SB

74

<TARGET><BILL>SB 74</BILL><SUBJECT>SB 74</SUBJECT><COMM>SHSS27</COMM></TARGET>

SENATE COMMITTEE REPORT
First Committee of Referral

DATE: 1/28/11

Date of 5-Day Notice: 3/24/11
(in accordance with Uniform Rule 23)

FURTHER: Labor and Commerce

DATE TURNED IN TO OFFICE: 3/30/11

Health and Social Services Committee considered SENATE BILL NO. 74

SB 74-INS. COVERAGE: AUTISM SPECTRUM DISORDER

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

and recommends:

[ ] be **replaced** with **CS** ________ (______) *[ ] Same Title [ ] New Title*

[ ] adopt **previous CS** ________ (______) *[ ] Same Title [ ] New Title*

[ ] attached amendment(s)

[ ] adopt ________ Letter of Intent

[ ] further referral to ________ Committee

Dept Abbr.	
ADM	LEG
CED	LAW
COR	LWF
CRT	MVA
EED	DNR
DEC	DPS
DFG	REV
GOV	DOT
DHS	UA

NEW FISCAL NOTE(S)				
Dept.	Fiscal	Indet.	Zero	FN #
DEC			✓	

PREVIOUS FISCAL NOTE(S)				
Dept.	Fiscal	Indet.	Zero	FN #

[ ] **APPROPRIATION - no fiscal note**

SIGNATURES AND RECOMMENDATIONS:	PRINTED LAST NAME	DO PASS	DO NOT PASS	NO REC	AMEND
[signature]	Meyer	X			
[signature]	Ellis	X			
[signature]	Egan	X			
[signature]	Dyson				X
CHAIR: [signature]	DAVIS	X			

Sponsored by:

AUTISM SOCIETY

Improving the Lives of All Affected by Autism

Alaska

Juneau · Soldotna · Anchorage · Fairbanks

Juneau, Alaska
Saturday, April 2, 2011
Dimond Field House Track
11a-1p

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ALASKA STATE LEGISLATURE

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•
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•
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•
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•
Committee on Committees

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Fax: (907) 465-2529
•
While in Anchorage
716 W. 4th Ave, Rm. 500
Anchorage, AK 99501
(907) 269-0169
Fax: (907) 269-0172

SENATOR JOHNNY ELLIS
RULES COMMITTEE CHAIR

SPONSOR STATEMENT – SENATE BILL 74

SB 74 – An act requiring insurance coverage for autism spectrum disorders

Autism is a devastating disorder affecting at least 1 in 110 American children. Despite being treatable, many children diagnosed with an Autism Spectrum Disorder (ASD) never receive the treatment they need. In fact, most insurance plans explicitly exclude treatment of ASDs, even when the service is otherwise covered by the health plan.

SB 74 would require insurance coverage for autism spectrum disorders, including the behavior therapies that after 30 years of study have shown to be the only effective treatment of these disorders. One of the nation's foremost actuarial firms has studied the cost of providing insurance coverage for autism spectrum disorders, and concluded that the cost to policy holders in Alaska would be minimal (estimated at between 0.28% and 0.68%, or $2.58 per month). This legislation allows Alaska to start this process on our own terms, without a federal mandate, and gives the state the needed time to build capacity to meet the demands created by SB 74.

Treatment has been shown to improve, often significantly, the symptoms of ASD. In some cases, effective treatment eliminates the need for special education services for a child with ASD. The cost savings in special education alone amounts to approximately $208,500 per capita while the child is in school. This number rises to over $1.08 million over the autistic person's lifespan. Furthermore, the incremental societal cost of not treating autism has been estimated to be approximately $3.2 million per capita.

Coverage of ASDs by insurers would not only provide a needed service to those families suffering directly from the affects of a child with autism, but saves the state and taxpayers exponentially over the lifespan of those diagnosed with autism. Though there is no cure for ASDs, this legislation would help significantly to treat individuals and families suffering from these disorders. Prompt passage of this legislation would allow the state to reap the health and economic benefits that would result from covering ASDs.

I respectfully ask for your careful consideration and support of SB 74.

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
STATE OF ALASKA

(907) 465-3867 or 465-2450
FAX (907) 465-2029
Mail Stop 3101

State Capitol
Juneau, Alaska 99801-1182
Deliveries to: 129 6th St., Rm. 329

MEMORANDUM March 28, 2011

SUBJECT: Sectional summary; insurance for autism spectrum disorders (SB 74, Work Order No. 27-LS0443\A)

TO: Senator Johnny Ellis
Chair of the Senate Rules Committee
Attn: Amory Lelake

FROM: Dennis C. Bailey
Legislative Counsel

You have requested a sectional summary of the above-described bill.

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.

Section 1. Requires a health care insurer to provide coverage for the costs of the diagnosis and treatment of autism spectrum disorder under a treatment plan prescribed by a physician or psychologist. Coverage is required only for individuals under 21 years of age; must not limit the number of visits for treatment; is subject to the same copayment, deductible and coinsurance terms applicable to other health care services; and may be coordinated with an education program. The health care insurer may not refuse to cover an individual or terminate coverage because the individual is diagnosed with autism spectrum disorder.

Section 2. The Act applies to a health care insurance policy effective after January 1, 2012.

Section 3. Provides for an immediate effective date.

DCB:ljw
11-199.ljw

ALASKA STATE LEGISLATURE

Rules Committee
•
Senate Finance Committee
•
Health & Social Services Committee
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Community & Regional Affairs Committee
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World Trade Special Committee
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Committee on Committees

While in Session
State Capitol, Rm. 119
Juneau, AK 99801
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•
While in Anchorage
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Anchorage, AK 99501
(907) 269-0169
Fax: (907) 269-0172

SENATOR JOHNNY ELLIS
RULES COMMITTEE CHAIR

SB 74
Insurance Coverage for Autism Spectrum Disorders

Sectional Analysis

Section 1 of this bill amends AS 21.42 by creating a new section AS 21.42.397 relating to insurance coverage for autism spectrum disorders.

Subsection (a) requires insurance plans to cover medically necessary treatment for autism spectrum disorders, and exempts plans offered by fraternal benefit societies.

Subsection (b) further defines the coverage that must be provided.

Subsection (c) establishes that this section does not limit coverage already provided.

Subsection (d) prohibits an insurance company from denying coverage to someone because they have an autism spectrum disorder

Subsection (e) defines "autism service provider," "autism spectrum disorders," health care insurance plan", "health care insurance," and "medically necessary."

Section 2 of the bill establishes that the provisions of section 1 only apply to insurance policies issued after January 1st, 2012.

Section 3 of this bill establishes an immediate effective date for this act.

FISCAL NOTE

STATE OF ALASKA
2011 LEGISLATIVE SESSION

Fiscal Note Number
Bill Version: **SB 74**
() Publish Date

Identifier (file name) SB074-CCED-INS-03-25-11
Title: Insurance Coverage: Autism Spectrum Disorder
Sponsor: Senator Ellis
Requester: Senate Health and Social Services

Dept. Affected: DCCED
Appropriation: Insurance Operations
Allocation: Insurance Operations
OMB Component Number: 354

Expenditures/Revenues (Thousands of Dollars)

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

	Appropriation Required	Information					
OPERATING EXPENDITURES	**FY 2012**	**FY 2012**	**FY 2013**	**FY 2014**	**FY 2015**	**FY 2016**	**FY 2017**
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants							
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							
1178 Micro-Loan Fund (RLF)							
Other (please identify)							
TOTAL	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Estimate of any current year (FY2011) cost 0.0

POSITIONS

Full-time							
Part-time							
Temporary							

Why this fiscal note differs from previous version (if initial version, please note as such)

Initial Version

Prepared by: Linda Hall, Division Director — Phone 465-2560
Division: Division of Insurance — Date/Time 3/25/11 12:30 PM
Approved by: Susan Bell, Commissioner — Date 3/26/2011
Commerce, Community, and Economic Development

(Revised 1/27/2011 OMB)

FISCAL NOTE

STATE OF ALASKA
2011 LEGISLATIVE SESSION

BILL NO. SB 74

Analysis

This legislation 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.

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STATE OF ALASKA
2011 LEGISLATIVE SESSION

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Bill Version: **SB 74**
() Publish Date:

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Insurance Coverage for Autism in Alaska

Lorri Unumb, Esq.
Autism Speaks

lorri.unumb@autismspeaks.org

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

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Autism Spectrum Disorder

- Curable? No
- Treatable? Yes

- Impaired Communication
- Impaired Social Interaction
- Repetitive or Stereotyped Patterns of Behavior
- Narrow Range of Interests

- Four times more common in boys than girls
- Average age of diagnosis: 5-1/2

Applied Behavior Analysis (ABA Therapy)

- One-on-one therapy based on principles of repetition, reinforcement, and extinction.

- When an environment supports a set of behaviors, they increase. When an environment does not support behaviors, they tend to extinguish and fade away.

ABA Therapy Is Not Experimental

- "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."

  Report of the Surgeon General of the United States, 1999

- "ABA therapy is not experimental or investigational in nature."

  McHenry v. PacificSource Health Plans (D. Oregon, Jan. 5, 2010)

- "The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research . . . . Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups."

