown to be effective for planning and providing services in the states of Missouri, Virginia, West Virginia, Florida, and Delaware. An autism registry will also facilitate early detection and diagnosis of people with autism.

Identification and Diagnosis
Recommendations

1. **Establish universal screening for autism spectrum disorders, using a tool such as the parent-completed Modified Checklist for Autism in Toddlers (M-CHAT), and provide systematic referral for a comprehensive assessment for children with positive screens.**

   Screening is a quick, simple and inexpensive process to identify children who have symptoms that could indicate a disorder. Like hearing or vision problems, early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children. Universal screening of children at well-child exams is recommended to ensure that children with ASD are identified as early as possible in life. The M-CHAT is a 23-question, parent-completed survey that can be used at well-child check-ups and is valid for children between the ages of 16 and 36 months.

Screening does not take the place of a comprehensive assessment; rather it identifies those children who would benefit from a complete evaluation. The next step for children who show possible signs of an ASD is to refer them to early intervention or the school district where the process of a developmental assessment can begin. A protocol for children with risk factors for ASD should be developed to ensure they are referred for further testing and a comprehensive developmental assessment.

Children who appear at risk of having an ASD require a comprehensive assessment across developmental and physical domains.

2. **Increase the diagnostic capacity throughout the state by developing a system to provide timely, comprehensive diagnosis of Autism Spectrum Disorders using a multidisciplinary team and systematic referral to appropriate services (i.e. Early Intervention/Infant Learning Program, school districts, medical and other clinical providers).**

Children who appear at risk of having an ASD require a comprehensive assessment across developmental and physical domains. Professionals from multiple disciplines are needed to conduct a complete assessment (i.e. neurodevelopmental pediatrics, psychology, speech, occupational and physical therapy, opthamology, audiology). For young children it is especially critical to perform a differential diagnosis to rule out any other possible genetic or medical disorders.

Currently few clinicians and specialists are skilled and trained in performing ASD assessments. Investing in training and developing specialists in ASD will reduce the time between screening and a comprehensive assessment, as all testing needs to occur before a definitive diagnosis can be made.

The comprehensive assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family. Families need information and active referral to link up with needed health, educational, financial and family support resources.

3. **Expand the educational definition of autism to include all disorders in the Autism Spectrum Disorder. See Appendix A for recommended definition language.**

The current definition of autism used by the Alaska Department of Education &

Early Development to determine the eligibility is restrictive, including Autism Disorder, but not other disorders in the spectrum. The Committee recommends a definition that includes Pervasive Development Disorder, Asperger's Syndrome, and Childhood Disintegrative Disorder.

It is important to define ASD broadly so that students receive an appropriate education. Some children with ASDs are incorrectly categorized as emotionally disturbed resulting in educational programs that disregard the neurological basis for the disorder, and instead treat the child as though they had a behavioral condition. Children receiving proper services are more likely to achieve better outcomes and exit the special education system earlier. A broad definition benefits the State by reducing costs, and providing more accurate data.

> Children receiving proper services are more likely to achieve better outcomes.

4. **Establish and maintain a statewide autism registry or surveillance program.**

Alaska does not have a reliable way of assessing the number of individuals in the state with ASD. Having valid statistics on the prevalence of ASD in Alaska is critical to understanding trends, planning and developing programs tc meet the educational and lifelong needs of individuals with ASD, future budgeting, and ensuring adequate numbers of people trained to provide specialized services. By understanding the prevalence of autism in Alaska, we will be better prepared to garner financial support from many sources to help Alaskan children and adults with ASD. The data collected will also allow our state legislature and school districts to better plan for growing needs for Alaskan's with autism.

5. **Develop capacity to diagnose Asperger Syndrome in older children and adults.**

Unlike other ASDs, Asperger Syndrome is typically not diagnosed in early childhood, but rather when the child is in school or even as an adult. A multidisciplinary team familiar with the features of Asperger Syndrome is needed to do an adequate assessment. Components of this assessment include taking a physical and developmental history, and conducting communication and psychological evaluations. Results of the evaluation need to be translated into a coherent picture and communicated to the child's family or the adult.

Service

There is a critical shortage of services for people with ASD in the state.

There is a critical shortage of services for people with ASD in the state. Reasons for this include an inadequate workforce, lack of evidence-based intervention programs within the state, especially for young children, and a need for more training for all those who work or come into regular contact with individuals with ASD. The lack of services influences the quality of the medical, dental, educational, and treatments offered to people with autism. Without these services, especially in the early childhood years when intervention can dramatically affect long-term outcomes, individuals with ASD and their families will fail to reach their potential, be less self-sufficient and more reliant on state-funded services, and unable to fully contribute as a citizen.

Where we are now

Providing medical and dental care for individuals with autism can be complicated. The most common medical problems linked with autism are seizures, accidents and injuries, infections, dental problems, and nutritional issues (Volkmar, 2000). Pediatricians are located only in urban areas of the state or on an itinerant basis to hub communities. Smaller communities may be served by family practice physicians, nurse practitioners, or physician assistants while remote areas of the state are most commonly served by community health aides and practitioners. While pediatricians in particular are familiar with autism, many families are unable to access a medical provider who can advise them about the treatment options families may learn about. As many of these treatment options are controversial, having a medical provider knowledgeable about the current status of autism treatment, would guide families in making informed decisions.

There are a number of evidence-based educational interventions used throughout the country. In Alaska, educational services are provided by the Early Intervention/Early Intervention/Infant Learning Program (EI/ILP) for children birth to three, and by school districts for children from 3 to 18 or 22, depending on the student's Individual Education Plan. The EI/ILP delivers services in the family's home. An early interventionist, early childhood special education teacher, speech therapist, physical therapist, occupational therapist and/or paraprofessional supervised by an early interventionist work with families to teach them ways to enhance their child's development. School districts serve children and youth with ASD through their Individual Education Plan, which outlines the goals and services to be delivered. A statewide assessment of school districts' educational programs for students with ASD has not been conducted. However, nationally-recognized intensive intervention programs designed specifically for individuals with ASD, such as applied behavioral analysis, floor time, and TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children) are largely unavailable to families unless they are able to pay for the services of a consultant outside the state. The Anchorage School District does provide some specialized classrooms for children with ASD.

Since individuals with ASD have different needs and abilities, providing a range of evidence-based treatments is extremely important.

This is a critical aspect of autism services because the major treatment for autism is early and ongoing educational intervention. Presently, there are some limited and inconsistent services provided by school districts, private and home programs. Most school districts do not have the capacity to provide intensive interventions for students with autism. Part of the problem is that in both the rural and urban parts of the state, there is difficulty in the recruitment and retention of staff experienced with autism. The intensive, one-on-one nature of many interventions is prohibitively expensive for many school districts. There is also currently a limited amount of time provided for extended school year services. These services may be provided by the school district to some children with developmental disabilities who regress when not in school and are offered during regular school breaks. When extended school year services provided by school districts, some children with autism behaviorally and cognitively regress.

Providing effective autism treatments is found to be deficient in Alaska. Since individuals with ASD have different needs and abilities, providing a range of evidence-based treatments is extremely important. Many parents are forced to go out of state and spend a lot of money to get the services their children need. There are currently pockets of well-trained professionals providing autism related services in Alaska, but they are mostly clustered in the major urban centers. In Alaska, Medicaid does not reimburse for intensive behavioral treatment as a medical service. Intensive behavioral treatment is an important component of autism treatment.

A contributing factor to the lack of treatment and services for individuals with Autism Spectrum Disorders, is an inadequate level of training, resources and support for professionals and parents. More in-state training is needed, especially due to the high turnover rate in the direct service field and in school districts throughout Alaska.

More in-state training is needed.

Service Recommendations

Medical Services

1. **Expand specialty clinics at hospitals for individuals with autism.**

   Medical services are critical because children with ASD are more likely to develop certain medical conditions such as seizures, accidents and injuries, infections, and dental and nutritional problems. This committee recommends that medical services be expanded to include consultation with the child's or adolescent's primary care provider and other service providers. Families and providers often need advice on such issues as medication, toileting, sleep disturbances, behavior and aggression, self-injurious behaviors, motor tics, social skills, and others.

2. **Amend Medicaid regulations to ensure reimbursement for evidence-based medical interventions and psychological assessments and interventions. Currently only psychologists working in mental health clinics or under the supervision of a psychiatrist are allowed to bill Medicaid.**

   School districts perform psychological evaluations every three years. Because children develop rapidly in the early years, a new evaluation is typically needed to complete an assessment. Child psychologists are uniquely qualified to perform cognitive and adaptive behavior skills, and this is an important element of the diagnostic process. Adding psychology services for Medicaid recipients would alleviate this problem.

Service Recommendations Cont...

3. **Develop the capacity of medical providers to work successfully with individuals with ASD.**

   Increasing the capacity of medical providers to work with individuals with ASD is essential to providing quality health and dental care for the ASD population. Communication and behavior problems as well as unusual and unpredictable response to stimuli complicate medical and dental care. Specialized training and skills will help medical and dental professionals provide quality care for those with ASD in Alaska.

   The Committee recommends that training on ASD be provided at medical conferences in Alaska.

> There is strong evidence supporting the validity of intensive early intervention beginning as early as possible after diagnosis.

Educational Services

1. **Adopt best practice guidelines and set measures of effectiveness of educational services for children with ASD.**

   The National Autism Center is developing national standards for the treatment of ASD. Using evidence-rating criteria the Center will produce a set of national research-based standards for education and behavioral intervention for children with autism. The Committee recommends that Alaska adopt best practice standards, based on national standards, for interventions and educational services provided to individuals with ASD in Alaska.

2. **Provide adequate funding to establish intensive early intervention services for children with autism through the Early Intervention/Early Intervention/Infant Learning Program, Head Start and school district preschool programs.**

   Intensive early intervention has been documented to be an effective intervention for children with ASD (Dawson & Osterling, 1997; Green, 1996). Although the specific intervention models are a source of controversy, there is strong evidence supporting the validity of intensive early intervention beginning as early as possible after diagnosis (Sheinkopf & Siegel, 1998).

   Children under three with developmental delays are served by the Early Intervention/Infant Learning Program. Some children receive a diagnosis of ASD before their third birthday and will begin receiving services through this program. Families receive periodic home visits

Service Recommendations Cont...

from an early intervention specialist, based on the child and family needs. Eligible three to five year old children attend public preschool or Head Start programs.

3. **Adequately fund and provide appropriate intensive interventions based on best practices to children with ASD in the educational system.**

   Currently, schools provide either limited or no ASD-specific intervention programs for children qualified to receive special education. Rather than endorsing a specific model, the Committee recommends that evidence-based models for ASD intervention become available in the educational system. Families need to be provided a choice of models and an opportunity to decide which approach will best meet their child and family's needs. Interventions require a time and lifestyle commitment from the families.

Research has documented the efficacy of early, intensive intervention (Sheinkopf and Siegel, 1998, Dawson and Osterling, 1997).

4. **Enlist Alaska's universities' support and collaboration in developing certification and degree programs for students interested in specializing in autism interventions.**

   The University of Alaska system and the small number of private colleges in the state are a resource that can be used to help develop the workforce needed to provide effective services for individual with ASD. Education, Special Education, Social Work, and Psychology degree programs, with a certification in autism interventions can help alleviate the current shortage of qualified personnel. The University of Alaska Anchorage also has the Washington, Wyoming, Alaska, Montano, and Idaho (WWAMI) Biomedical program affiliated with the University of Washington School of Medicine. This program can be used to increase the number of medical doctors in state who specialize in diagnosing and treating children with ASD.

5. **Build capacity for all early intervention and childcare programs, and school districts, to adopt evidence-based, non-aversive behavioral interventions, such as positive behavioral support and best practice interventions with proven outcomes.**

   Challenging behaviors often accompany ASD. When individuals are limited in their communication skills, they may use behaviors as a way to let others know what they want and need. Positive behavior support helps adults decipher the communication intent of behavior, and teaches alternative ways individuals can express themselves. Programs that serve children with ASD need training and tools for helping the adults better support the communication and behavioral needs of students with ASD.

Children with ASD present unique and difficult needs that require specific skills from teachers and education professionals. Currently, no specific certification in ASD interventions for teachers and educational professionals exists in the state.

6. **Investigate amending Medicaid regulations to allow reimbursements to districts for school-based intensive autism interventions to Medicaid eligible students.**

About half of Alaska's children are Medicaid eligible. Adding intensive intervention for ASD as a Medicaid service would permit the state to collect federal funds to help cover the expense. Shifting some of the cost of intervention would permit school districts to use their funding to reach non-Medicaid students as well.

Children with ASD present unique and difficult needs that require specific skills from teachers and educational professionals.

Home and Community-Based Services

1. **Change Medicaid to ensure that children with ASD are able to receive time-limited, intensive intervention services.**

The Deficit Reduction Act permits flexibility within state Medicaid plans. It is recommended that Alaska modify their Medicaid Plan to include time-limited autism intervention services. If modifying the Alaska Medicaid Plan is not feasible, the Committee recommends that the state develop an Autism waiver modeled after Minnesota or Wisconsin. A third alternative would be to change eligibility within the Home and Community Based Waiver to ensure children with ASD receive time-limited intensive services.

2. **Provide supplemental grant funding for providers to offer treatment services for individuals with autism who are not eligible for Medicaid or meet level of care.**

Not all individuals with ASD meet level of care requirements for a Medicaid Home and Community-based waiver or TEFRA, but would benefit from intervention. The DD grant program supports individuals with developmental disabilities who are not eligible for a waiver. Additional funding in the DD grant program would help meet the needs of children and adults with ASD.

Service Recommendations Cont...

3. **Bring training on diagnosis and interventions to Alaska.**

   Alaska faces a shortage of clinically trained personnel experienced in performing diagnostic assessments and follow-up treatment. The Committee recommends improvement in the availability and expertise of these specialists to assess and treat ASD. Very few psychologists in Alaska are experienced in administering assessment tools for autism and evaluating the results, especially for young children.

   Several University-based Autism centers provide training that, if brought to Alaska, would expand statewide capacity for timely and accurate diagnosis and appropriate intervention.

Bring training on diagnosis and interventions to Alaska.

4. **Change Medicaid regulations to provide reimbursement for autism treatments as a medical service.**

   Although research has shown promising results stemming from autism interventions for some individuals with ASD, there are significant differences in the costs, degree of family involvement required, availability, and content and structure of these programs. The Committee believes a continuum of intervention options should be available and billable through Medicaid. Such interventions may significantly reduce the lifetime cost of care for individuals with ASD.