  American Academy of Pediatrics

Applied Behavior Analysis: Sample Therapy Structure

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

Applied Behavior Analysis: Cost of a Sample Therapy 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**

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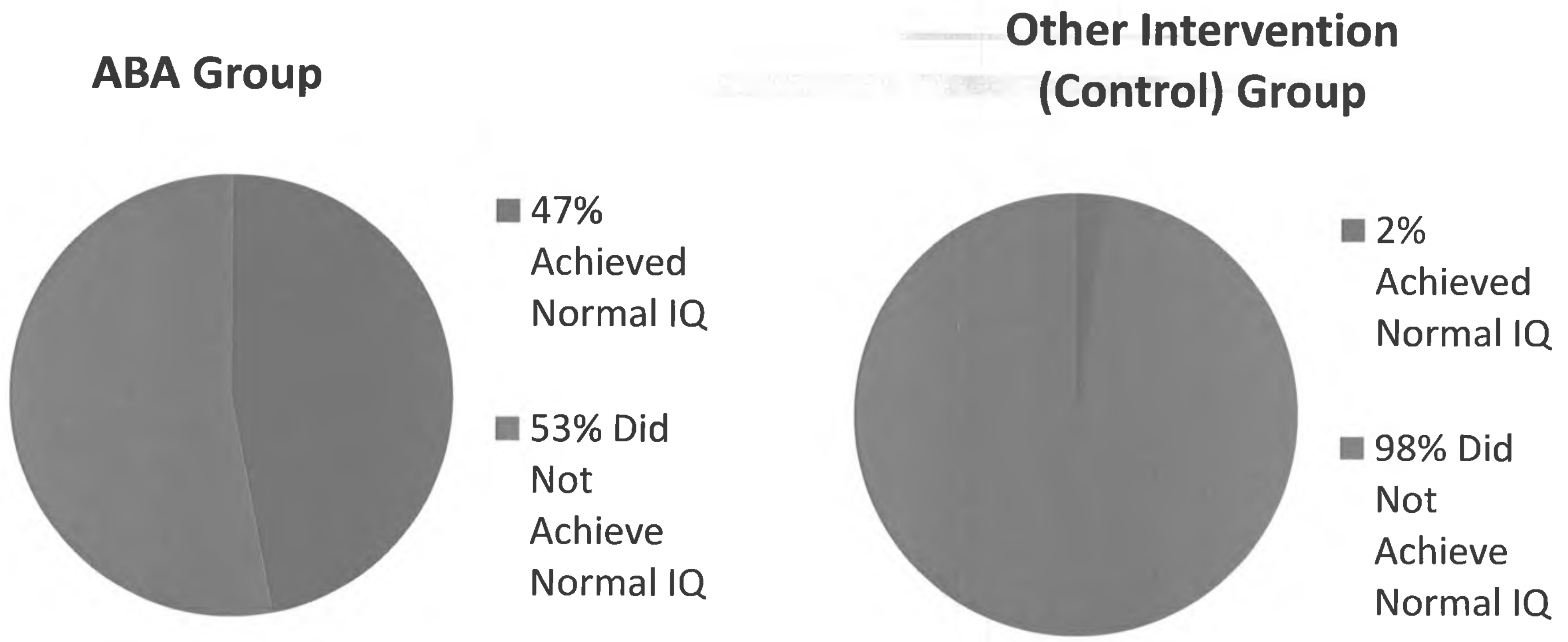
Savings to the State: Special Education

Outcome of 1987 UCLA Study on Efficacy of ABA



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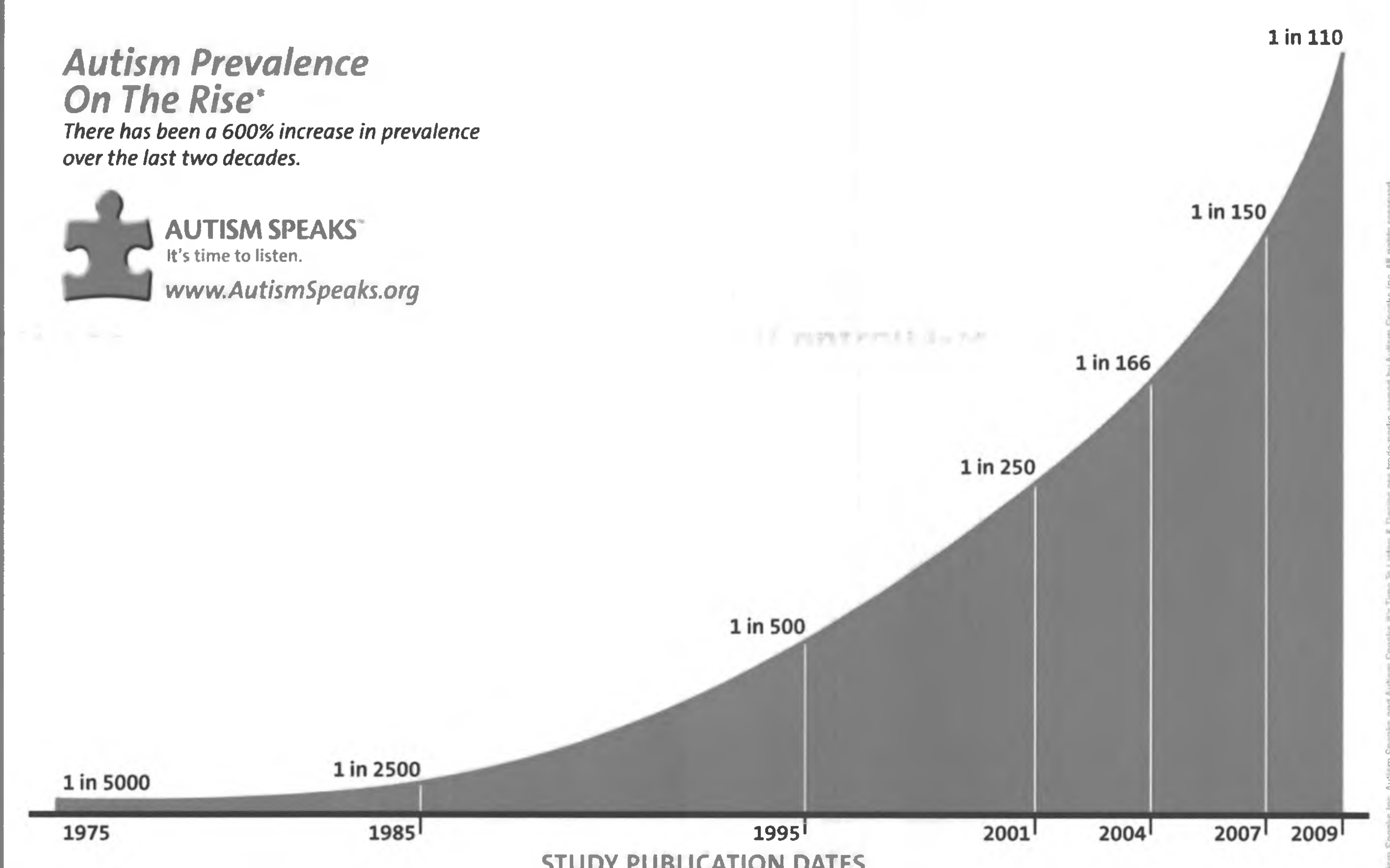
Societal Costs of Autism

- Harvard School of Public Health (Ganz, 2006)
- $3.2 million per person over lifetime
  - Includes direct and indirect costs, such as lost productivity

- Pennsylvania (Green, Jacobson & Mulick, 1998)
- Over $1 million per person



*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.

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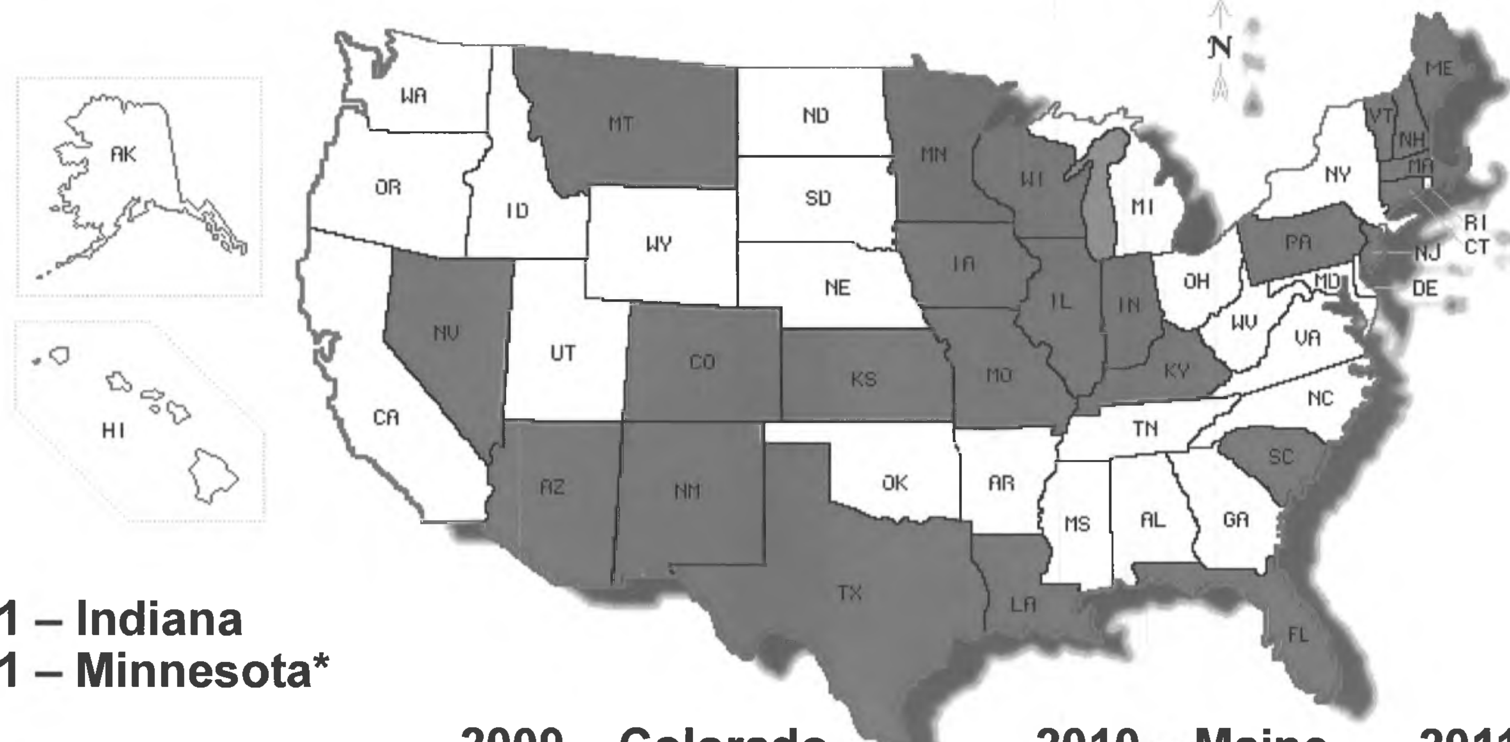
States with Autism Insurance Reform