5. **Remove licensing barriers that prevent out-of-state autism specialists from practicing in Alaska.**

   Out-of-state autism specialists would help provide quality treatment for those with ASD in Alaska. Current state licensure and billing regulations that prohibit out-of-state health providers from practicing in the state need to be reviewed and revised so they may provide services for individuals with ASD in Alaska.

Parent Training

1. **Greatly expand services offered through an autism resource center, so that it is well funded, independent, and highly visible with a long-range plan for satellite programs throughout the state.**

Several activities are envisioned to expand the functions of an autism resource center. These include:

- An annual comprehensive fair/institute for families to provide up-to-date medical information, guidance in navigating the system, and other topics. Disseminate the institute through a CD or a webcast for people who cannot attend in person;
- The establishment of local resource centers across Alaska that are independent in nature, but collaborative with other providers, and state/local/national experts;
- Training for parents in systems advocacy/political advocacy;
- Regional, technical assistance traveling teams with professional oversight; and
- Comprehensive parent training in education, systems advocacy, guardianship, medical services, and other topics as needed.

There is a critical shortage of staff to work directly with individuals with developmental disabilities.

Service Provider Development

1. **Fund and deliver training to develop qualified staff who will provide evidence-based autism treatment services in home, child care and community-based settings.**

   There is a critical shortage of staff to work directly with individuals with developmental disabilities. The failure to provide evidence-based services to children and adults with Autism Spectrum Disorders impedes their development and limits their potential over their entire lifetime. Training is inadequate for those who provide care to individuals with Autism Spectrum Disorders.

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APPENDIX A

PROPOSED DEFINITION OF AUTISM
FOR THE DEPARTMENT OF EDUCATION AND EARLY DEVELOPMENT

1. **Autism Spectrum Disorders (ASD)**

To be eligible for special education and related services as a child with ASD, a child must:

a. 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

b. require special facilities, equipment, or methods to make the child's educational program effective; and

c. be diagnosed as having an autism spectrum disorder by a psychiatrist, physician, or psychologist; and

d. be certified by a group consisting of qualified professionals and a parent of the child as qualifying for and needing special education services.

Characteristics of ASD include:

- 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

A child who manifests the above characteristics after age 3 may also be diagnosed as having autism spectrum disorder.

A child who is diagnosed as having Asperger's Syndrome or Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) and who manifests the above characteristics may be found eligible for special education under the category of ASD.

Early Intensive Intervention Services for Alaska Children with Autism:
A Policy Analysis

The Governor's Council on Disabilities & Special Education

SB 250 Autism Insurance Coverage
Used in (S)HSS hearing 3/15/2010

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Introducti

Autism is the fastest growing developmental disorder and affects more children than those with diabetes, AIDS and cancer combined.

From the covers of Time and Newsweek magazines, to the Centers for Disease Control and Prevention's Morbidity and Mortality Weekly Report, autism is in the news (Centers for Disease Control and Prevention, 2007c; Kantrowitz & Scelfo, 2006; Nash, 2002). It is the fastest growing developmental disorder and affects more children than those with diabetes, AIDS and cancer combined (Kennedy Krieger Institute, 2007). No longer considered a rare disorder, autism impacts a wider and wider segment of our society. This pervasive developmental disorder affects communication, behavior, social skills and play, and is diagnosed in the early childhood years.

In Alaska, the growing prevalence of autism has resulted in a groundswell of advocacy for improved services for children. When a child is diagnosed, families learn there are evidence-based intervention options but quickly discover the services are not generally available and/or financially accessible, especially in Alaska. Even more disheartening is that intervention is most effective when delivered as soon as the diagnosis is made, accentuating the urgency for services.

In response to frequent public testimony about this need, the Governor's Council on Disabilities and Special Education formed an Ad Hoc Committee on Autism in 2005 to develop recommendations for the Alaska Legislature and the administration. A report of this Committee suggests four high priority recommendations — universal screening for autism, enhanced diagnostic capacity, expanded resource and referral services, and time-limited intervention services (Governor's Council on Disabilities & Special Education, 2006). The Council successfully advocated for increased funding for identifying and diagnosing children with autism as well as for additional resource and referral services. Activities are underway to develop universal screening. The final recommendation — a mechanism to provide time-limited, intensive early intervention services — is the topic of this policy analysis.

Purpose

This policy paper provides the state of Alaska with an analysis of options for the provision of time-limited, early intensive intervention services for children with autism.

The following five options for developing time-limited interventions for young children were reviewed:

1) exploring the options for offering autism services under the Deficit Reduction Act;

2) applying to the Centers for Medicare and Medicaid Services for an Autism Waiver;

3) attaching intensive autism intervention services to an overhaul of the entire Medicaid system in Alaska through an 1115a waiver;

4) offering intensive early intervention as part of the existing Medicaid program, e.g., by designating treatment through the EPSDT program; and

5) mandating that insurance companies coverage for autism services.

Background

Autism is a pervasive, life-long, brain-based disorder that is present from birth or the early stages of development. It affects thinking, social interaction, communication, imagination, and relationships with others (Centers for Disease Control and Prevention, 2007d; Lord & McGee, 2001; National Institute of Mental Health, 2005). Differences in sensory processing and unusual behaviors and interests are also symptomatic of autism (Centers for Disease Control and Prevention, 2007d). Language development ranges from limited or no use of speech, to unusual speech patterns such as echolalia. About 30 percent of individuals with autism are nonverbal (Akshoomoff & Stahmer, 2006).

Intellectual functioning varies among people with autism from mental retardation to above average intelligence. Some individuals become very knowledgeable about a subject of interest to them. Play is often restricted to a narrow range of interests, such as a preoccupation or atypical attachments with objects such as trains or cars. Rather than playing with other children, a child with autism may choose to play repetitively with objects in unusual ways.

These characteristics are manifested as a spectrum in individuals with autism, ranging in severity, symptoms and age of onset. Autism is classifed as a group of pervasive developmental disorders, or Autism Spectrum Disorders (ASD). This group of disorders includes Pervasive Developmental Disabilities — Not Otherwise Specified (PDD-NOS), Autistic Disorder, and Asperger Syndrome. While each of these disorders share some characteristics, they manifest in individuals at different ages, and vary in the nature and severity of these symptoms. For example, children with Autistic Disorder are typically diagnosed in early childhood, while Asperger Syndrome is diagnosed during the school years. Some children with Autistic Disorder are essentially nonverbal, while children with Asperger Syndrome develop speech but differ in their use of language.

Prevalence

As is happening across the country, increasing numbers of children in Alaska are diagnosed with an ASD. Recently released national prevalence data reveal that one in 150 children have an ASD (Centers for Disease Control and Prevention, 2007a).

While Alaska does not track autism prevalence, in 1994, 37 children enrolled in special education were classified as having autism; in 2006 that number had grown to 477, an increase of approximately, 1200% (Alaska Department of Education & Early Development, 1994, 2006). It should be noted that autism was not used as a classification within special education until 1993 and for students to receive services under the category of autism a diagnosis of Autistic Disorder is required. Asperger Syndrome and Pervasive Developmental Disorder — Not Otherwise Specified do not qualify as autism according to the Department of Education & Early Development, although these children may be receiving special education under a different category. Previous to 1993, all children with ASD were classified in categories such as Other Health Impaired, Severely Emotionally Disturbed, Mentally Retarded, or Developmentally Delayed.

The Anchorage School District estimates that one in 80 of their students has an ASD, and that one of nine special education students in the district has an ASD (Comeau, 2007).

Literature Review

Many individuals with ASD require lifelong supports at a cost estimated at $3.2 million per person (Ganz, 2006). Governments and society often bear the cost of this care in paying for early intervention, special education, and then adult services such as habilitation, supported living and supported work. There is also an expense to society related to lost productivity of the individual with autism as well as his or her family, and behaviors that sometimes lead to involvement with the criminal justice system (Ganz, 2006).

Two studies documented similar cost-savings associated with early intensive behavioral intervention. Researchers in Texas found the state could expect a total savings of $84,300 per child in state-budgeted funds, and $208,500 per child in the actual costs (including local, state and federal), achieved over total school years when children with autism received early intensive intervention

(Chasson, Harris, & Neely, 2007). In Pennsylvania, the average savings to the educational system per child ranged from $274,700 to $282,690 with inflation (Jacobson, Mulick, & Green, 1998). This study projected cost savings to age 55 with inflation ranging from approximately $2,439,700 to $2,816,500 per person.

Although there is a body of evidence supporting the effectiveness of early intervention, no single treatment approach has gained acceptance as the best-practice model for all children with ASD (Canadian Paediatric Society, 2004; Dawson & Osterling, 1997; Feinberg & Vacca, 2000; Lord & McGee, 2001; Steuernagel, 2005). However, the essential elements of successful intervention models have been defined (Dawson & Osterling, 1997; Lord & McGee, 2001).

- Intervention begins early and is intensive in hours.
- Families are active participants in their child's intervention.
- Staff are well-trained and knowledgeable about autism.
- There is objective evaluation of the child's progress.
- The curricula is highly structured resulting in a predictable daily routine and is focused on developing communication skills as well as other developmental skill areas.
- Teaching procedures emphasize generalization and maintenance of skills.
- Transitions to school are carefully planned and well supported.

Autism has significant impacts on the family (Hastings et al., 2005; Lord & McGee, 2001). Beyond typical parenting roles, children with autism may demand hypervigilance from their caregivers to ensure their safety. Other behavioral issues, such as smearing feces, limited tolerances for food and impaired communication are challenges most parents do not have to face. These behaviors make it very difficult for family members to engage in ordinary, day-to-day activities such as grocery shopping, visiting friends, working, sleeping, eating out and even taking a shower. The additional burden on families raising a child with autism is important in policy discussions. Families need to be able to choose an intervention program that fits with their values, lifestyle and available time.

Options for Financing Early Intensive Intervention

Currently there are four ways families typically receive services:

1) through the Early Intervention/Infant Learning Program up to age three;
2) through the school district from ages 3-21;
3) through Senior and Disabilities Services for home and community based Medicaid waiver or grant funded services; and
4) through private therapists and/or paraprofessionals.

Recommended intervention models for autism involve intensive instruction requiring active engagement with the child for a minimum of 25 hours a week, 12 months per year (Lord & McGee, 2001). These interventions are generally not available at that level of intensity in Alaska. The following options suggest ways to finance additional services to supplement what is already provided to children with autism.

Deficit Reduction Act (DRA). Section 6086 of the DRA contains provisions for expanding home and community-based services typically offered under a waiver to individuals with disabilities. States may adopt these services through a State Plan Amendment. There are several new options for states under the DRA.

First, states may offer home-and-community-based services, without applying for a waiver, to eligible individuals who meet Medicaid financial guidelines (currently at 150 percent of the federal poverty level). Currently only individuals receiving services under a Medicaid waiver are eligible for these services.

Second, a less stringent disability standard is required for home-and-community-based services under the DRA, broadening the group of individuals who may access these services. Recipients do not need to demonstrate that an institutional level of care would otherwise be needed. Rather, states must adopt criteria that are more restrictive for waivers than for services through the DRA.

Third, services now available through Medicaid waivers are allowed under the DRA, but states may set limits. These services include case management, homemaker, personal care, adult day health, habilitation, respite care and day treatment (Mollica, 2006).

In addition to the changes to services, there are numerous other provisions of Section 6086 of the DRA that need to be considered. States can set caps on enrollment and establish waiting lists. They may also change the criteria by which level of need is established. This means that individuals may begin receiving services, but when criteria are modified, would no longer qualify. If this were to occur, individuals continue to receive services for at least 12 months from the date services began, not from the date the criteria changed.

The primary advantage to the DRA option is the ability to extend services to individuals with less severe disabilities. The state is offered more flexibility and may change eligibility and eliminate or reduce services without seeking approval from the Centers for Medicare and Medicaid Services. The state may also impose waiting lists and caps on services. Financial eligibility is more restrictive, meaning those with income above 150 percent of the federal poverty level would not qualify.

Medicaid 1915(c) Waiver. Another option is to apply for a Medicaid waiver specific to children with autism. This would allow children to receive time-limited services (typically for three years). An autism waiver requires that individuals meet an institutional level of care and therefore would be targeted to those with more severe forms of autism. As with other waivers, the state will set a cap on the number of individuals to be served, maintain a waiting list, and must prove that the cost of service is less than what would be incurred in an institutional setting.

With waivers, states must seek approval for changes in the number of individuals to be served, eligibility and changes in services. While this is more cumbersome administratively, it also offers recipients a greater level of assurance that if changes are to occur, there will be a review from the federal government. More individuals would meet financial eligibility standards as they are higher than for the DRA.

The state would need to make decisions regarding eligible diagnoses, qualifying ages, qualifications of interventionists, number of waiver slots, caps on services, as well as determine which intervention models will be reimbursable.

Medicaid 1115a waiver. The Pacific Health Policy Group recommended the state consider applying for an 1115a waiver as part of overall Medicaid reform. More study is needed before a decision will be made about applying for this waiver, but autism services could be included in preliminary, exploratory activities.

The primary disadvantage to the state with an 1115a waiver is the assumption of financial risk. The state would need to negotiate an overall cap on all Medicaid spending, and should the state exceed that cap, it would not receive matching funds for any expenses

Options for Financing continued . . .

over the negotiated amount. However, in adopting a managed care model, the state would essentially become a managed care provider and thus pay itself a premium for every enrolled person. These funds can be used flexibly for other health-related activities, and might present an opportunity to provide autism services for a broader group.

Medicaid and Early Periodic Screening, Diagnosis and Treatment. Medicaid's Early Periodic Screening, Diagnosis and Treatment (EPSDT) program entitles children under 21 to well child checks, hearing, vision, and dental screening as well as services to ameliorate any conditions discovered during screening and/or diagnosis. Providers may treat the condition, refer families to another provider, or recommend they seek treatment from a qualified provider.