2001 – Indiana
2001 – Minnesota*

2007 – South Carolina
2007 – Texas

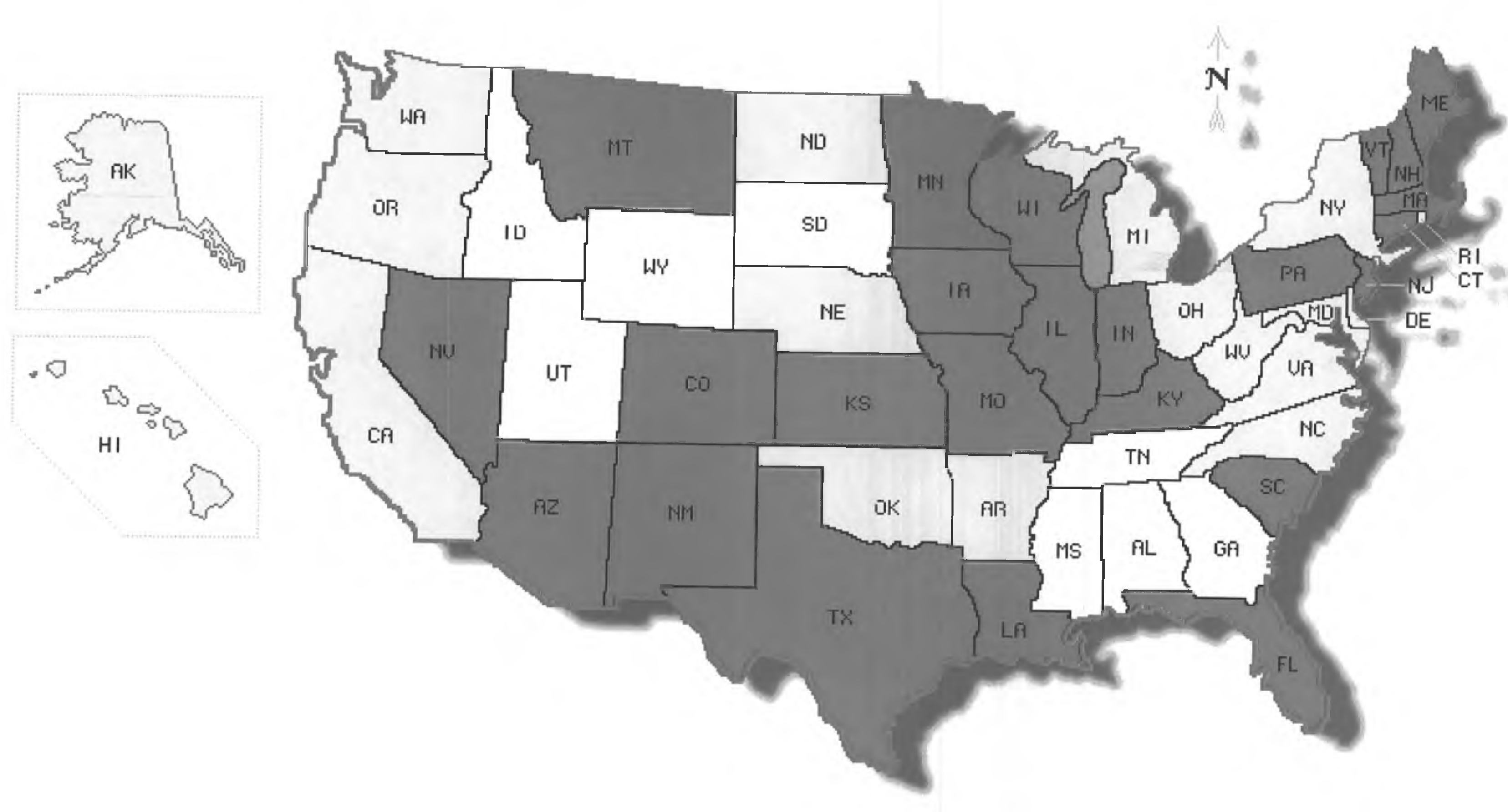
2008 – Arizona
2008 – Florida
2008 – Louisiana
2008 – Pennsylvania
2008 -- Illinois

2009 – Colorado
2009 – Nevada
2009 – Connecticut 1-19-11
2009 – Wisconsin
2009 – Montana
2009 – New Jersey
2009 – New Mexico

2010 – Maine
2010 – Kentucky
2010 -- Kansas
2010 -- Iowa
2010 -- Vermont
2010 – Missouri
2010 – New Hampshire
2010 -- Massachusetts

2011 – Arkansas

+ States with Bills Pending



1-19-11

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Comparison of Autism Benefits

State	Annual Cap	Age Cap
Indiana	None	None
Minnesota**	None	None
South Carolina	$50,000 - ABA	16
Texas	None	11
Pennsylvania	$36,000	21
Montana	$50,000/$20,000 at 10	18
Arizona	$50,000/$25,000 at 9	17
Missouri	$40,000	18
New Hampshire	$36,000/$27,000 at 13	21
Kansas*	$36,000/$27.000 at 7	19
Massachusetts	None	None
Vermont	None	6, or 1st grade***
Iowa*	$36,000	21

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Behavioral Therapy Benefits for Autism

Major Group

Student Guide

State of South Carolina
State Health Plan Autism Spectrum Disorder Benefit

Effective with the 2009 Plan Year, the State Health Plan began covering Applied Behavior Analysis (ABA) for children diagnosed with an Autism Spectrum Disorder. The Employee Insurance Program (EIP) asked APS Healthcare to develop guidelines for administering the new benefit. Just like other services covered by APS for behavioral health diagnoses, the new Autism Spectrum Disorder (ASD) benefit services must be pre-authorized as medically necessary by APS, and providers must be contracted with APS as in-network providers. Only ABA providers fully certified by the Behavior Analyst Certification Board will be part of the network and be able to file claims for ABA services. All reimbursements for ABA services will be made by APS directly to ABA providers.

Board Certified Behavior Analysts (BCBA's) contracted with APS must provide direct supervision to their staff including Board Certified Associate Behavior Analysts and/or any non-certified ABA therapists. Direct supervision includes the observation and oversight of the delivery of "hands on" ABA therapy by behavioral therapy staff.

The new benefit became effective on **January 1, 2009.** Following is a summary of requirements for coverage under the new benefit.

Eligibility Requirements:

1) Member must be covered by the State Health Plan and under sixteen (16) years of age with no pre-existing condition exclusions.
2) Member must be diagnosed by age eight (8) with Autistic Disorder, Asperger's Disorder or Pervasive Developmental Disorder Not Otherwise Specified by a Physician or Certified Registered Nurse Practitioner.
3) Diagnosis by age 8 must be confirmed by the following diagnosis-specific tests/screening tools:
   a. Autistic Disorder using one of the following:
      1. Checklist for Autism in Toddlers (CHAT); or
      2. Modified Checklist for Autism in Toddlers (M-CHAT); or
      3. Screening Tool for Autism in Two-Year Olds (STAT); or
      4. Social Communication Questionnaire (SCQ) (recommended for children four-years of age or older)
   b. Asperger's Syndrome using one of the following (recommended for school-age children):
      1. Autism Spectrum Screening Questionnaire (ASSQ); or
      2. Childhood Asperger Syndrome Test (CAST); or
      3. Krug Asperger's Disorder Index (KADI)
   c. Pervasive Development Disorder, NOS using the following:
      1. One of the previously mentioned tools to rule out Autism and Asperger's; and
      2. DSM-IV Diagnostic Criteria/Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

4) Member must be evaluated by an appropriate diagnostician to rule out the following as a sole explanation for symptoms of Autism Spectrum Disorder:
   a. Neurological Disorder (must be by an MD)
   b. Lead Poisoning (must be by an MD),
   c. Primary Speech Disorder, and
   d. Primary Hearing Disorder.

5) Member must be evaluated by a licensed Psychologist within the last 6 months for current validation of the ASD Diagnosis, using
   a. Autism Diagnostic Observation Schedule (ADOS); or
   b. Autism Diagnostic Interview (ADI-R); or
   c. Childhood Autism Rating Scale (CARS); or
   d. A DSM-IV Diagnostic Criteria which validates one of the three ASD diagnoses

Excerpt from 2009 Report of Council of Affordable Health Insurance: "Health Insurance Mandates in the States"

BENEFITS:	Est. Cost	#
Alcoholism	1-3%	45
Autism	<1%	23
Contraceptives	1-3%	29
In Vitro Fert.	3-5%	15
Prescriptions	5-10%	3

Actual Claims Data
BCBS of Minnesota (2007)

- Dates
  - In effect 2001
- Population
  - State has population of 5.3M
  - BCBS has 2100 members with ASD
- Terms
  - No dollar cap
  - No age cap
- Cost
  - Total claims = $12M
  - 315 of the 2100 members accounted for $9.7M of the $12M cost
- Premium impact PMPM (per member per month)
  - $0.83 commercial mrkt
  - $0.79 public programs
- Average annual cost for behavioral health treatment = $30,000

South Carolina State Employee Plan

- Dates
  - Statute passed in 2007
  - Applicable to state health plan as of 1-1-09
- Population
  - State has 4.5 M
  - State health plan has 350-390,000 members
- Terms
  - $50,000 cap <u>on ABA</u>
  - To age 16

- Projected Cost

  Original: $18.9 million

  Revised: $9 million
- Actual cost

  2009: $856,371

  PMPM - 20 cents

  2010: $2,042,392

  PMPM - 44 cents

  PEPM – 75 cents

  (228,048 employees/subscribers; 79 kids accessing coverage)

Alaska Fiscal Impact Worksheet

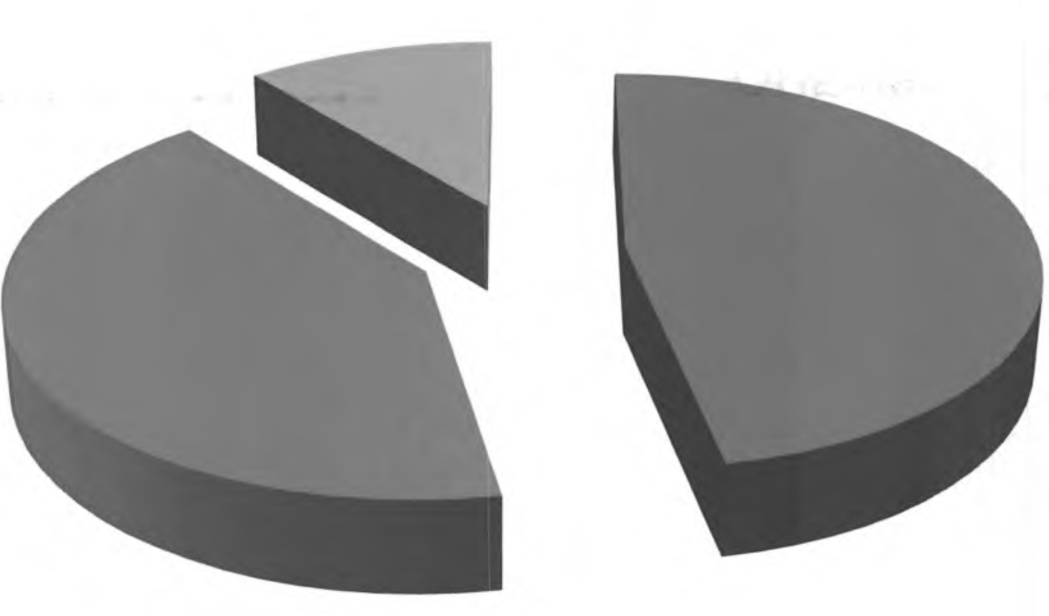
- Number of *employees* in state plan ___________
- X
- Per *employee* per month (PEPM) cost 75 cents

  (using 2010 South Carolina actual claims data; SC has age 16 & $50,000 cap on ABA)
- = ______________
- X
- Number of months in year 12 months

  =
- Total annual cost ______________
- (To determine total cost to state's general fund, discount the above total by percent of health insurance premium that a state employee pays, if any.)

Outcome of 1987 UCLA Study

Educational Placements for Group That Received ABA



- 47% = Mainstreamed with No Support
- 42% = Low-Intensity Special Education Placement (for language delay)
- 11% = High-Intensity Special Education Placement (for autism or intellectual disability)

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Savings to the State: Special Education

"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."

Source: 2009 Report of the Joint Legislative Audit and Review Commission to the Governor and General Assembly of Virginia (JLARC Report)

"Educational in Nature"?

- False choice
- What does "educational in nature" mean?
- *Schools provide?*
- *Schools would provide if adequate resources?*
  - No obligation under IDEA or state law to <u>treat</u> medical condition
    - Schools are required to accommodate the disabling condition, not remedy it.
- Is speech therapy "educational in nature"? AAP report.
- *Provided by school personnel?*
- Academic goals
- ASD is diagnosed by a doctor, not a principal
- Argument du jour
  - Rejected in 23 states
  - Rejected in federal court

“Educational in Nature”?

- *McHenry v. PacificSource Health Plans* (D. Oregon, Jan. 5, 2010)
- “While ABA therapy may have beneficial effects on an autistic child’s social and academic skills, its defining characteristic is application of techniques to modify behavior in every area of an autistic child’s life. In this regard, a sports analogy is instructive. While participation in sports can benefit a student’s academic and social skills, no one would classify sports as academic or social skills training.
- Similarly, the incidental benefits in these areas resulting from ABA therapy, while real, do not dictate that it be classified as either academic or social skills training.
- . . . While aimed at improving social and academic functioning, it does this by specifically addressing behavioral deficits possessed by autistic children that interfere with every area of their life, not by educating kids on social norms or teaching study skills or other tools specific to academic success.”

Impact of Federal Health Care Reform

- 2009 Amendments by Rep. Doyle (Pa.) & Sen. Menendez (NJ)
- Changed "**Mental health and substance use disorder services**", one of ten required benefits, to "**Mental health and substance use disorder services*, including behavioral health treatments***".
- Applies to plans issued through Exchanges as well as small group and individual plans.
- N/A to existing coverage, large groups, self-funded
- Starts in 2014.
- http://www.autismvotes.org/site/apps/nlnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=7522291

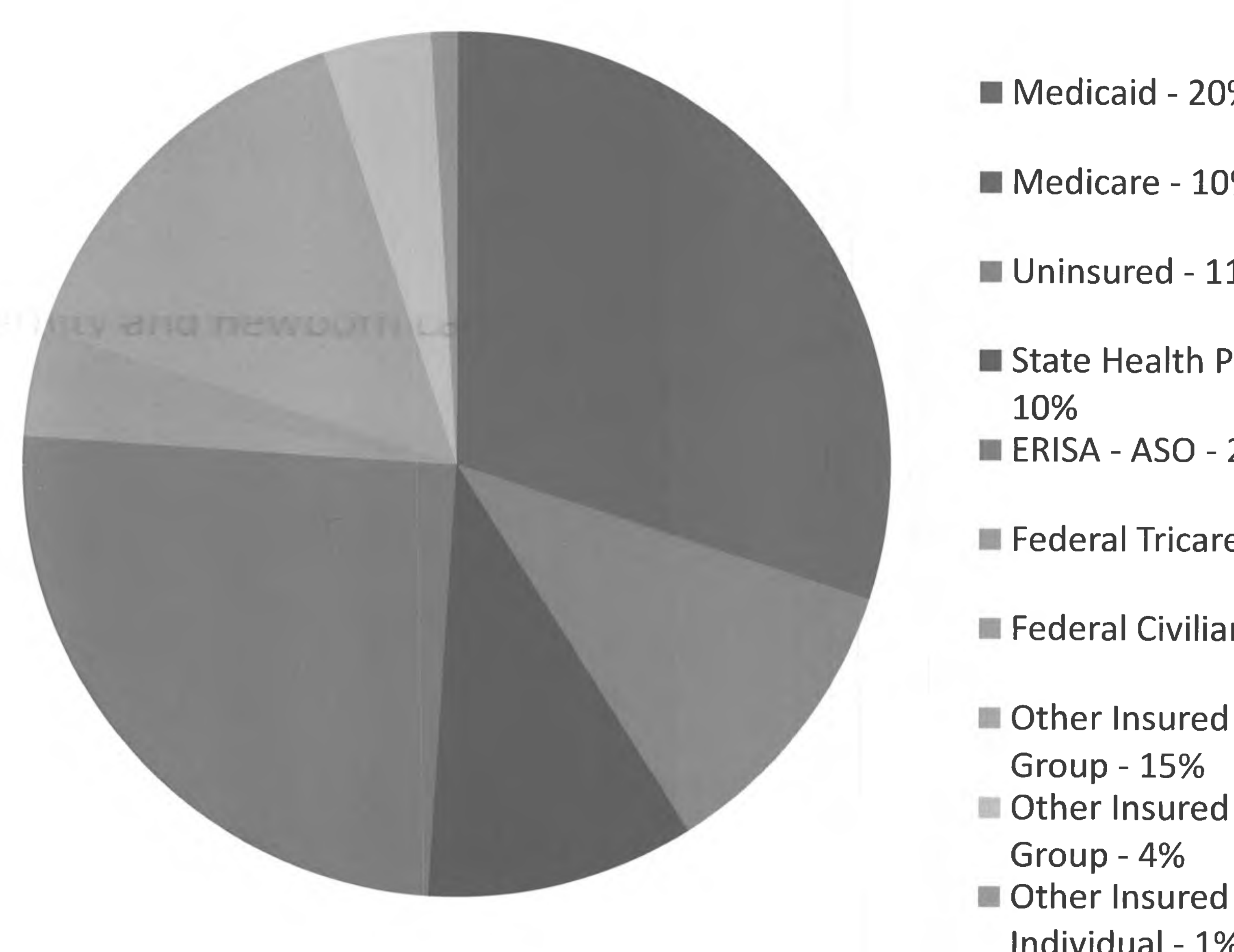
The Essential Benefits Package

- Ambulatory patient services
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health and substance use disorder services, including behavioral health treatment
- Prescription drugs
- Rehabilitative and habilitative services and devices
- Laboratory services
- Preventive and wellness services and chronic disease management
- Pediatric services, including oral and vision care

Impact of 2008 Federal Mental Health Parity Law

- 2008 Wellstone-Domenici Act prohibits **treatment limitations** and **financial requirements** on "mental health benefits" if not on physical health benefits.
- Wellstone MHP law applies only to large group fully-funded and self-funded policies.
- Illinois, Iowa, Maine, Montana, New Hampshire, New Jersey explicitly and Connecticut, Florida, Kansas, Kentucky, Missouri implicitly include autism within their state definition of mental illness.
- All of these states except Florida have passed capped autism mandates since the passage of the Wellstone federal MHP law.

Sources of Health Care Coverage



Self-Funded ERISA Plans

- "Overall, self-funded plans voluntarily cover 86% of the cost of mandated services."
- 2008 Report of Maryland Health Care Commission

The MARYLAND
HEALTH CARE COMMISSION

Self-Funded ERISA Plans That Cover Autism Treatments

- Microsoft
- Home Depot
- Intel
- Arnold & Porter
- Halliburton
- Eli Lilly
- Deloitte
- Ohio State University
- Time Warner
- Blackbaud
- Lahey Clinic
- Partners Healthcare
- Wells Fargo
- Lexington Medical Center
- University of Minnesota
- Progressive Group
- Greenville Hospital System
- Symantec
- DTE Energy
- Cerner
- State Street Financial
- Children's Mercy
- EMC
- Yahoo
- Sisters of Mercy
- Princeton University
- And many more . . .