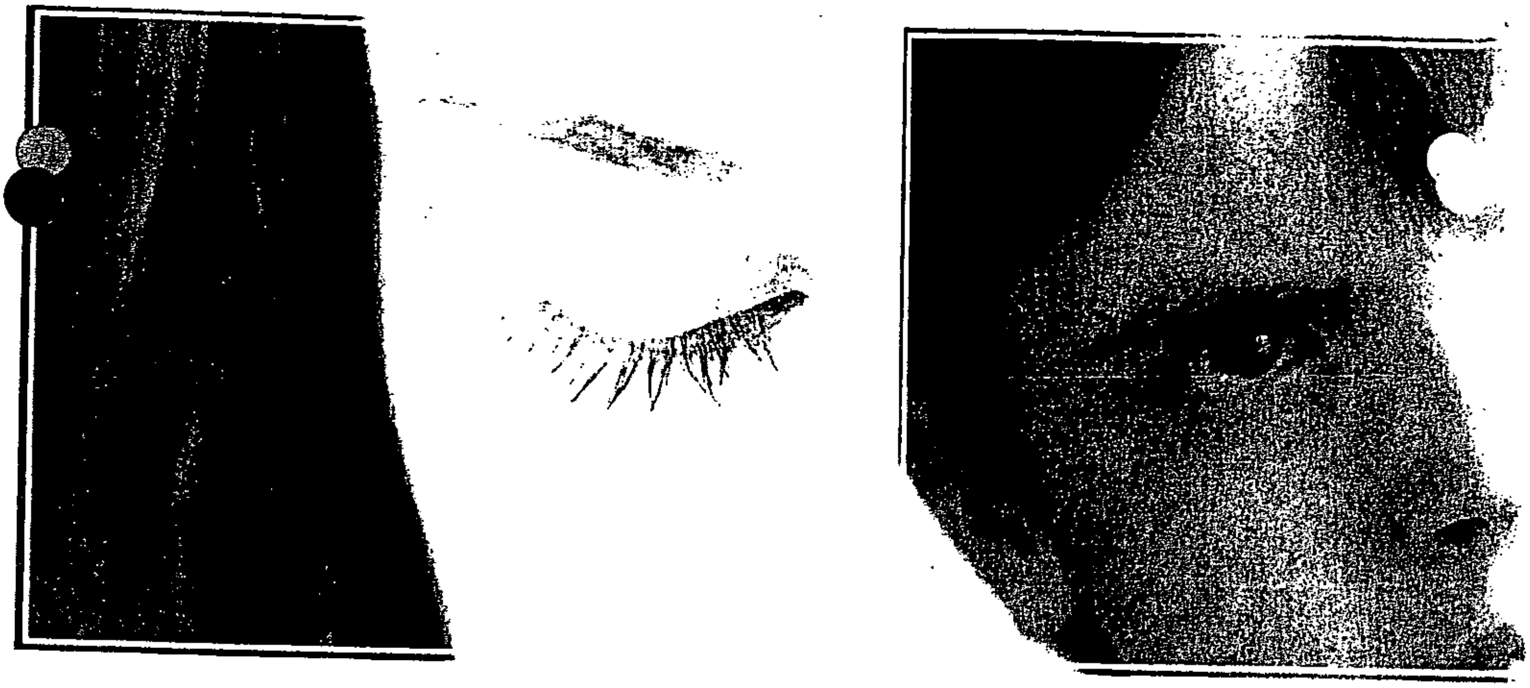
EPSDT is intentionally broad and states that Medicaid

> "requires that any medically necessary health care service listed at Section 1905(a) of the Act be provided to an EPSDT recipient even if the service is not available under the State's Medicaid plan to the rest of the Medicaid population.
>
> "It also enables them to assess the child's health needs through initial and periodic examinations and evaluations, and also to assure that the health problems found are diagnosed and treated early, before they become more complex and their treatment more costly" (Centers for Medicare and Medicaid Services).

At first glance, this appears to be a mechanism by which children with autism could receive intensive intervention services. However, there is controversy over whether autism intensive intervention services are permitted. EPSDT does not cover some services, such as respite care, and targeted case management. It also does not cover habilitation services — those services that help an individual acquire and or improve skills. EPSDT does, however, cover rehabilitation under mental health codes. Autism may be perceived to fall into an abyss between the two, with no coverage under either category. In fact, lawsuits seem to be the avenue by which a determination is made on a state-by-state basis.

Insurance Mandates. Sixteen states have enacted some form of autism insurance legislation. This ranges from designating autism as a mental health disorder or a neurological disorder, so that autism is reimbursed according to the same caps and co-pays applied to these conditions generally, to mandating coverage for autism intervention.

There is an emerging trend toward state legislative action around insurance for individuals with autism. More study is needed to determine whether services would be reimbursed at a higher rate if designated a neurological condition versus a mental health condition, which generally reimburses at 50 percent of the usual and customary charge.



Conclusion

is in the best interests of the state as well as families to work quickly to establish a mechanism for providing care

While Infant Learning and School District providers in Alaska use a variety of treatment approaches, there is evidence that many providers are not offering services at the recommended level. This is expected given the level of financial support provided to districts and the Infant Learning Program, as well as the lack of Medicaid services for autism that potentially could supplement educational programming.

However, it is obvious that the responsibility for payment of services cannot be borne by a single service system. Blended or coordinated funding from Medicaid, Infant Learning, and special education is needed to provide intensive services. Due to the high cost of providing intensive intervention services, if one service system were to assume the entire expense, funding would be directed away from children with other disabilities who also need early intervention, educational, and Medicaid services.

New funding for enhanced resource and referral as well as diagnostic and screening for autism which was obtained through the advocacy of the Governor's Council will generate an even greater demand for services. It is in the best interests of the state as well as families to work quickly to establish a mechanism for providing care that is coordinated across the medical, early intervention and educational systems. The return on this investment will become apparent in future years, but will require an up-front infusion of funds.

Alaska has an opportunity to learn from other states with autism services, and to use the experiences of these states to develop a model that builds on lessons learned. In particular, it can be expected that workforce development will be a barrier, especially in rural Alaska. Setting provider standards to ensure quality

and availability of personnel will be especially challenging in Alaska.

Some options open up more risk than others. With Medicaid costs rising at an unsustainable rate, heightened scrutiny of any Medicaid service can be expected. Carefully choosing an option that does not place other Medicaid services at risk is an important policy consideration. A combination of options is also a strong possibility.

Finally, it is crucial to build a strong evaluation component. Accountability for public funds is essential, and there must be evidence of cost-effectiveness of the services. Evaluation should also be used to make mid-course corrections and to strengthen the services that children and families receive. Intervention strategies inherently employ data collection and it is reasonable to assume that this data be used to evaluate the efficacy of programs.

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SB 250 Autism Insurance Coverage
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Actuarial Cost Estimate: Alaska House Bill 187

An Act Requiring Insurance Coverage for Autism Spectrum Disorders

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Executive Summary

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 insurance benefits for autism spectrum disorders (ASD) mandated by Alaska House Bill 187 (HB 187). The most significant treatment mandated by HB 187 is applied behavior analysis, or ABA which accounts for a large portion of the additional costs under HB 187. The key provisions of HB 187 are explained further in Section 4 of this report.

Our analysis involved developing a robust model that reflects the likely behavior of consumers, providers and insurers of ABA services and includes Alaska demographic and insurance market information. Key assumptions including the treated prevalence of ASD, the age of diagnosis, ABA program utilization by age, ABA annual costs by age, and additional other (i.e. not ABA) medical costs, as well as the modeling methodology are explained in detail in Sections 5 and 6 of this report and summarized through graphs in the Appendix.

Our analysis included scenario testing to develop cost estimates under a range of assumptions. Our "Middle" estimate is that, in the long-term, costs would increase by about 0.33% of premiums and premiums would increase about 0.39% should HB 187 be enacted. Our estimated range of long-term premium increases is 0.26% to 0.56% based on our "Low" and "High" estimates. We expect that premium increases would be lower in the years immediately following the passage of a law consistent with the provisions of HB 187, with first year cost increases in the range of 0.09% to 0.37% percent of premiums. Our expectation of lower first year costs is based on experiences in other states that have seen low initial costs when ASD benefits are mandated. These lower costs can be expected due to the lags typically seen in accessing new benefits and the limited supply of ABA providers.

The estimated cost increases for our "Middle" scenario along with some statistics for the individual, small, and large group markets are shown in the table below; we would expect that costs for any government plans would be similar to those estimated for large groups.

Long-Term Cost Estimates - "Middle" Cost Scenario

	Market			
	Individual	Small Group	Large Group	All
Covered Persons	26,000	47,000	59,000	132,000
Average Premium per Person	$2,700	$4,700	$4,300	$4,127
Annual Mandate Claim Cost per Covered Person	$13.70	$13.70	$13.70	$13.70
Claim Cost as a Percentage of Premium	0.51%	0.29%	0.32%	0.33%
Estimated Premium Increase with Admin @ 15%	$16.10	$16.10	$16.10	$16.10
Premium Increase as a Percentage of Premium	0.60%	0.34%	0.37%	0.39%

For our scenario testing we varied the assumptions that drive cost estimates. The assumptions under the "Low", "Middle", and "High" scenarios and premium increase estimates are summarized in the table below.

Scenario	% Diagnosed Under Age 6 Starting ABA	Avg. Annual ABA Program Cost	Avg. Annual non-ABA Cost	Annual Premium Increase per Covered Person	Premium Increase (% of Premium)
Low	40.0%	$25,000	$2,100	$10.70	0.26%
Middle	50.0%	$30,000	$3,150	$16.10	0.39%
High	66.7%	$33,823	$4,200	$23.10	0.56%

Section 7 also includes cost estimates with without an annual benefit maximum.

While this analysis focused primarily on estimating the insured costs of mandated medical benefits, in Section 8 we summarize information related to the lifetime costs of ASD which include the costs associated with medical services, education, custodial care, and the lost productivity and wages of individuals affected by ASD, as well as their family caregivers. We also outline the potential savings to government financed education and medical programs associated with effective ASD treatments based on several studies.

2

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 of the benefits mandated by Alaska HB 187, which provides coverage for the diagnosis and treatment of autism spectrum disorders.

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 thirteen 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 187 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.

3

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 187 and the associated premium impact on the individual, small group, and large group markets affected by HB 187. This analysis also identifies and partially quantifies identified offsetting cost savings associated with successful ASD treatment.

We note that cost estimates for autism mandates have varied widely state to state based on differences in the state-specific mandates and the methods and assumptions used in estimating costs, though typically independent estimates show premium increases due to mandated autism benefits of less than 1%. A March 2009 report of The Council for Affordable Health Insurance (CAHI) states: "CAHI's actuarial working team estimates that an autism mandate increases the cost of health insurance by about 1 percent."[1] The reason for this variability is that the largest component of the increase in costs under HB 187 mandated ASD benefits is for behavioral therapy, including 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.

The reader is further 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 uncertain. Insurance policies often cover some services for children diagnosed with an ASD, although the mandate could cause the insured costs for certain services to increase because ASD exclusions or limitations are common, and certain services that may have been denied or terminated following utilization review might be covered due to the mandate.

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[1] The Council for Affordable Health Insurance. "The Growing Trend Towards Autism Coverage." March 2009.

4

Description of Key HB 187 Provisions and their Impact on Covered Benefits

Insurance Markets Covered by the Mandate

HB 187 states: *"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."*

In reviewing the relevant section of the Alaska Statutes (AS 21.54.500) that defines *health care insurer*, it appears that HB 187 applies to all health insurance plans that Alaska has regulatory jurisdiction over. We are assuming that this means all insured plans other than those excluded specifically in the bill would be covered.

Covered Benefits

HB 187 provides for the diagnosis and treatment of autism spectrum disorders by stating that *"(a) 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,*

... (2) "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..."

The inclusion of applied behavioral analysis (ABA), in the definition of habilitative or rehabilitative care is especially important. The coverage of behavioral therapies, including ABA, has the most significant impact on cost of any mandated service. For the purpose of this report, reference to ABA encompasses ABA and all similar behavioral therapies. We note ABA is the most widely accepted behavioral therapy and that we would expect other approved behavioral programs to have similar costs.

ABA programs are marked by intensive therapy that may include 30-40 hours of therapy a week under the most intensive programs, although many programs would not utilize that level of resources. Key assumptions underlying our ABA cost estimates are outlined in Section 6.

Coverage Limits and Maximum Benefits
HB 187 states: *"Coverage under this section ... must provide a maximum benefit of $36,000 a year, adjusted annually, beginning January 1, 2011, 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..."*

In our modelling, we assumed that HB 187 would cap ABA annual benefits at $36,000 in 2010. We also provide an alternative range of illustrative estimates without an annual benefit maximum.

Maximum Age for Benefits
HB 187 states: *"Coverage under this section ... (1) is required to be provided only to individuals under 21 years of age"* so we developed our estimates assuming that covered benefits under HB 187 are to be provided to individuals under the age of 21, only.

Medical Necessity and Treatment Review
HB 187 states: *"(1) 'medically necessary' means any care, treatment, intervention, service, or item prescribed by a licensed physician or psychologist in accordance with accepted standards of practice ..."*

We assume that ASD benefits under HB 187 will be subject to utilization review procedures currently in place by insurers. This is important as insurers will develop protocols to review treatments and manage care to which will limit unnecessary treatments outside of accepted standards of practice if utilization reviews are done appropriately.

5

Modeling Methodology

The following outlines the general modeling methodology used to develop our cost estimates. Estimates were developed both on a per covered person per year basis, and as a percentage of average annual premiums, as shown in Section 7. Details of key assumptions are discussed in Section 6 and illustrated graphically in the exhibits shown in Appendix 1.

Modeling Perspective

Our model was developed to produce costs under a range of assumptions, but generally assumes that a sufficient supply of 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 CDC diagnosed prevalence estimates.

We would expect that it would take a minimum of 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 treatment of their children's disorders. Developing an adequate supply of providers may prove to be very difficult based on the geography and limited population of Alaska, however, we did not make any adjustment in our modeling for these factors which could mean there is some conservatism in our ABA utilization assumptions.

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 over a longer term 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.

Acknowledging that short-term costs are also important to policymakers, in the sections outlining our cost estimates, we have included illustrative exhibits showing the possible progression of costs for mandated benefits by assuming that initial costs would be roughly one-half of the long-term estimates. We also assumed that it would take five years for costs to reach their ultimate levels, although these assumptions varied by cost scenario.

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 policyholders 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.[2] 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[3]), 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. A treated prevalence estimate for Alaska was developed based on the Center for Disease Control and Prevention's (CDC) Mortality and Morbidity Weekly Report (MMWR) on autism prevalence dated December 18, 2009.
2. Prevalence rates by diagnostic subtype (autistic disorder, PDD-NOS, Asperger's Syndrome) were estimated separately, since 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 ages of diagnosis implicit in the modeling are consistent with publicly available age at diagnosis statistics.[4]
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 ABA by age 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.
7. Non-ABA costs were estimated based upon studies of medical costs for children diagnosed with ASD 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.

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

[3] NAIC Annual Statements for 2007.

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

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 Alaska, and Kaiser Family Foundation coverage data. These assumptions are further documented in Section 5.
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 under a range of assumptions to develop "Low," "Middle," and "High" cost scenario estimates.

6

Summary of Key Assumptions

Key assumptions underlying the cost estimates for the proposed mandated benefits are summarized in this section. In order to better illustrate the sensitivity of costs to various assumptions, we developed assumptions for "Low," "Middle," and "High" cost scenarios. Appendix 1 further illustrates these assumptions for the "Middle" scenario.

Treated Prevalence and Age at Diagnosis

The December 18, 2009 CDC MMWR[5] report included the following information related to the prevalence of ASD:

1. *Children aged 8 years with a notation of an ASD or descriptions consistent with an ASD were identified through screening and abstraction of existing health and education records containing professional assessments of the child's developmental progress at health-care or education facilities. Children aged 8 years whose parent(s) or legal guardian(s) resided in the respective areas in 2006 met the case definition for an ASD if their records documented behaviors consistent with the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision (DSM-IV-TR) criteria for autistic disorder, pervasive developmental disorder–not otherwise specified (PDD NOS), or Asperger disorder. Presence of an identified ASD was determined through a review of data abstracted from developmental evaluation records by trained clinician reviewers.*[6]

2. *In 2006, the overall identified ASD prevalence per 1,000 children aged 8 years varied across ADDM sites ...The average across all 11 sites was 9.0 (CI = 8.6–9.3) per 1,000 children.*[7] A prevalence rate of 9 per 1,000 is approximately 1 in 110.

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[5] Centers for Disease Control and Prevention. Morbidity and Mortality Weekly Report. December 18, 2009. http://www.cdc.gov/mmwr/. Accessed January 2010.

[6] Ibid, p. 1

[7] Ibid, p. 7

3. *In general, estimated ASD prevalence was lower in ADDM sites that relied solely on health sources to identify cases (mean: 7.5 per 1,000 population; CI = 7.0–7.9) compared with sites that also had access to education sources.*[8]

4. *Among all children meeting the ADDM ASD surveillance case definition, approximately 77% had a documented ASD classification in their records.*[9]

5. *All children initially identified for screening were first stratified by two factors highly associated with final case status: information source (education only, health only, or both types of sources) and the presence or absence of either an ASD ICD-9 code (299.0 or 299.8) or an autism special education eligibility. The potential number of cases missed because of missing records, and the impact on prevalence, was estimated on the assumption that within each of the strata, the proportion of children with missing records who ultimately would be confirmed as having ASD cases would have been similar to that of children for whom no records were missing.*[10]

In estimating treated prevalence, which drives medical services utilization and costs, we used the population prevalence as a starting point, and then made adjustments based on details in the MMWR study which would indicate that treated prevalence could be expected to be lower than population prevalence. Treated prevalence rates would be expected to be lower than population prevalence rates for several reasons:

1. As noted in 4. above, approximately 77% of children had documented ASD classification in their records. Without a documented ASD diagnosis, it is not likely that someone would receive treatments for ASD covered by insurance. Note 77% of the 9.0/1000 population prevalence means a documented diagnosis prevalence rate of approximately 1 in 144.

2. There is a reasonable expectation that covered medical ASD services would be supported by documentation in health records. Based on a review of health records, only, the population prevalence of ASD is approximately 7.5/1000, or 1 in 133.

3. The CDC methodology assumed that where records and information were missing, the proportion of children with missing records who ultimately would be confirmed as having ASD cases would have been similar to that of children for whom no records were missing. There is a reasonable likelihood that records would be less likely to be missing for children with documented ASD diagnoses who would seek treatment.

4. With ASD, as with any other disease or disorder, there will be some subset of the diagnosed population that will not seek treatment for any number of reasons.

Based on our analysis of the CDC report, including the key items from the report noted above, a reasonable assumption for the treated prevalence of ASD is 1 in 150. While there is

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[8] Ibid, p. 7

[9] Ibid, p. 9

[10] Ibid, p.7

obvious rationale for modeling cost sensitivities to changes in prevalence, we did not do so since the range of likely costs based on the sensitivity testing outlined in the remainder of this report provides a fairly wide range and illustration of potential costs, and determining the impact on costs of different treated prevalence rates is a simple task.

Prevalence by diagnostic subtype was estimated based on an academic study published in the American Journal of Psychiatry.[11] 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 treated prevalence and age at diagnosis assumptions for Alaska are shown below:

Alaska Treated Prevalence

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**	

The average age of diagnosis stated in the 2009 CDC MMWR report is 53 months[12] which is higher than the average age used in our cost modeling of about 42 months, we believe that this difference is reasonable and explainable in that we are using parent reported data that is likely provided by the same parents who would most likely utilize insured benefits. Note a lower age of diagnosis results in higher cost estimates, all other things being equal.

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, and many others diagnosed with ASD, especially those in more rural areas, may have difficulty accessing a provider. For this reason, we have assumed that 40% to 66.7% (40% for "Low" scenario, 50% for "Middle" and 66.7% for "High") of diagnosed children under age 6 will begin an ABA program. Based on discussions with ABA providers and researchers, actual utilization of ABA programs has been lower in many cases due to the lack of providers, the lack of coverage, and to some extent the limited understanding of ABA programs and their efficacy.

In Minnesota, a state that is widely regarded as having some of the most extensive ABA coverage and services in the nation, provider data indicates ABA utilization of approximately 20% of diagnosed three to six year olds[13], which is considerably lower than assumed in each

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

[12] Centers for Disease Control and Prevention. Morbidity and Mortality Weekly Report. December 18, 2009. p. 9.

[13] Discussion with Dr. Eric Larsson Executive Director, Clinical Services, The Lovaas Institute for Early Intervention Midwest Headquarters regarding ABA utilization research in Minnesota. February 2009.

of the scenarios in our modeling. While our range of assumptions for ABA utilization may appear conservative, and likely is conservative in the near-term, we feel that the range is reasonable since insurers will likely have some conservatism in their cost estimates and premium rates. Private insurance utilization will also likely be higher than under the public/private programs in Minnesota, and utilization could increase over time due to increased awareness of ASD, and potentially, an increased supply of ABA providers.

In addition to the likelihood of starting a program, program continuance assumptions have a very significant impact on overall ABA utilization and cost estimates. ABA programs are generally geared towards addressing deficits in younger children and are 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 annually thereafter a large percentage of remaining programs would terminate until only a very small percentage of children have ABA programs by the time they reach their teenage years. Programs would be expected to terminate if a child has experienced sufficient progress whereby 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 by age for our "Middle" scenario is shown in the table below:

% of Diagnosed Children w/ ABA	
Under 6	50.0%
6	37.5%
7	25.0%
8	16.7%
9	11.1%
10	7.4%
11	4.9%
12	3.3%
13 to 21	2.5%

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 offer ABA benefits.[14] We developed a distribution of expected hours that resulted in the annual averages shown in the table below:

Average ABA Program Hours	
Ages Under 8	1,500
Ages 8 to 12	671
Ages 13 to 21	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 over half by

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[14] Autism Therapy Reference- Microsoft Corporation (administered by Premera Blue Cross).

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. It would then again be reduced significantly 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 Alaska, based on Bureau of Labor Statistics[15] health care wage data. The resulting average cost per hour of ABA therapy in Alaska is about $53 for a program based on the assumption that staffing will be in line with what best practices might recommend. This is the cost underlying our "High" assumption, though we note that costs would vary based on the mix of professionals and technicians providing the services, and likely would be lower if less experienced ABA practitioners need to be employed to meet the increasing demands for services.

Range of Annual ABA Program Costs for Scenario Estimates

Given the actual cost of an ABA program could vary significantly for many reasons, we have assumed annual average program costs by scenario as follows:

"Low" cost scenario - assumes average ABA program cost is $25,000 per year.
"Middle" cost scenario - assumes average ABA program cost is $30,000 per year.
"High" cost scenario - based on the assumptions outlined in this section for the continuance of ABA programming, the number of annual hours for ABA programming, an annual cap of $36,000 and an hourly rate of $53.47, the calculated average annual cost for an ABA program for all ages is $33,823.

Other (than ABA) Medical Costs

Based on several studies[16], we estimated that children with ASDs had costs covered by insurers of approximately three times the average for non-inpatient medical services under current benefit programs. It is also clear that the mandate would mean that some services that an insurer could currently deny or exclude would now be covered. In our range of estimates, we assumed that the mandate would result in additional insured medical costs of 50% to 100% of the current level of estimated covered non-inpatient costs for services to children diagnosed with an ASD which we assumed are currently three times higher than the population costs in the absence of the benefit mandates under HB 187 for children under 21 diagnosed with an ASD.

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

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

The estimated annual cost for additional non-ABA services (note many non-ABA medical services are already provided to individuals with ASD) that would be covered as a result of the mandate are shown for each scenario in the table below:

Scenario	Annual non-ABA Cost
Low	$2,100
Middle	$3,150
High	$4,200

(Amounts in 2010 dollars)

Administrative Costs

Typically, medical claim 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.

Alaska 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 Alaska was available for 2006[17], so we trended this based on average recent employer premium increases provided from the Kaiser Family Foundation HRET[18] survey to estimate the 2010 average annual premium per member necessary to compute the cost of mandated benefits as a percentage of annual premiums.

To estimate average premiums for the individual market, we reviewed survey results developed by America's Health Insurance Plans[19] that showed average premiums and members per policy by state.

As part of our development of premiums and membership estimates, we completed reasonableness tests by reviewing Alaska insurer annual statement exhibits to ensure that the group premium estimate is not unreasonable.

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

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

[19] AHIP Individual Health Insurance 2006 - 2007: A Comprehensive Survey of Premiums, Availability, and Benefits. http://www.ahipresearch.org/pdfs/Individual_Market_Survey_December_2007.pdf. Accessed January 2009.

7

Cost Estimates

Long-Term Cost Estimates - "Middle" Cost Scenario

The table below summarizes our "Middle" scenario average annual cost estimates and premium increases on a per covered person basis, and as a percentage of the annual premiums. Our "Middle" estimate is that, in the long-term, the premium increase associated with the mandated benefits provided by HB 187 would be about 0.39% of insured premiums across all markets. However, we expect that costs would be lower in the years immediately following the passage of HB 187 based on experiences in other states that have mandated ASD benefits, lags typically seen in accessing new benefits, and the limited supply of ABA providers. We expect that government programs would have cost increases comparable to insured large groups.

The estimated cost increases for the large group market is shown in the table below. The annual claim cost per covered person estimate of $13.70 and premium increase of $16.10 are in 2010 dollars.

	Market			
	Individual	Small Group	Large Group	All
Covered Persons	26,000	47,000	59,000	132,000
Average Premium per Person	$2,700	$4,700	$4,300	$4,127
Annual Mandate Claim Cost per Covered Person	$13.70	$13.70	$13.70	$13.70
Claim Cost as a Percentage of Premium	0.51%	0.29%	0.32%	0.33%
Estimated Premium Increase with Admin @ 15%	$16.10	$16.10	$16.10	$16.10
Premium Increase as a Percentage of Premium	0.60%	0.34%	0.37%	0.39%

Scenario Estimates

As discussed in Section 3, very little insurance data exists that can be used to directly estimate the costs of ABA benefits mandated by HB 187. This causes uncertainty in developing actuarial assumptions and cost estimates. Due to this uncertainty, it is useful to develop cost estimates for scenarios using optimistic and pessimistic assumptions.

Cost estimates are very sensitive to various assumptions, especially those related to ABA utilization and costs. Therefore, we varied our assumptions to develop estimated costs for ASD services under "Low," "Middle," and "High" cost scenarios, as shown in the table below:

Scenario	% Diagnosed Under Age 6 Starting ABA	Avg. Annual ABA Program Cost	Avg. Annual non-ABA Cost	Annual Premium Increase per Covered Person	Premium Increase (% of Premium)
Low	40.0%	$25,000	$2,100	$10.70	0.26%
Middle	50.0%	$30,000	$3,150	$16.10	0.39%
High	66.7%	$33,823	$4,200	$23.10	0.56%

Short-Term Cost Estimates by Scenario

In addition to the uncertainty associated with long-term cost estimates, how quickly costs could reach their ultimate level due to the limited supply of ABA therapists is also uncertain. We have provided the table below to illustrate the potential short-term increases in premiums, and how they could grade into the long-term estimates over time.

Estimated Increase in Premiums due to HB 187						
Scenario	Year 1	Year 2	Year 3	Year 4	Year 5	Years 6 and Beyond
Low	0.09%	0.12%	0.16%	0.19%	0.22%	0.26%
Middle	0.20%	0.23%	0.27%	0.31%	0.35%	0.39%
High	0.37%	0.41%	0.45%	0.48%	0.52%	0.56%

Illustrative Cost Estimates without $36,000 Annual Benefit Maximum

Recently enacted federal mental health parity legislation and its associated federal rules may impact annual benefit caps for ASD services. For this reason, we also developed illustrative cost estimates assuming no annual benefit maximum, and that the remaining provisions in the Bill remain the same; cost estimates for the three scenarios are summarized in the table below:

Scenario	% Diagnosed Under Age 6 Starting ABA	Avg. Annual ABA Program Cost	Avg. Annual non-ABA Cost	Annual Premium Increase per Covered Person	Premium Increase (% of Premium)
Low	40.0%	$45,000	$2,100	$15.60	0.38%
Middle	50.0%	$55,000	$3,150	$23.80	0.58%
High	66.7%	$67,756	$4,200	$36.80	0.89%

Individual Market Comment

In developing the individual and small-group market cost estimates, we did not develop any assumptions regarding the impact of anti-selection which could lead to average cost and premium increases in excess of those shown in this report due to the guaranteed issue and adjusted community rating rules in Alaska. Determining the impact on the individual market premiums of adding a population of children with ASD, along with their family members to this market would require an assessment of the likely costs of those added to the individual pool relative to those currently in the pool. Completing an assessment of the potential for anti-selection to increase premium rates under HB 187 is complicated for several reasons, and beyond the scope of this review.

8

Cost – Benefit Analysis for ASD Treatments

There have been several studies related to the efficacy of ABA treatment programs, and the costs associated with ASD treatments, care, and supports. In this section, we summarize some of these studies.