Provider Credentials

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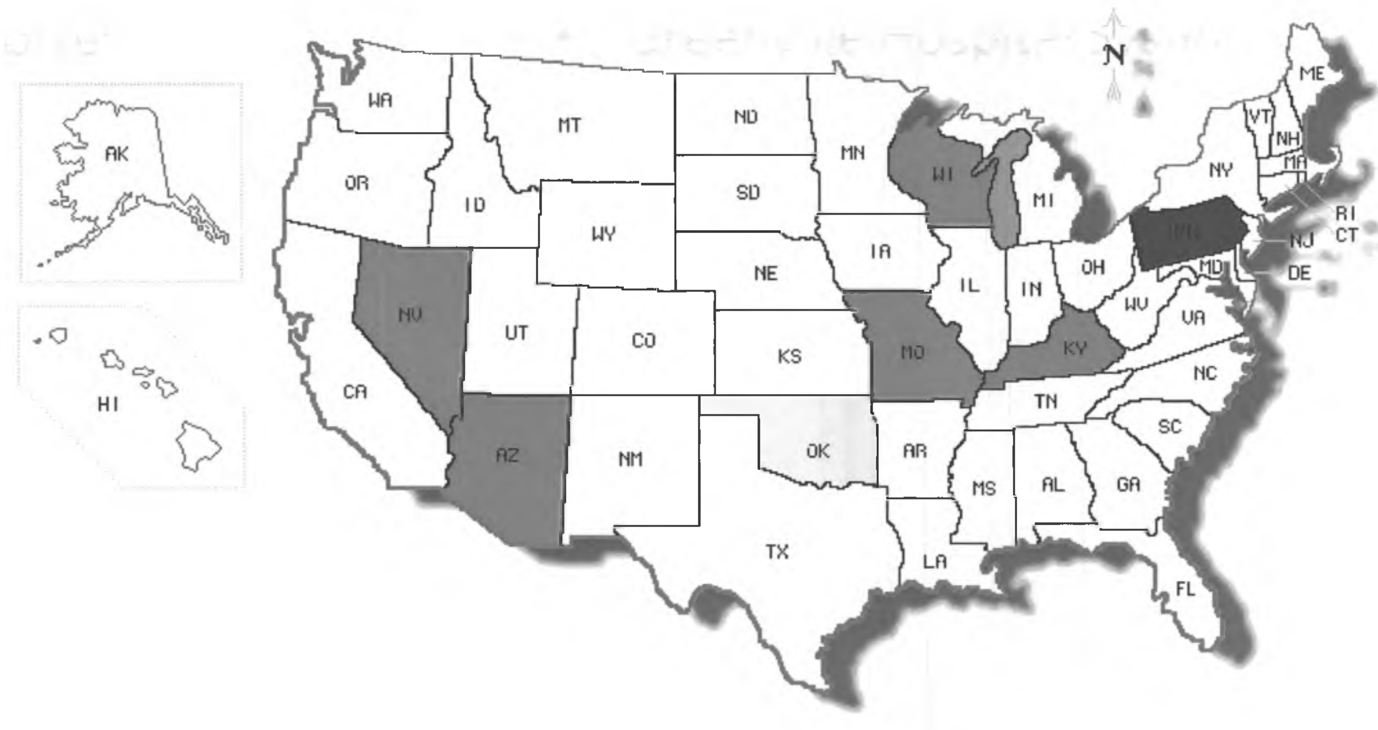

5-29-10

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.

Why Our Job Is Not Done

- May 27, 2010 at 5:08pm
- Subject: thanks
- I just wanted to say thank you for accomplishing what many people would not have attempted. I live in Charleston, SC. My husbands insurance is self funded so we are having to give up custody of our autistic 2 year old to my parents because their insurance is better. ABA is really helping and there is nothing I wouldn't do for him. You are inspirational to me and a hero. God bless you.

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

New York Times, 12/20/04

Autism Speaks

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

Eight arguments defining the justification for autism insurance reform legislation

February 2009

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Contents

Page 4 **Executive Summary**

Page 5 **About Autism Speaks**

Page 5 **About Autism**

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

Page 6 *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.**

Page 7 *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.**

Page 10 *Argument 3:* **Mandated private insurance coverage will bring effective autism services within the reach of children who need them. The efficacy of Applied Behavior Analysis (ABA), the centerpiece of this legislative mandate's benefits, has been established repeatedly.**

Page 12 *Argument 4:* **Government and scientific organizations have endorsed Applied Behavior Analysis (ABA) and other structured behavioral therapies.**

Page 14 *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.**

Page 16 *Argument 6:* **The costs of this insurance reform are small and will have very little impact on the cost of health insurance premiums for the individual consumer.**

Page 17	*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.**
Page 19	*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.**
Page 21	**Conclusion**
Page 22	**References**

Executive Summary

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

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

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

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

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

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

What is Autism Speaks?

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

What is Autism?

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

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

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

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

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

Variable	Children With Autism (n = 324 000)*	Children Without Autism (n = 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	13.0	5.9 (3.8-9.1)
Fair	7.4	2.0	7.7 (4.3-13.8)
Poor	3.5	0.4	21.1 (9.3-47.9)
Does the child use more medical care, mental health or educational services than is usual for most children of the same age?	90.6	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 (31.9-61.9)
Does the child have any emotional, developmental or behavioral problem for which she needs treatment or counseling?	75.4	7.0	36.9 (25.7-53.1)
Does the child currently need or use medicine prescribed by a doctor, other than vitamins?	54.7	21.1	3.5 (2.6-4.7)
If yes, is this for a condition expected to last 12 mo or longer?	51.4	14.5	11.0 (1.6-76.0)

Abbreviations: CI, confidence interval; OR, odds ratio.
*Data are given as the percentage of each group and are based on sampling fractions and weighted extrapolation from parent report of 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.

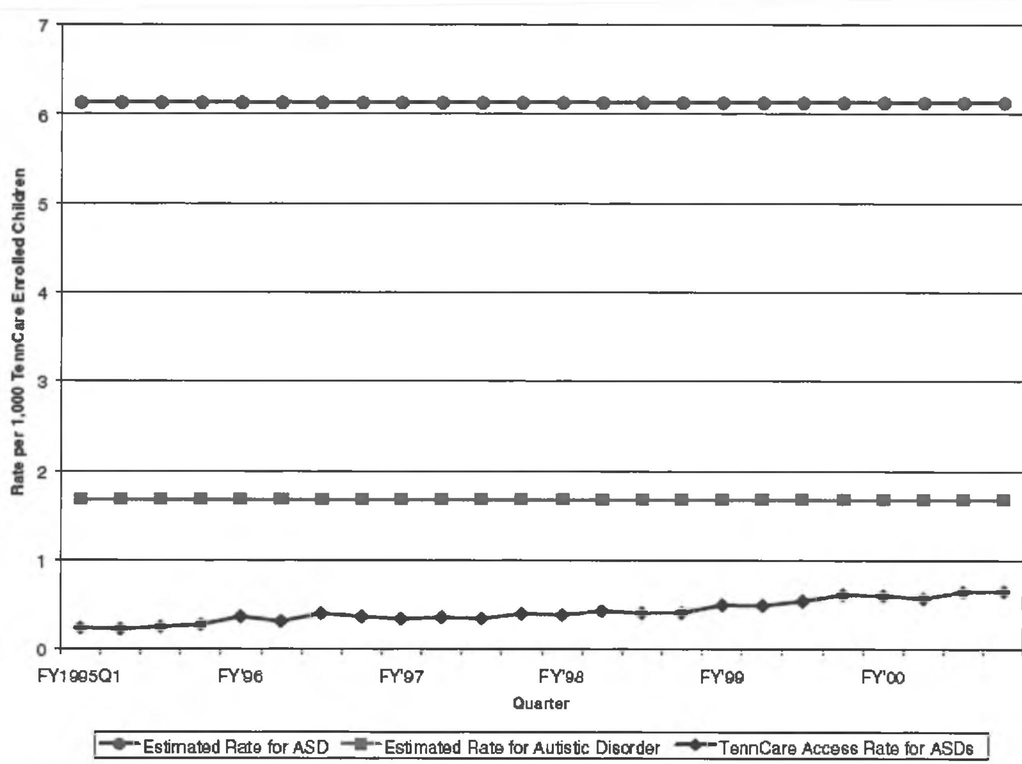

Fig. 1. Estimated incidence rates vs. service rates of autism spectrum disorders (ASDs) in TennCare for children ages 0–17 years, by quarter.

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	43 066
8-12	0	41 138
13-17	0	38 453
18-22	0	36 060
23-27	32 703	10 036
28-32	32 620	3136
33-37	30 852	0
38-42	29 122	0
43-47	26 800	0
48-52	24 531	0
53-57	17 776	0
58-62	0	0
63-66	0	0
Total lifetime costs	971 072	904 926

*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 68 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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Autism's origins lie hidden in a perplexing maze of behaviors and biology. Step by step, researchers are finding their way inside.

BREAKING Through

by KRISTIN SAINANI

photograph by TIMOTHY ARCHIBALD

Ricardo Dolmetsch was studying the basic biology of nerve cells when two events propelled him into autism research. In 2004, a mutation in one of the proteins he specialized in was pinpointed as the cause of Timothy syndrome, a rare ▶

Eli Archibald, photographed by his father, from the book *Echolilia*.

genetic disorder associated with autism. Then in 2006, Dolmetsch's oldest son, who was 4, was diagnosed with autism.

"At the time, we were very worried. We didn't know what was happening," says Dolmetsch, PhD '97, assistant professor of neurobiology. "So I went home and sat down with my wife, [Asha Nigh, '93,] who is also a scientist, to try to figure out what we could do."

There was solid research in psychology and behavioral treatments for autistic patients. But except for some progress in genetics, the biology of autism was virtually unknown, Dolmetsch says. "It was a little bit shocking that there was very little in the way of really good basic research."

Dolmetsch was in a unique position to do something about this gap. "I decided to shift the focus of my lab completely."

He is among a group of researchers at Stanford who are trying to untangle the root causes of autism. Some have been in the field for decades; others, like Dolmetsch, are newcomers, spurred by personal and professional motivations to understand a disorder that affects 1 in every 110 kids. (The rate is 1 in 70 for boys and 1 in 315 for girls.)