Societal Costs of Autism- Ganz Report

One of the most often cited reports explaining the financial costs of ASD is *The Lifetime Distribution of the Incremental Societal Costs of Autism* by Michael Ganz, MS, PhD was published in 2007. This report summarized the modeled costs of a hypothetical cohort of children born in 2000 and diagnosed with autism in 2003. A study result is that the incremental societal cost of autism is $3.2 million per capita in 2003 dollars.[20] The report is very helpful in identifying specific costs of ASD, and in providing a framework for quantifying these costs, as well as providing actual cost estimates.

Direct Medical

- Physician and Dental
- Drugs
- Complementary and Alternative Therapies
- Behavioral Therapies
- Emergency and Hospital
- Home Healthcare
- Travel

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[20] Ganz, Michael L. *The Lifetime Distribution of the Incremental Societal Costs of Autism.* Archives of Pediatrics & Adolescent Medicine. April 2007. Volume 161.

Direct Nonmedical

- Child Care
- Adult Care
- Respite Care
- Home Improvements
- Special Education
- Supported Work
- Other

Indirect

- Own Indirect- lost productivity and lower wages
- Not Own Indirect - lost productivity and lower wages of others (typically family)

Cost Savings to State and Local Governments

The Ganz study is probably the most comprehensive in terms of assessing the breadth of the financial costs associated with caring for individuals with ASD. Several other studies have attempted more limited quantifications of costs and savings to governments associated with providing early intensive behavioral interventions (EIBI) or ABA programs for young children. In summary, the studies quantify the costs of EIBI, assume success rates associated with EIBI based on efficacy studies, and then assume cost savings to educational and other government financed programs like Medicaid associated with these treatments.

Virginia's independent Joint Legislative Audit and Review Commission (JLARC) issued a report in August 2009: *Report of the Joint Legislative Audit and Review Commission To the Governor and The General Assembly of Virginia - Assessment of Services For Virginians With Autism Spectrum Disorders*. As part of this report, JLARC reviewed several studies related to the efficacy of EIBI, and potential cost savings to State and Local governments associated with effective EIBI treatments. The JLARC report outlines their assessment of the cost savings associated with EIBI as follows[21]:

> *"A study published in a national journal found that Pennsylvania could save an average of $187,000 to $203,000 on each child who received three years of EIBI relative to one who received special education services until age 22. The Pennsylvania study also suggested that cost savings would likely continue to accrue after children exit the school system. The study found that the state could save from $656,000 to $1.1 million per child if expenditures up to age 55 are included. Another study published in a national journal found that Texas could save an average of $208,500 in education costs for each student who received three years of EIBI relative to a student who received 18 years of special education from ages four to 22. Applied to the estimated 10,000 children with ASDs in Texas, it was estimated that the state could save almost $2.1 billion by implementing intensive treatment programs.*
>
> *By applying the methodology used in the Pennsylvania and Texas studies to Virginia-related data, JLARC staff estimate that the Commonwealth could save approximately $137,400 in special education costs per student with an ASD if EIBI was consistently provided. In fact, the analysis*

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[21] *Report of the Joint Legislative Audit and Review Commission To the Governor and The General Assembly of Virginia - Assessment of Services For Virginians With Autism Spectrum Disorders*, p. 15. http://jlarc.virginia.gov/reports/Rpt388.pdf. Accessed December 2009.

indicates that Virginia could realize savings as long as at least 42 percent of students with ASDs who received EIBI make moderate improvements (require less intensive services and fewer supports), which is a substantially more conservative outcome than the outcomes reported in the research literature."

The actual success rates of EIBI treatments will drive the benefits derived from these treatments. Also, as noted in the JLARC report, moderate improvements in functioning could also lead to significant financial savings. The JLARC report also discusses various studies of the efficacy of EIBI and Table 3 on page 15 of the report summarizes the findings on the efficacy of EIBI of three research studies. This table is reproduced below:

Table 3: Multiple Studies Demonstrate Children Who Receive Intensive Treatment Fare Better Than Those Who Receive Less Intensive Services

	Outcomes	
Group	**Average Change in IQ Points**	**Educational Placement**
EIBI compared to less intensive public school special education (2006 study)		
Treatment	+25	• 29% in general class without supports • 52% in general class with supports
Comparison	+14	• 5% in general class
EIBI compared to less intensive parent-training model (2000 study)		
Treatment	+16	• 27% in general class without supports
Comparison	-1	• No children in general class without supports
EIBI compared to less intensive treatment (1987 study)		
Treatment	• 47% achieved IQ in normal range (94-120)	• 47% in general class without supports • 42% in less intensive special education class for language delayed • 11% in intensive special education class for children with autism or intellectual disability (ID)
Comparison	• 2% achieved IQ in normal range	• 2% in general class without supports • 45% in less intensive special education class for language delayed • 53% in intensive special education class for children with autism or ID

Note: A more detailed table on the results of these studies can be found in Appendix C.

We currently do not have Alaska specific data that would allow us to provide estimates of the potential educational and medical savings that could be achieved through EIBI. Under the assumption that the costs of ASD services and efficacy of EIBI are in line with those indicated in the studies noted, we would expect that the costs of ABA treatments covered under HB 187 could be recovered through reductions in educational and medical expenditures, alone. We would also expect that benefits associated with successful treatments would be realized in the areas noted in the beginning of this section through reducing other costs of care and improving the productivity of individuals with ASD and their caregivers, in addition to non-economic or quality of life benefits.

Appendices

Cost Assumptions – Illustrative Exhibits, and HB 187 Text

EXHIBIT I - SUMMARY OF HB 187 "MIDDLE" SCENARIO ASSUMPTIONS AND COSTS

State Alaska

Age Limits for Autism Benefits

Minimum	0
Maximum	20

Additional Annual Medical Costs for Non ABA Services

All Ages $ 3,150

Annual Limits by Covered Service

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

Key Assumptions:

United States Treated Prevalence

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**	

Alaska Treated Prevalence

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**	

% of Diagnosed Children w/ ABA

Under 6	50.0%
6	37.5%
7	25.0%
8	16.7%
9	11.1%
10	7.4%
11	4.9%
12	3.3%
13 to 21	2.5%

Average ABA Program Hours

Ages Under 8	1,500
Ages 8 to 12	671
Ages 13 to 21	401

Average cost of ABA Program: $30,000

	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	26,000	$ 2,700	$ 70,200,000	$ 356,200	0.51%	$ 13.70	$ 419,000	0.60%	$ 16.10
Small Group	47,000	4,700	220,900,000	643,900	0.29%	13.70	758,000	0.34%	16.10
Large Group	59,000	$ 4,300	$ 253,700,000	$ 808,300	0.32%	$ 13.70	$ 951,000	0 37%	$ 16.10
Total	132,000	$ 4,128	$ 544,836,000	$ 1,808,400	0.33%	$ 13.70	$ 2,128,000	0.39%	$ 16.10

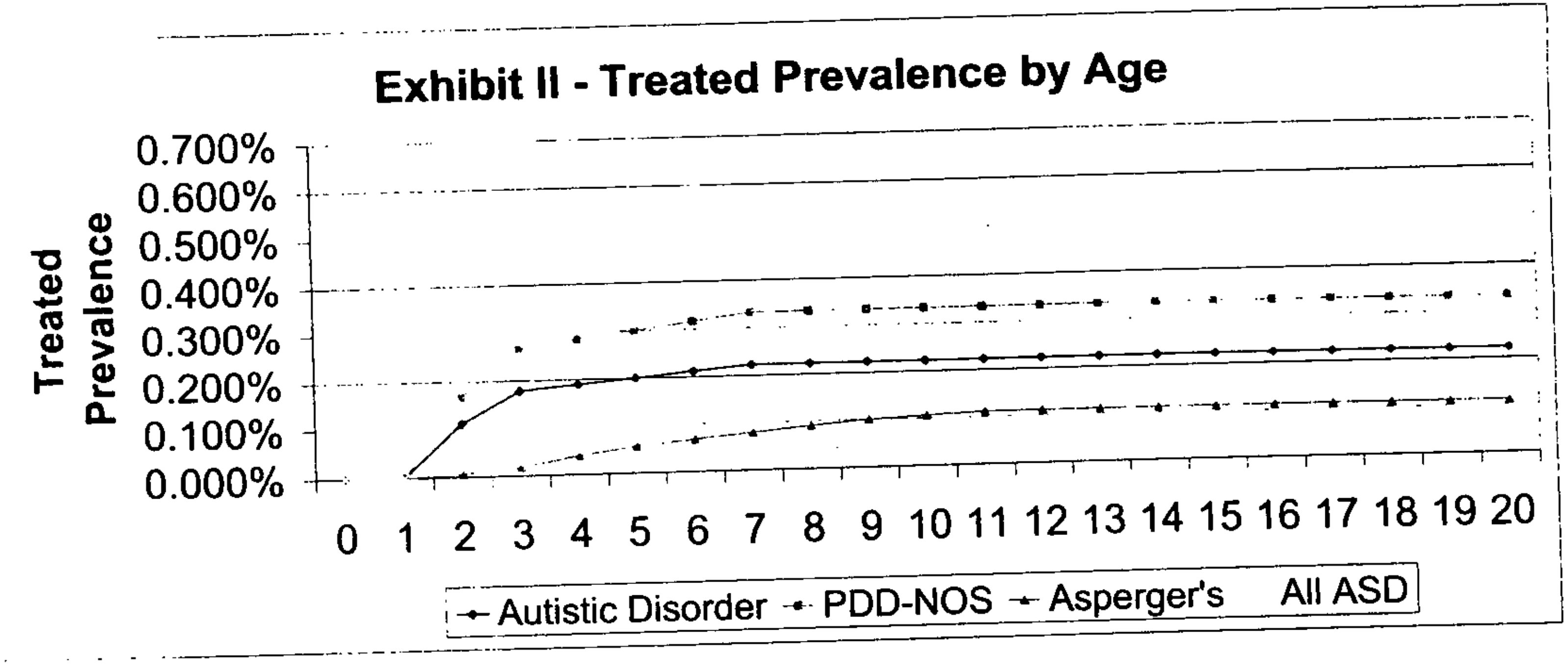
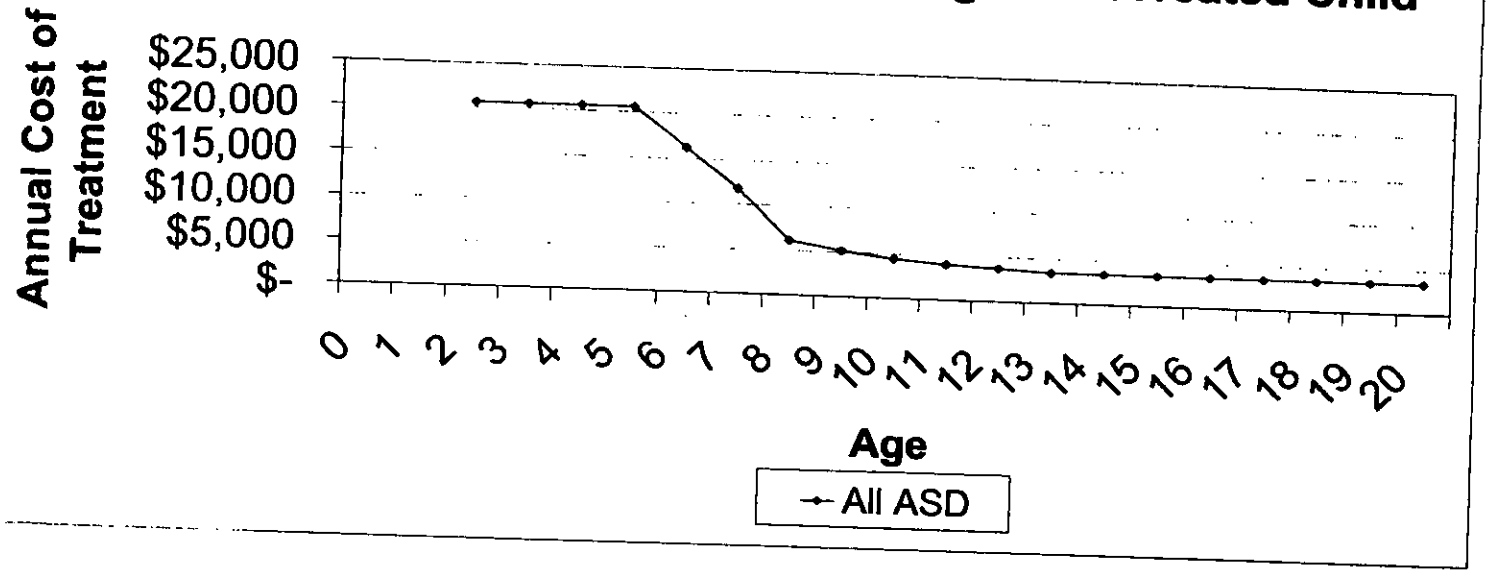