Autism is a spectrum of disorders that share three core features—language deficits, social deficits, and repetitive interests and movements. On one end of the spectrum are people with Asperger's syndrome, who are socially awkward but who often have above-average intelligence. Dolmetsch's son has this diagnosis: He was late to speak and when he did speak, he talked in a stilted and peculiar way—more like a little adult than a child; and he has problems socializing. The most serious autism cases involve severe mental disabilities (about 40 percent of children with autism have IQs below 70) and behavioral problems. Between these two extremes, children may have normal intelligence but pronounced language and social impairments.

J.C. Flores, '87, has 15-year-old identical twins with autism. Lomasi can speak, but she avoids talking and gives mostly one-word answers. Marielle can say only a few words and has no functional communication system. "They're sweet and they like to hang around people," Flores says. "But they don't really feel the need to communicate. They don't see why you have to."

In about 10 percent of cases, autism is secondary to a more pervasive genetic disorder, such as fragile-X syndrome or another chromosomal abnormality. But the vast majority of cases are unexplained, or idiopathic. Awareness about autism is at an all-time high, but public discussion has largely been dominated by questions such as: What accounts for the rapid increase in cases? Or is something in the environment causing autism? Though these questions are important (see sidebar), Dolmetsch and others at Stanford and elsewhere are trying to answer a more fundamental question: What is the underlying biology of autism? It's only by answering this question that they believe they can achieve real breakthroughs—the kinds that lead to cures.

A GENETIC PUZZLE: Flores's identical twin daughters both have autism but have different capabilities.

COURTESY J.C. FLORES

Autism is a CATCH-ALL DIAGNOSIS that likely includes a host of DISTINCT DISORDERS.

One of the biggest challenges is that autism is not one thing: It's a catchall diagnosis that likely includes a host of biologically distinct disorders. Though children with autism share a set of symptoms, these symptoms are quite varied and may have many, diverse biological origins. "Autism is incredibly heterogeneous. We've been lumping everyone together under this name autism, and unfortunately it makes it very difficult to study the biological features when we are treating multiple groups as one," says Sophia Colamarino, '90, vice president of research for Autism Speaks—a science and advocacy group—

and consulting associate professor of psychiatry and behavioral science. To get a toehold into the biology, researchers will need to identify unique subgroups of autism, she says. Researchers across the globe are defining subgroups based on genes, molecular pathways, or signatures in the brain and blood.

Another impediment: access to the brain. Scientists can slice cancer cells out of a tumor and study them directly, but they can't just scoop cells out of the brain. Stanford is on the forefront of solving this problem—in fact, Dolmetsch's solution seems straight out of a science fiction novel.

Although much remains unknown, these efforts are giving the world its first glimpses into the biology of autism.

JOACHIM HALLMAYER describes himself as a "grandfather in the field of autism." He's been chasing down the genes for the disorder for 20 years, beginning as a postdoctoral fellow in genetics at Stanford. At that time, the disease was considered rare (4 out of 10,000 kids). "I knew in a snap everybody in the Bay Area who ever diagnosed a child with autism," says Hallmayer, associate professor of psychiatry and behavioral science.

Hallmayer joined the field because of a parent: Carmen Pingree, the mother of an autistic boy in Utah, who approached his mentors at Stanford, urging them to study the disease. Hallmayer collaborated with Pingree, who used her ties in the Mormon community to assemble pedigrees for 146 families with multiple cases of autism. It was the largest genetic study of the disease at the time. The parents of children with autism continue to motivate him, he says.

Autism is particularly heartbreaking because it colors the most fundamental social bond—that between a parent and a child. Even children with milder forms of autism may have trouble displaying or returning affection. "Autistic children are as emotional as other children; I'm very convinced of this. But they don't show it," Hallmayer says. "They show it in a different way. And it's a very, very hard learning process for most parents."

Studies of twins have shown that autism has a large genetic component, but it's not all genes. Identical twins have the same DNA, but sometimes only one twin gets autism. In other cases, as with Flores's daughters, Lomasi and Marielle, the severity of the disorder differs. The genetics are also complex. Different genes may be involved in different people; and, in

Why the Increase? (No, it's not vaccines.)

Twenty years ago, people diagnosed with autism were relatively rare, and the public's awareness of the disorder was chiefly limited to Hollywood depictions such as that in the 1988 Academy Award-winning movie *Rain Man.* Today, many people know a neighbor, friend or classmate who is dealing with autism —prevalence has risen about twentyfold since 1990. But what's behind this startling increase? Scientists agree that some of it is due to changes in diagnosis and awareness, but just how much is hotly debated.

"The best papers I've seen suggest that there is a genuine increase," Ricardo Dolmetsch says. "But it's not as big as it seems. A big, big contribution is societal awareness and changes in diagnostic criteria."

There have been at least two shifts in diagnosis, Dolmetsch says. First, some kids who might have once been diagnosed as mentally retarded now are recognized as autistic. Second, children with autism display some of the same characteristics as those who have attention-deficit hyperactivity disorder (ADHD). When the diagnosis is ambiguous, doctors in California tend to diagnose autism rather than ADHD, because the state pays for services (such as behavioral therapy) for autism but not ADHD, Dolmetsch says.

Moreover, the medical establishment's thinking about what constitutes abnormal behavior has shifted, Joachim Hallmayer says. "There's no doubt that what we diagnose as autism is different than what we diagnosed 20 years ago." Autism has been on the rise globally, but the explosion of cases occurs at different times in different countries, which points to a large role for societal awareness, Hallmayer says.

Some of the increase is definitely real, though, according to Antonio Hardan. He cites two contributors. More premature babies are surviving, and preemies are at high risk of autism (about 10 percent will develop it), and more couples are having babies when they're older, which increases the risk of genetic errors that can lead to autism.

Could something in the environment also be a factor? Maybe, the researchers say, but there is little scientific evidence to back any such claim. Despite widespread concerns about a link between pediatric vaccinations and autism, vaccines have been soundly exonerated, they say.

Paula Gani, '91, says her 4-year-old son Marcus, who has a milder form of autism, "is one of those kids who would not have been diagnosed 20 years ago." But the diagnosis and early intervention he's received are likely rewriting his future. He made limited eye contact and didn't engage socially when he was diagnosed two years ago, but "yesterday, we were going out to pizza with another mom and her kid. And he took the other little boy's hand and started singing 'The more we get together, together, together . . . '," she recounts. "It's a huge difference."

Dolmetsch is using an astonishing NEW TISSUE MODEL. 'We're making little pieces of BRAIN IN A DISH.'

any given individual, the disease may arise from changes in one gene, changes in several genes, or a combination of genetic and environmental factors. (Though no specific environmental triggers have been identified, researchers are testing everything from exposure to heavy metals and pesticides to TV watching.) Tackling this complexity requires large studies.

Hallmayer has spearheaded several massive, multisite collaborations. He chairs the committee of senior investigators for the Autism Genome Project, an international consortium of more than 50 universities that has collected data on 2,000 families with multiple cases. He also has assembled a study of 220 pairs of twins from California in which at least one twin has autism.

In the past decade, geneticists have discovered a handful of genes that when mutated or missing can cause autism. Though rare, these genes have given scientists some of their best clues about the disease's biological underpinnings. "I think it's very exciting, even if it's rare cases. We can at least get a better understanding of one piece of the puzzle and then we can branch out from there," Hallmayer says. For example, several of these genes are involved in communication between neurons. In a 2010 paper in *Nature*, Hallmayer and his colleagues from the Autism Genome Project greatly expanded this list of genes—reporting hundreds of rare genetic events that may be involved in autism.

It's long been known that about 5 percent of autistic kids have a chromosomal abnormality that can be seen under a microscope—part of a chromosome is missing, duplicated or in the wrong place. Because these changes affect a large number of genes, the children often have many problems in addition to autism. What wasn't known until recently is that we all have slight imperfections in our chromosomes—small regions of DNA that are duplicated or deleted. When these stretches of DNA contain genes, people can end up with one or three copies of the genes instead of the standard two. Technological advances have made it possible to detect these "copy-number variants," or CNVs. And it turns out they're important in autism and some psychiatric disorders. For example, a region of chromosome 16—containing about 25 genes, some involved in brain function and development—is deleted or duplicated in 1 to 2 percent of people with autism (and some with schizophrenia). Scientists are beginning to study these patients as an autism subgroup.

Hallmayer and his colleagues scanned the genomes of thousands of people with autism and 2,000 healthy individuals looking for rare CNVs. They found that children with autism had more rare CNVs that overlapped genes, including genes previously implicated in autism. Some CNVs were inherited from a parent, but some arose spontaneously in the child, likely due to a genetic error in the sperm or egg. They identified disruptions in hundreds of genes that occurred only in autism cases, never in controls. Not all of the genes will turn out to be relevant to autism, but the ones that are could explain maybe 10 to 15 percent of cases, Hallmayer says.

DOLMETSCH IS STUDYING several subtypes of autism defined by genes, including Timothy syndrome and the chromosome 16 CNV, using an astonishing new tissue model. Essentially, he says, "We're making little pieces of brain in a dish."

In 2007, scientists in Japan figured out how to genetically reprogram adult cells into pluripotent stem cells—which, like embryonic stem cells, can give rise to any other cell type in the body. Using this technology, Dolmetsch's team recreates human neural development. They take skin cells from patients with autism, turn them into stem cells, and then, using a cocktail of proteins, coax these cells to form a neural tube. A neural tube is the earliest neural structure to form and later grows into the brain at one end and the spinal cord on the other. The researchers then take slices of cells from the neural tube and direct them to become specific parts of the brain, such as the cortex. "It sounds like science fiction. It's kind of incredible this even works," Dolmetsch says. "Nobody had ever actually made neurons from autistic people before."

Timothy syndrome is caused by a defect in calcium channels, which play a critical role in electrical activity in the brain and heart. Because Timothy patients often have life-threatening heart arrhythmias, Dolmetsch's team is also making "little pieces of heart."

Sitting in his office on the second floor of the Fairchild Research Building, Dolmetsch shows movies of the hearts on his computer. The ball of cells looks like one chamber of a fetal heart beating on an ultrasound. Those laboratory hearts—

FROM TOP: PHOTOS COURTESY STANFORD SCHOOL OF MEDICINE (4); JENNY PEGG

developed from the cells of a healthy subject—beat just like the real thing, 60 times per minute. When grown from the cells of Timothy patients, however, the hearts beat erratically —they miss a beat, or have a double beat. Dolmetsch's team has already used the models in a practical way: They screened 20 different drugs that correct heart arrhythmias and found the one that works best for Timothy patients. "You can't give a child 50 drugs and see which one works, but you can do that with these cells," Dolmetsch says.

He also shows movies of thousands of lab-created neurons firing. When given an electric pulse, the blue-colored cells light up in a sudden flash of green, like fireworks going off, and then they flicker and shimmer in a fallout of electrical activity. He is studying these neurons to figure out what is different in the autistic brain, starting with Timothy patients. The results so far: In addition to abnormal calcium signaling, kids with Timothy syndrome have too many cells that produce the neurotransmitters dopamine and norepinephrine. They also have too few cells that form long-distance connections and too many that form local connections.

"This may help to explain why children with autism often have problems integrating lots of different classes of information, but they can often perform quite well in one domain," Dolmetsch says. (In other words, the wiring that impairs, say, the ability to discern symbolism in Shakespeare, might enable an extraordinary ability to memorize a scene from *Hamlet*.) "This is the first time that anybody has ever seen any cellular defects associated with any psychiatric disease, much less autism." A group from UC-San Diego also has adopted this technology—they recently reported specific defects in neurons created from patients with Rett syndrome, another genetic anomaly that can cause autism.

Dolmetsch's team has grown brain cells from 20 patients with Timothy syndrome or other known mutations. Their ultimate goal, however, is to grow brain cells from patients with autism who have no known genetic defect and then to classify these patients according to their cellular and molecular defects—such as problems with neural communication or problems with calcium channels.

Dolmetsch plans to use these models to screen for treatments that can reverse or overcome the biological defects. He also could use them to screen potential environmental contributors to autism. Some environmental agents may injure developing neurons in ways that mimic known genetic hits, he says.

LIKE DOLMETSCH, Thomas Südhof was a basic biologist working on fundamental questions about the brain when he was drawn into autism research a few years ago. Südhof is an expert in synapses, the junctions between neurons. He played an instrumental role in working out the molecular details of how messages travel across synapses—work for which he shared the $1 million Kavli Prize in neuroscience in 2010. Serendipity brought Südhof, professor of molecular and cellular physiology, to autism research. A number of autism cases were traced to rare mutations in synapse pro-

Solution Set?

RICARDO DOLMETSCH
Uses human tissue to simulate a developing autistic brain in lab-grown models.

JOACHIM HALLMAYER
Helps oversee the Autism Genome Project, collecting data on thousands of families.

THOMAS SÜDHOF
Rare mutations in brain proteins offer insights about autism's effects on synapses.

ANTONIO HARDAN
MRIs of children with autism show differences in neural connections.

KAREN PARKER
Defects in the hormone oxytocin may play a role in social deficiencies.

FROM TOP: PHOTOS COURTESY STANFORD SCHOOL OF MEDICINE (4); JENNY PEGG

teins, including two that Südhof discovered in the 1990s—neurexins and neuroligins.

These proteins bind to each other across the synapse to help neurons connect and communicate; they also are believed to play a role in "synaptic plasticity"—changes in the ability of the synapse's chemistry and structure that underlie learning and memory. What's interesting about autism, Südhof says, is that the brain is not globally impaired—for example, kids who are unable to speak have normal motor skills. "You really need a pretty good brain for that," he says. Thus, autism is likely due to subtle changes in the brain's wiring, such as how neurons connect physically, or how they communicate.

In a 2007 paper in *Science*, Südhof and his colleagues reported the first mouse model of idiopathic autism. They took a mutated form of the neuroligin gene that was discovered in two brothers, one with autism and the other Asperger's, and inserted it into mice. The mice showed some features of both autism and Asperger's. (They were less inclined to hang out with other mice, but faster at learning a water maze.) In 2009, Südhof engineered mice to have a neurexin deletion that, in humans, is associated with 1 in 200 autism cases. The mice had increased repetitive behaviors, such as excessive self-grooming, but no obvious changes in social behavior. The neurons of both sets of mice had altered synaptic signaling.

The mice aren't a perfect replica of human autism (animal models are inherently limited—after all, mice don't have language), but they have yielded important insights. Südhof's team has begun testing many other genes that have been implicated in autism in mouse models to see if they also affect synapse function. "One thing is clear: Anything in the brain involves the synapse, so the synapse is a good bet," he says.

Once you pinpoint molecular pathways that underlie autism, such as problems with calcium channels or problems with synapses, then you can develop targeted treatments. Recent advances in fragile-X syndrome are a perfect example, Colamarino says. Patients with fragile-X (about one-third of whom also have autism) are missing a protein that helps regulate synaptic function. Without this protein, there is an excess of synaptic signaling, which scientists believe could lead to intellectual disabilities. Several companies have begun testing drugs that dampen the noise. In mice with fragile-X, the drugs can reverse some neurological symptoms. It's too early to say if the drugs can reverse mental disabilities in people with fragile-X, but they have eased behavioral symptoms in short-term trials of affected adults.

No one thought it was possible to reverse symptoms of a neurodevelopmental disorder in adulthood, Colamarino says. "The idea that you can do this has completely reinvigorated the field of autism treatment research."

At 10 P.M. on a Friday night at the Lucas Center, postdoctoral fellow Kari Berquist, doctoral student Grace Lee and senior research assistant Sweta Patnaik are waiting in a darkened MRI control room. The silhouettes on the other side of the glass window finally appear motionless. There's a moment of breathless anticipation as the father sneaks away from his sleeping son on the MRI table. Then 4-year-old Joshua (patients' names have been changed) wakes up again. They won't be able to get the scan done tonight. The father emerges from the MRI room; Joshua, who cannot yet speak, cries, kicks and clings to his dad, making *bbb* and *mmm* sounds. Joshua's mother buckles her other son—a healthy 11-month-old who already says

The 'cuddle hormone' may yield important clues

Oxytocin is the hormone that promotes social bonding, so it makes sense that defects in oxytocin might play a role in some cases of autism. Karen Parker is exploring whether changes in oxytocin levels in the blood or cerebrospinal fluid could be a marker of the disorder. "My work is thinking about the biology of social functioning," says Parker, an assistant professor of psychiatry and behavioral sciences. Oxytocin is sometimes called the cuddle hormone or the love hormone, because it's released during physical contact and sex; it also plays a role in social interaction, trust and empathy, as well as monogamy in certain animals. A behavioral neuroscientist, Parker studied the role of oxytocin in voles and monkeys before moving to autism research.

Parker has collected blood from children with autism, their healthy siblings (who sometimes show more subtle social deficits) and normal controls to try to detect differences in their oxytocin levels. She also is setting up one of the first studies in the cerebrospinal fluid (CSF). Studies in monkeys show that blood oxytocin may be normal even when brain levels, reflected in the CSF, are low. It's difficult to obtain CSF because it requires a spinal tap. Her team is investigating genetic variation in the oxytocin receptor and other genes involved in the oxytocin pathway. If Parker's and Hardan's studies show an oxytocin deficiency, patients could receive replacement oxytocin.

It's promising research because low oxytocin is treatable, Parker says. In a recent study, when 13 autistic adults were given an oxytocin nasal spray (which delivers the drug straight to the brain), they had significant improvements in reading social cues and in making eye contact. "I think it's actually fascinating that you can apply oxytocin once and see these pretty acute social changes," Parker says. "Oxytocin is the only drug that's been shown to alter social functioning. There's nothing else that touches the social deficits."

The wiring that impairs, say, the ability to DISCERN SYMBOLISM in Shakespeare, might enable an extraordinary ability to MEMORIZE A SCENE FROM *HAMLET.*

"bubble" and "mama"—into his car seat for the ride home.

MRI machines are noisy and require the patient to lie perfectly still for several minutes at a time, so most children—especially those with autism—cannot tolerate them while awake. So the idea is to bring them in already sleeping. However, the next study participant also arrives awake. But 4-year-old Padma, who has autism but is high-functioning, surprises everyone by agreeing to be scanned, enticed by the promise that she will get pictures of her brain. It's a partial success: The team gets one usable scan before they finally give up at 11:30 p.m. Padma proudly tells the researchers that she is going to post her brain pictures on Facebook.

Antonio Hardan is studying these brain pictures looking for signatures of autism and of subgroups of autism. Unlike others on campus who are working from the genes up, Hardan is working backward from the brain to the underlying biology. Hardan, who sees patients in addition to conducting research, has been involved with autism since he began volunteering to work with autistic patients in medical school. "And 27 years later, that's my life in a way, my research life," says Hardan, associate professor of psychiatry and behavioral science. "When you connect with something emotionally, then that's what you want to do."

It's long been known that children with autism have larger-than-normal brains early in their development. Hardan has refined this observation, showing that some (but not all) children with autism have an increase in the thickness of the cortex—the part of the brain responsible for complex functions such as language and social behavior—that disappears as they grow. It might be possible to link this back to genetics, says Hardan, who frequently collaborates with Hallmayer. We know some of the genes that contribute to cortical thickness, he says.

Hardan is exploring new brain imaging technologies that offer an unprecedented level of detail. For example, diffusion tensor imaging (DTI) shows the individual axons (the elongated parts of neurons) that connect different parts of the brain. And MRI spectroscopy measures the levels of specific chemicals in various parts of the brain. DTI studies from several universities suggest that autistic children have abnormal long-distance brain connections, an observation that dovetails with Dolmetsch's studies in neurons. Using MRI spectroscopy, Hardan also has detected specific chemical imbalances in the brains of children with autism. He's looking for treatments that can normalize these imbalances.