Exhibit II - Treated Prevalence by Age

Exhibit III - Annual Cost Per Diagnosed/Treated Child



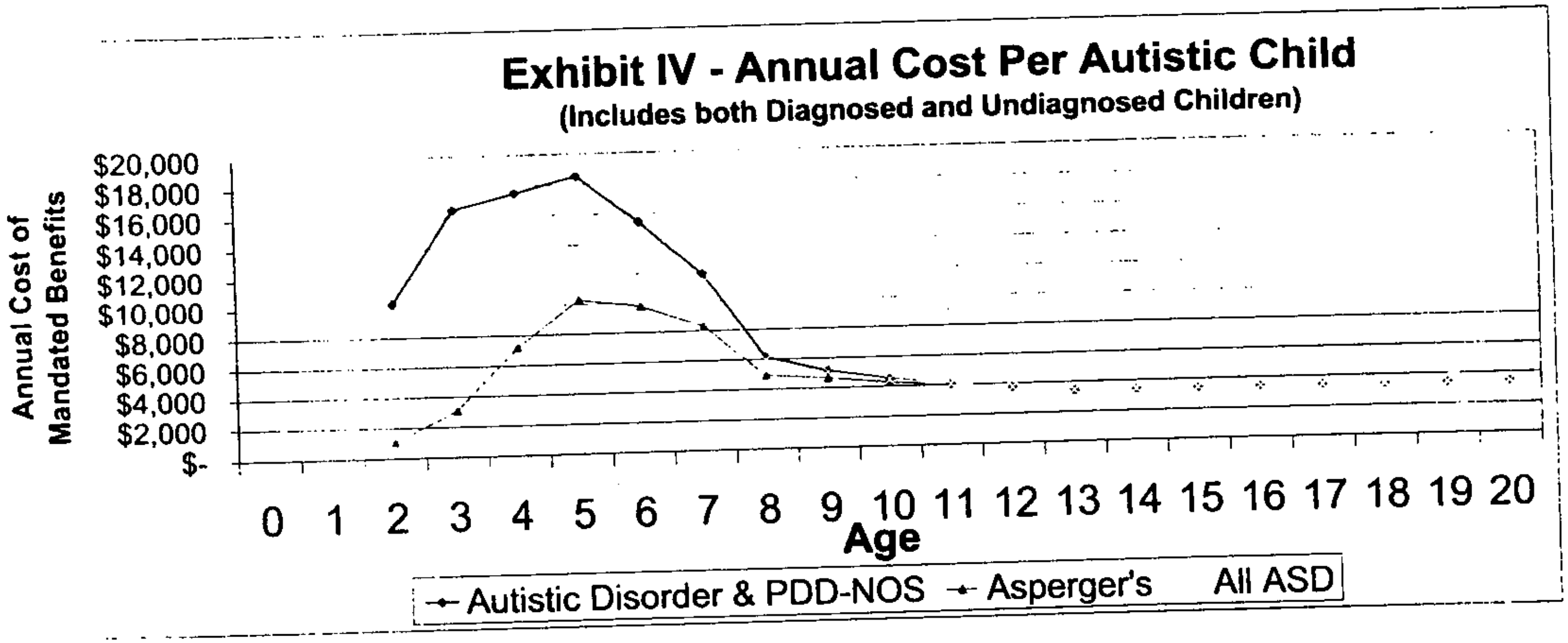


Exhibit IV - Annual Cost Per Autistic Child

(Includes both Diagnosed and Undiagnosed Children)

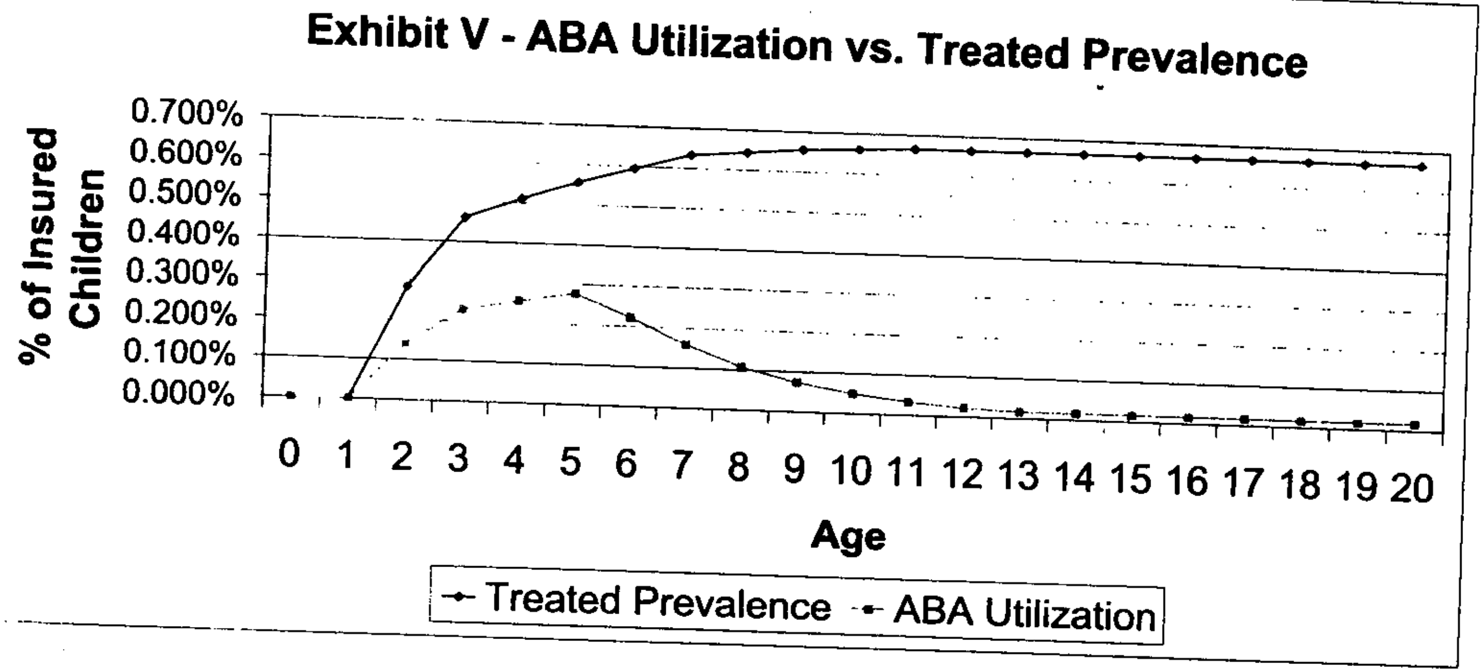
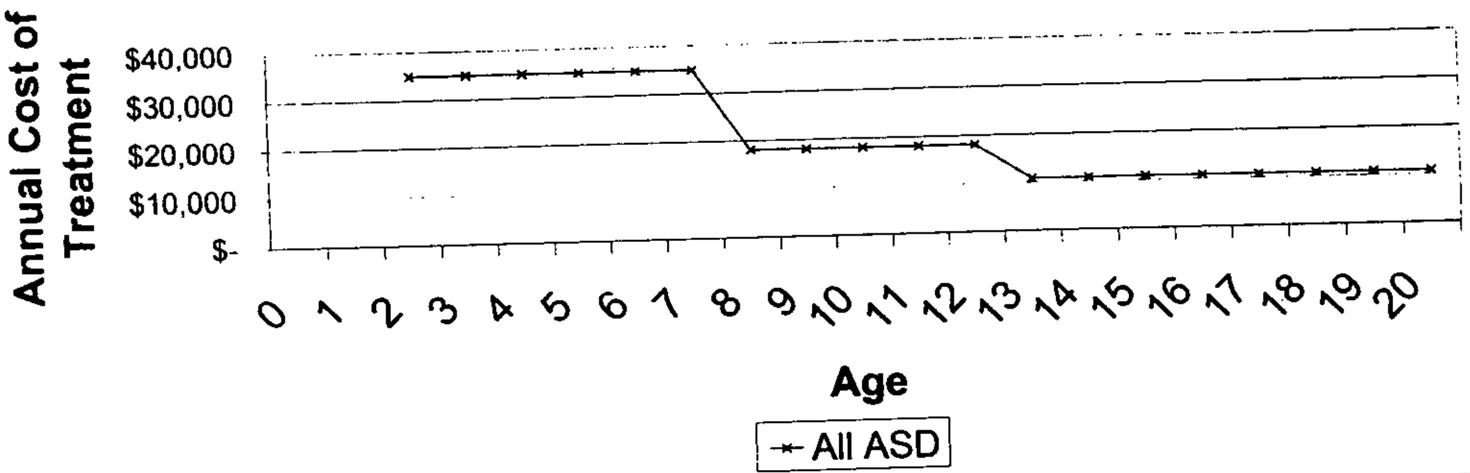


Exhibit V - ABA Utilization vs. Treated Prevalence

Exhibit VI - Annual Cost per Child With ABA Program



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SB 250 Autism Insurance Coverage
Used in (S)HSS hearing 3/15/2010

Autism Speaks

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

cure autism now & AUTISM SPEAKS
Working Together

October 24, 2007

Contents

Arguments in favor of a legislative mandate for coverage of autism:

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.

AK?

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.

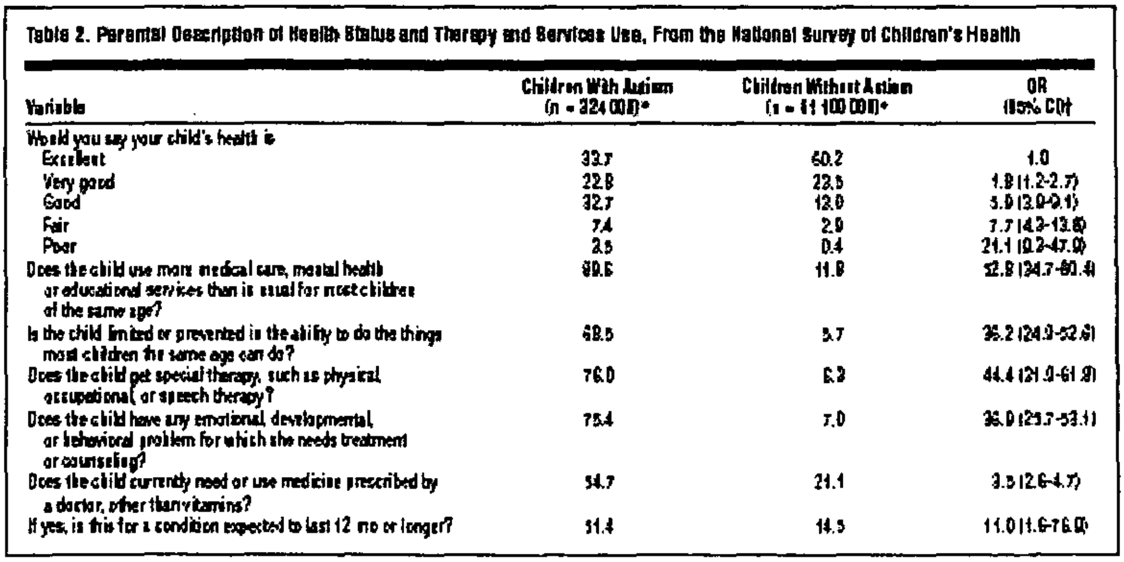

Table 2. Parental Description of Health Status and Therapy and Services Use, From the National Survey of Children's Health

Variable	Children With Autism (n = 324 000)*	Children Without Autism (n = 61 100 000)*	OR (95% CI)†
Would you say your child's health is			
Excellent	33.7	60.2	1.0
Very good	22.8	23.5	1.8 (1.2-2.7)
Good	32.7	12.0	5.9 (3.9-9.1)
Fair	7.4	2.9	7.7 (4.3-13.8)
Poor	2.5	0.4	21.1 (9.2-47.9)
Does the child use more medical care, mental health or educational services than is usual for most children of the same age?	89.6	11.8	52.8 (34.7-80.4)
Is the child limited or prevented in the ability to do the things most children the same age can do?	68.5	5.7	36.2 (24.9-52.6)
Does the child get special therapy, such as physical, occupational, or speech therapy?	76.0	6.3	44.4 (31.9-61.8)
Does the child have any emotional, developmental, or behavioral problem for which she needs treatment or counseling?	75.4	7.0	38.0 (25.7-56.1)
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 483 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.

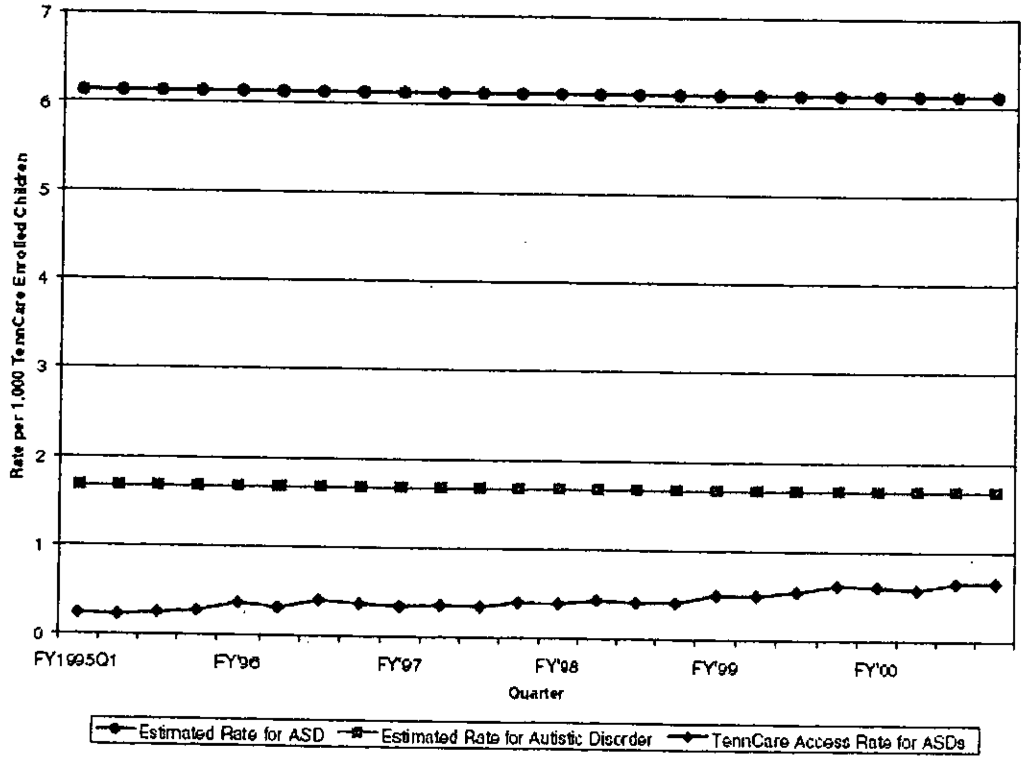

Fig. 1. Estimated incidence rates vs. service rates of autism spectrum disorders (ASDs) in TennCare for children ages 0–17 years, by quarter.

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.

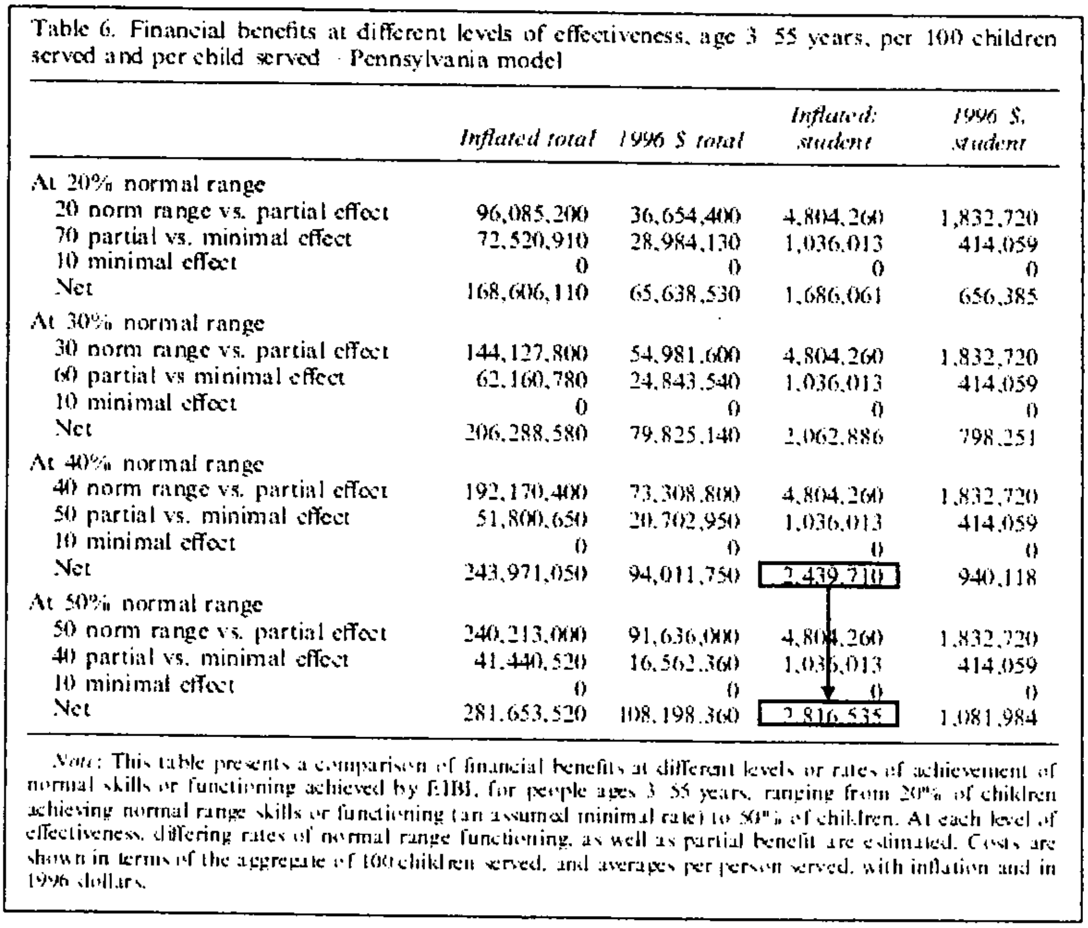

Table 6. Financial benefits at different levels of effectiveness, age 3–55 years, per 100 children served and per child served – Pennsylvania model

	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.

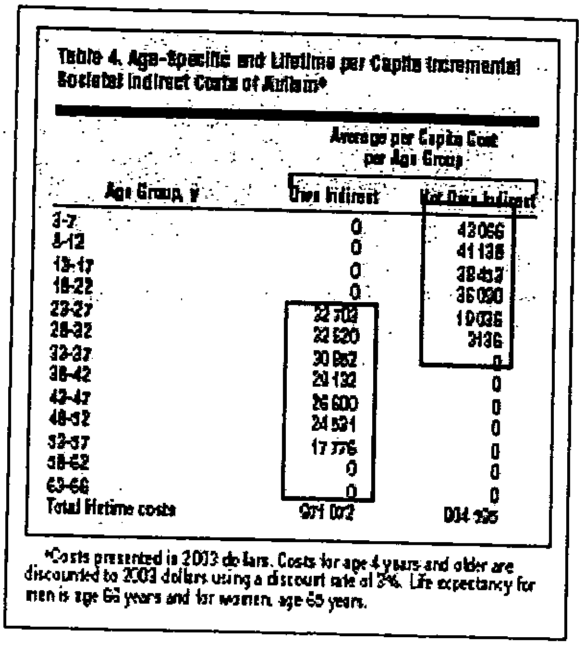

Table 4. Age-Specific and Lifetime per Capita Incremental Societal Indirect Costs of Autism*

Age Group, y	Average per Capita Cost per Age Group	
	Own Indirect	Not Own Indirect
3-7	0	43066
8-12	0	41138
13-17	0	38457
18-22	0	36090
23-27	22 702	19035
28-32	22 520	3136
33-37	30 962	0
38-42	29 132	0
43-47	26 600	0
48-52	24 531	0
53-57	17 376	0
58-62	0	0
63-66	0	0
Total lifetime costs	971 072	004 935

*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 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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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.

Plauch, Chris, and Aae Johnson, MD, MEd. Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics. Vol. 120, No. 5. American Academy of Pediatrics, November 2007.

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).

Lovaas Institute for Early Intervention. See http://www3.scoe.net/npsa/index/index.cfm?fuseaction=basicDetails&id=420&searchType=adv.

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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.

Myers, Scott M. Management of Children with Autism Spectrum Disorders. American Academy of Pediatrics, October 29, 2007.

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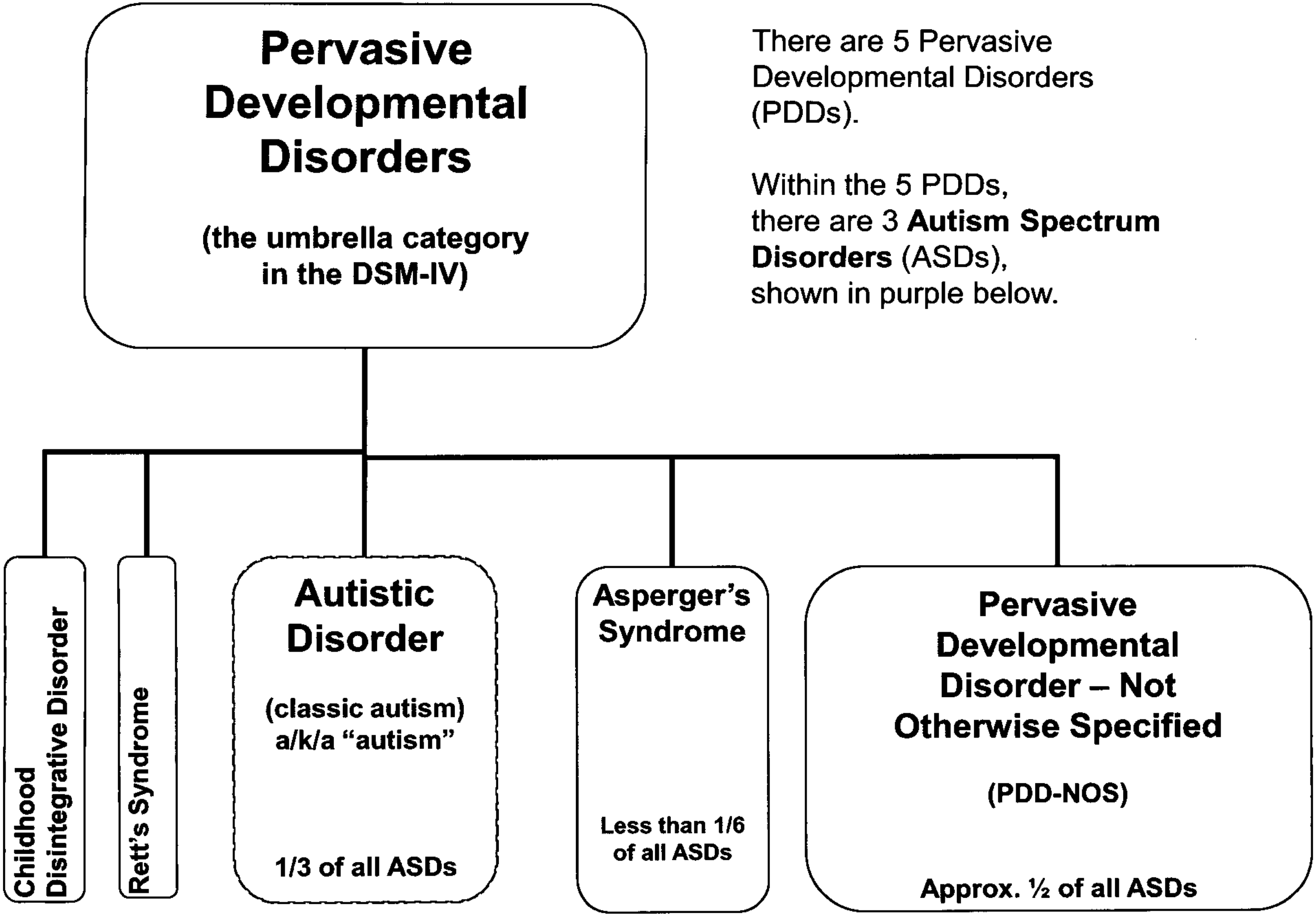
John W. Jacobson, James A. Mulick, Gina Green, Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case. 13 Behavioral Interventions, 201-26 (1998).

Autism Insurance in Missouri

Lorri Unumb, Esq.
Autism Speaks



Pervasive Developmental Disorders

(the umbrella category in the DSM-IV)

There are 5 Pervasive Developmental Disorders (PDDs).

Within the 5 PDDs, there are 3 **Autism Spectrum Disorders** (ASDs), shown in purple below.

Childhood Disintegrative Disorder

Rett's Syndrome

Autistic Disorder

(classic autism) a/k/a "autism"

1/3 of all ASDs

Asperger's Syndrome

Less than 1/6 of all ASDs

Pervasive Developmental Disorder – Not Otherwise Specified

(PDD-NOS)

Approx. ½ of all ASDs

Applied Behavior Analysis: A Sample Program

- Consultant
  - Highly educated and trained
  - Board certified
  - Evaluates, designs, trains
  - 3-6 hours per month
- Mid-level supervisor (lead therapist)
  - Highly educated and trained
  - May be board certified
  - Updates programming; trains; oversees
  - 6 hours per week
- Line therapists
  - May be college students, trained by above
  - Provide 40 hours per week of direct therapy, usually in 3-hour shifts

Applied Behavior Analysis: Cost of a Sample Program

- Consultant
  - 3-6 hours per month
  - $100-$150/hour
  - 6 hours x $150 = $900/month
  - $900 x 12 months = **$10,800**

- Mid-level supervisor (lead therapist)
  - 6 hours per week
  - $30-$60/hour
  - 6 hours x $60 = $360/week
  - $360/week x 52 weeks = **$18,720**

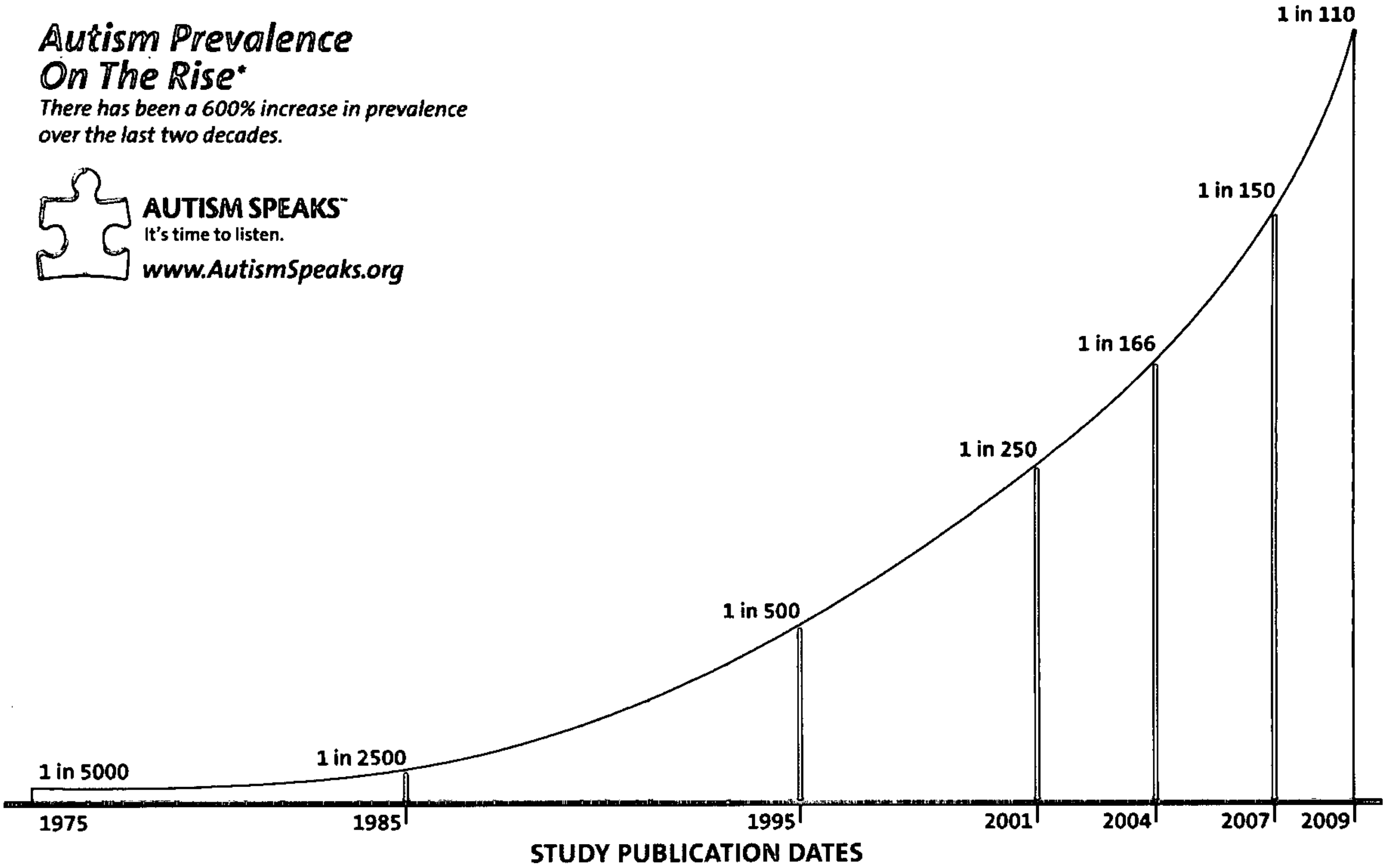
- Line therapists
  - 40 hours per week
  - $10 - $30/hour
  - 40 hours x $20 = $800/week
  - $800/week x 52 weeks = **$41,600**

- $10,800 + $18,720 + $41,600 = **$71,120**

*Autism Prevalence On The Rise**

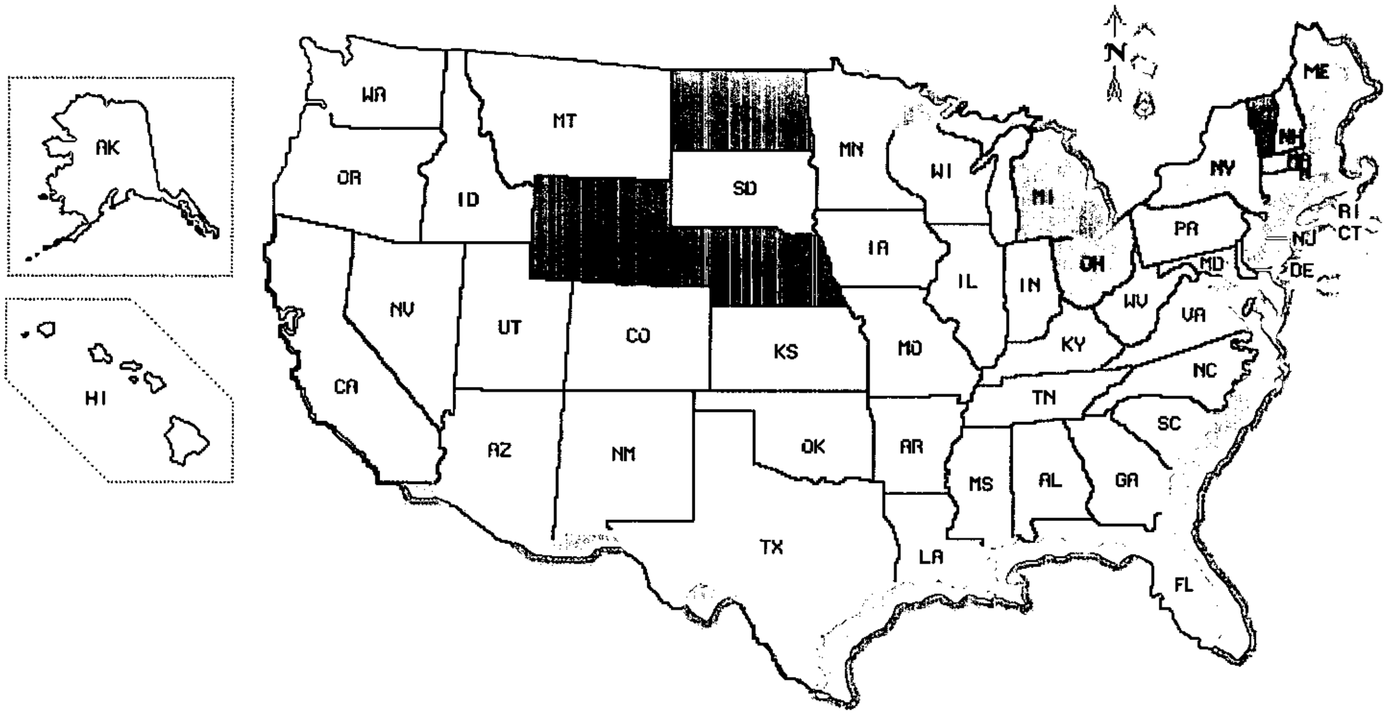
There has been a 600% increase in prevalence over the last two decades.

AUTISM SPEAKS™
It's time to listen.
www.AutismSpeaks.org



*Recent research has indicated that changes in diagnostic practices may account for at least 25% of the increase in prevalence over time, however much of the increase is still unaccounted for and may be influenced by environmental factors.

States with Autism Insurance Reform



8-19-09

2001 – Indiana
2001 – Minnesota*

2007 – South Carolina
2007 – Texas

2008 – Arizona
2008 – Florida
2008 – Louisiana
2008 – Pennsylvania
2008 – Illinois

2009 -- Montana
2009 – New Mexico
2009 – Colorado
2009 -- Nevada
2009 -- Connecticut
2009 – Wisconsin
2009 – New Jersey

Green = passed; Red = intro'd in 2009; Yellow – developing bill; Blue – not currently pursuing

Excerpt from 2008 Report of Council of Affordable Health Insurance: "Health Insurance Mandates in the States"

BENEFITS:	Est. Cost	#
Alcoholism	1-3%	45
Autism	<1%	11
Contraceptives	1-3%	31
In Vitro Fert.	3-5%	13
Prescriptions	5-10%	2

Available at www.CAHI.org.

The Council for Affordable Health Insurance is a research and advocacy association of insurance carriers active in the small group, individual, HSA, and senior markets. CAHI is an active advocate for market-oriented solutions to the problems in America's health

South Carolina
State Employee Health Plan

- Autism insurance statute passed in 2007
- Applicable to state health plan as of 1-1-09
- Population: 4.5 M
- State health plan has 350,000 members
- Projected annual fiscal impact to state:
  Estimates ranged $9 million - $18.9 million
- Actual cost in 2009:
  $856,371
  PMPM: 20 cents

"[N]o disability claims more parental time and energy than autism."

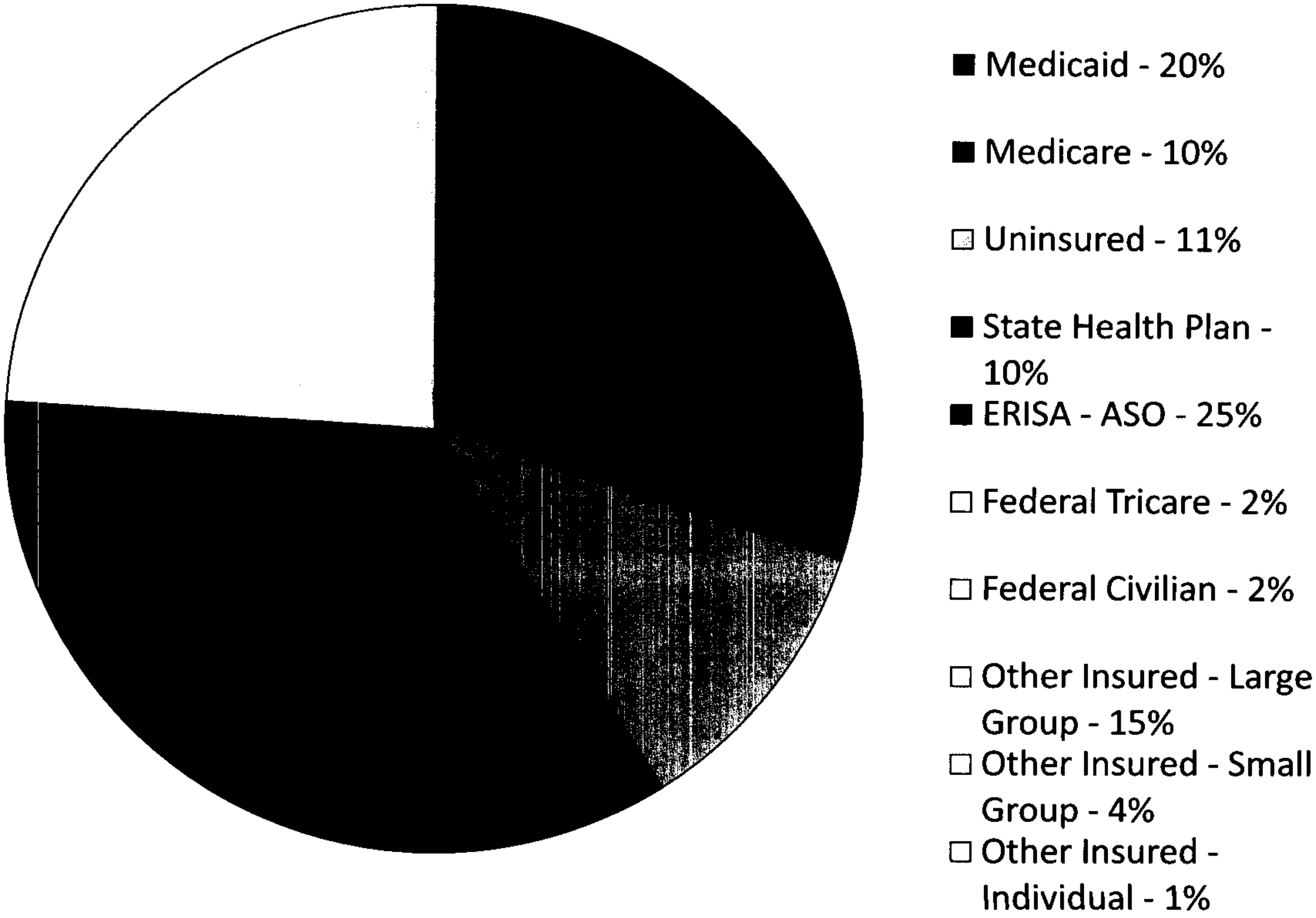
New York Times,
12/20/04

Comparison of State Autism Benefits

	S.C.	Minnesota BCBS	Ariz.	Montana	Indiana	Penn.
Annual Cap	$50K (cap only on ABA)	Unlimited	$50K thru 8; $25K 9-16	$50K thru 9; $20K 9-18	Unlimited	$36K
Benefits until age	16	No age cap	17	18	No age cap	21

Treatment must be prescribed by licensed physician or psychologist.

Sources of Health Care Coverage



Self-Funded ERISA Plans

- Microsoft
- Home Depot
- Intel
- Arnold & Porter
- Halliburton
- Eli Lilly
- Deloitte
- Ohio State University
- Lexington Medical Center
- University of Minnesota
- Progressive Group
- Michelin
- Greenville Hospital System
- Symantec

Provider Credentials

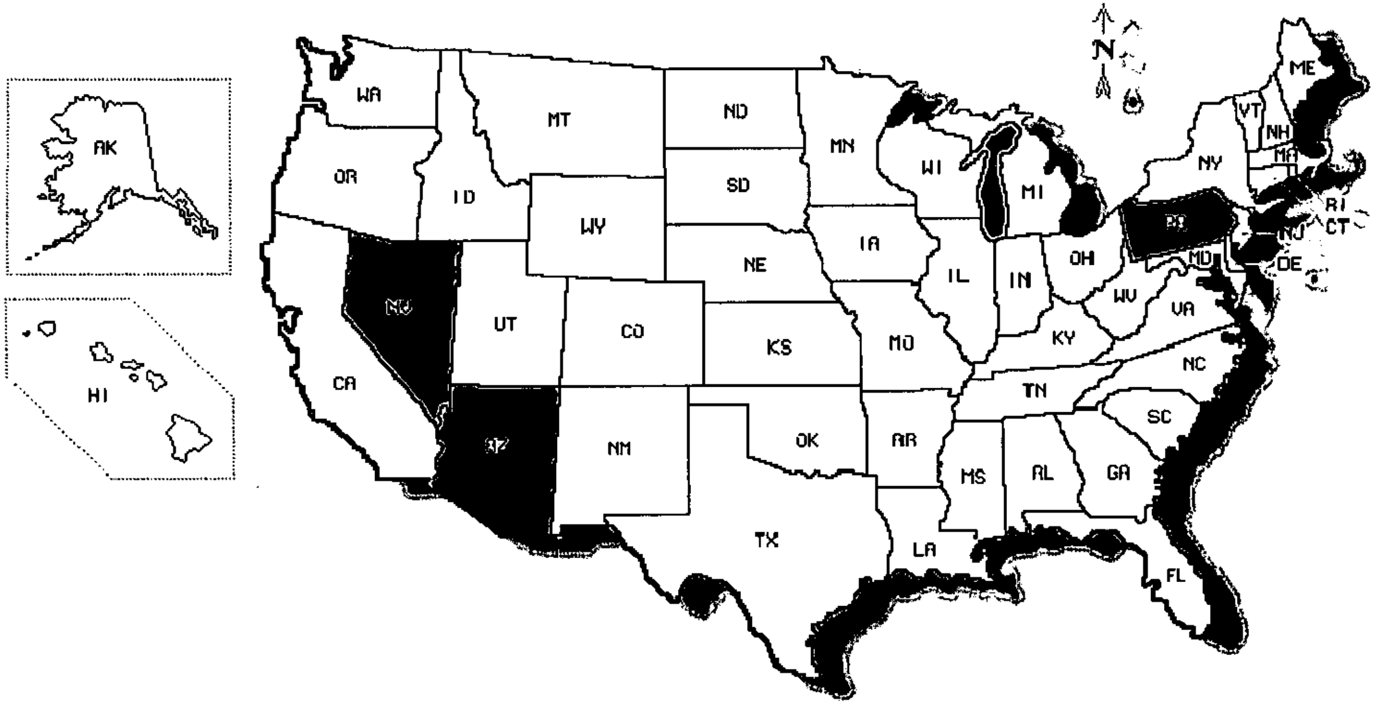
www.BACB.com

The Behavior Analyst Certification Board, Inc.® (BACB®) is a nonprofit corporation established as a result of credentialing needs identified by behavior analysts, state governments, and consumers of behavior analysis services.

The BACB's mission is to develop, promote, and implement a voluntary international certification program for behavior analyst practitioners. The BACB credentials Board Certified Behavior Analyst® BCBA®} and Board Certified Assistant Behavior Analyst® (BCaBA®).

Insurance States that License Behavior Analysts

Licensure states



1-19-10

Neurology

January 2007 Issue

Table 3 Summary of evidence: Incidence and prevalence of 12 neurologic disorders

			Median estimates					
			Annual incidence		Prevalence			
Disorder	Class of evidence	Range of ages included (y)	Rate/ 100,000	No.*	Rate/ 1,000	No.*	Rate ratio, M/F†	Age(s), y, of peak incidence
Autism spectrum disorders	I, II	2–15	—	—	5.8	500,000‡	4.2	—
Cerebral palsy	I, II	3–13	—	—	2.4	207,000‡	1.3	—
Tourette syndrome	II	7–17	—	—	3.5§	301,000	4.8	—
Migraine	I, II	12–65	—	—	121	35,461,000	0.4	—
Epilepsy	I, II	All	48	142,000	7.1	2,098,000	1	<1, ≥80
Multiple sclerosis	I	All	4.2	12,000	0.9	266,000	0.5	30
Traumatic brain injury	I	All	101	298,000	—	—	2.1	20, ≥80
Spinal cord injury	I,II	All	4.5	13,000	—	—	4.2	20
ALS	I, II	All	1.6	5,000	0.04	12,000	1.3	≥60
Stroke	I, II	All	183	541,000	10	2,956,000	1.1	≥80
		≥65	1,093	401,000	—	—	—	
Alzheimer disease	I,II	≥65	1,275	468,000	67	2,459,000	0.5	≥80
Parkinson disease	I,II	≥65	160	59,000	9.5	349,000	1.8	≥70

* Estimated number of cases in United States in 2005, rounded to nearest 1,000.

† Ratio of rates among males to rates among females.

‡ Estimated number of cases among children younger than 21 years of age only.

§ Data inadequate for firm estimate.