Hardan's team is involved in about 15 different clinical studies. Whenever possible, he tries to link treatment responses to changes in brain images and to a subgroup of people with autism. For example, Joshua and Padma were being re-scanned after they'd received a behavioral intervention that can improve language. These images may give clues as to how the treatment is working in the brain and what subgroups of patients are likely to respond. Hardan also is collaborating with Karen Parker, who is looking for biomarkers of autism in the blood and cerebraospinal fluid. (See sidebar, page 52.)

The commitment of parents keeps him going, Hardan says. "It's amazing what they would do for their kids. My admiration of these parents fuels what I do."

WHILE AUTISM remains largely a mystery, scientists are making inroads, bit by bit.

As a parent, Dolmetsch says he's been very fortunate. When faced with his son's diagnosis, there was something concrete he could do. Thanks in part to behavioral therapy, his son, now 8, is doing well. "He's at the edge between character and dysfunction. And some days it's very dysfunctional; other days it's just character."

Having a child with autism has changed the way he thinks about science. "You always want to publish findings that are correct, but the bar is higher when your own child is involved, he says. "You don't want to do anything to mislead the field when they are trying to find a cure for your kid."

He also cares less about doing things first. "I just want somebody to do it," he says. "I just want somebody to come up with some plausible biological explanations, so we can convince people that it's worth developing treatments." ■

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ARTICLE

The Lifetime Distribution of the Incremental Societal Costs of Autism

Michael L. Ganz, MS, PhD

Objective: To describe the age-specific and lifetime incremental societal costs of autism in the United States.

Design: Estimates of use and costs of direct medical and nonmedical care were obtained from a literature review and database analysis. A human capital approach was used to estimate lost productivity. These costs were projected across the life span, and discounted incremental age-specific costs were computed.

Setting: United States.

Participants: Hypothetical incident autism cohort born in 2000 and diagnosed in 2003.

Main Outcome Measures: Discounted per capita incremental societal costs.

Results: The lifetime per capita incremental societal cost of autism is $3.2 million. Lost productivity and adult care are the largest components of costs. The distribution of costs over the life span varies by cost category.

Conclusions: Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. The substantial costs resulting from adult care and lost productivity of both individuals with autism and their parents have important implications for those aging members of the baby boom generation approaching retirement, including large financial burdens affecting not only those families but also potentially society in general. These results may imply that physicians and other care professionals should consider recommending that parents of children with autism seek financial counseling to help plan for the transition into adulthood.

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AUTISM IS A VERY EXPENSIVE disorder costing our society upwards of $35 billion in direct (both medical and nonmedical) and indirect costs to care for all individuals diagnosed each year over their lifetimes.[1] Given the financial and nonfinancial costs we face and given increasingly more options for treatment and possibly for prevention, information on the distribution of costs is needed to help us decide on how to best allocate scarce resources to support individuals with autism and their families. Because the complementary (or competing) treatment and prevention strategies currently available, or yet to be developed, vary in effectiveness or implementation costs, understanding how total costs due to autism are distributed across the life cycle is important to make better decisions.

Relatively little is known about the societal costs of autism, in total and at different points across the life cycle. In earlier work, the per capita and total societal costs for individuals with autism were described.[1] Although the per capita and societal costs were described overall and across 17 components of direct medical, direct nonmedical, and indirect costs, age-specific costs were not. Because certain categories are more relevant and more costly and because these costs are borne by different parties at different ages, presenting the age distribution of the costs of autism can provide policy makers information that is helpful for cost-utility analyses and for current and future resource planning activities. The focus of this study is to present estimates of the costs of autism along with some detail on how the estimates were constructed. Although no clinical data are presented, these data should be useful to health care professionals, families, and agencies in planning for future care, especially with respect to nonmedical costs.

METHODS

A detailed description of the sources of data and computational methods used to compile the costs of autism has been presented elsewhere.[1] Briefly, cross-sectional cost data from different age groups were used to create prevalence-based cost estimates that approximate incidence-based estimates (ie, those constructed by longitudinally tracking an incident cohort over time). A prevalence-based cohort, also known as a synthetic, or hypothetical, cohort,[2] allows us to approximate the lifetime experiences of a single incident cohort by using the prevalence-based cost patterns as if

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they were observed longitudinally from an incident cohort. Although an incidence-based cost-of-illness approach is more appropriate because it captures the full experience of autism, including any comorbid conditions, formidable data requirements preclude it.[3]

The total costs of autism equal the sum of its direct and indirect costs. Direct costs measure the value of goods and services used and indirect costs measure the value of lost productivity due to autism. These direct and indirect costs represent the value of other activities that these resources could have purchased (ie, opportunity costs).[4,5] Physician and other professional services, hospital and emergency department services, drugs, equipment and other supplies, and medically related travel and time costs are typical components of direct medical costs. Direct medical costs were obtained either from the literature or from an analysis of the Medical Expenditure Panel Survey (MEPS)[6] and the National Health Interview Survey (NHIS).[7] Special education, transportation, child care and babysitting, respite care, out-of-home placement, home and vehicle modifications, and supported employment services are typical components of direct nonmedical costs. Nonmedical costs were obtained from the literature. Multiple cost estimates within categories were averaged to obtain a single cost estimate for each category. Indirect costs are the value of lost or impaired work time (income), benefits, and household services of individuals with autism and their caregivers because of missed time at work, reduced work hours, switching to a lower-paying but more flexible job, or leaving the workforce. Indirect costs were computed using a human capital approach[3,8] that combines average earnings, benefits, and household services with information on average work-life expectancies and labor force participation rates for men and women at different ages.

In the analyses that follow, the incremental costs of autism are presented, which are defined as those additional costs that are due exclusively to autism. For example, costs due to use of medical services for periodic well-child preventive care or care related to the common cold are not considered herein because those costs are common to children with and without autism; however, costs specifically due to autism are considered herein. When incremental costs were not available or otherwise specifically presented in the source materials, they were computed by subtracting national average costs calculated from the MEPS from the costs reported in the source documents. For example, if a source document presented an average cost of $\$X$ for all children with autism and the national average for all children for that same category was $\$Y$, then the incremental cost was computed as $\$(Y-X)$. Because of the broad impact of autism on families, insurers, taxpayers, and society and because of the considerable public autism funding, a societal perspective was used, as recommended by the Panel on Cost-effectiveness in Health and Medicine.[8]

The Harvard School of Public Health Human Subjects Committee had previously exempted this study from institutional approval.

DIRECT COSTS

Literature Review

An in-depth targeted literature review concentrating on US-based studies was conducted to obtain data on use and costs. British and Canadian studies were also used when data were otherwise unavailable. Data on physician, outpatient, clinic services, dental care,[9] prescription medications,[9-11] complementary and alternative therapies,[12-18] behavioral therapies,[19-22] hospital and emergency services,[9,23] allied health, equipment and supplies, home health,[9] and medically related travel[9] were classified as direct medical. Data on child care,[9,19] adult care,[19,20] respite and family care,[9,19,20] home and care modifications,[9,24] special education,[19,20,25-27] supported employment,[20,28-34] and other costs[9,24] were classified as direct nonmedical. Although some dimensions of care may be misclassified between direct medical and direct nonmedical (for example, many special education programs provide behavioral therapies), because the degree of misclassification is not known, no corrections were made. Costs, as reported in the source materials, were inflated to 2003 US dollars using the all-item consumer price index.[35] State-specific costs were transformed to national averages[36] and foreign costs were converted to US costs using the latest available Federal Reserve exchange rates.[37] Use measures were translated to costs by multiplying the use measures by age group–specific survey-adjusted average costs from the MEPS.[6] More in-depth information on how the cost estimates were constructed from these sources is available elsewhere[1] and in a technical appendix available on request.

Survey Analysis

Data from the NHIS[7] and the MEPS[6] were also used to supplement data on costs of autism and to also compute average costs for use in deriving the incremental costs of autism. Because confidentiality concerns constrain the MEPS to only report the first 3 digits of diagnosis codes, individuals with an *International Classification of Diseases, Ninth Revision* (*ICD-9*) diagnosis code of 299, which includes autism diagnoses (299.0*x*) as well as disintegrative psychoses (299.1*x*) and early childhood psychoses (299.8*x*/299.9*x*), were used as proxies for individuals with autism. Specific autism questions were available in the NHIS during 1997-2000. Information from those questions was combined with an *ICD-9* diagnosis code of 299 in the NHIS and was linked to the MEPS to increase the number of usable cases. Survey-adjusted means for expenditures were then computed as described earlier. Further information is available elsewhere[1] and from the technical appendix.

INDIRECT COSTS

Productivity losses for people with autism were estimated by combining standard average work-life expectancies for all men and women taken from the economics literature (ages 23-57 years for men and 23-53 years for women),[34] with average income and benefits (from Tables 696 and 628 of the *Statistical Abstract of the United States*[36]) and estimates of age- and sex-specific labor force participation rates.[38] Average incomes are projected for future years based on estimated productivity growth rates[35] to estimate average total earnings and benefits at each age. These estimates are adjusted for the fact that while some adults with autism are unable to work, others are (35% of adults with lower levels of disability and 10% of adults with higher levels of disability work in supported work environments). Finally, the lost value of sex-specific household services is added.[3,39] These estimates do not account for the effects of taxes or lost leisure time. Similar methods were used to estimate productivity for parents. Fathers of children with lower levels of disability were assumed to be unemployed 10% of the time (and working full-time during the remaining 90%) and mothers were assumed to be unemployed 55% of time (and were working half-time 25% of the time and full-time, 20%).[40,41] Fathers of children with higher levels of disability were assumed to be unemployed 20% of the time and mothers were assumed to be unemployed 60% of time (and were working half-time 30% of the time and full-time, 10%). These assumptions were combined with the same average earnings, benefits, productivity growth, labor force participation rates as used for individuals with autism, and the appropriate work-life expectances. These estimates assumed households in which both a mother and a father care for 1 child with autism. These estimates will differ based on different family configurations.

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Table 1. Age-Specific and Lifetime per Capita Incremental Societal Costs of Autism*

Age Group, y	Average Per Capita Cost per Age Group: Direct Medical	Direct Nonmedical	Indirect	Total Per Capita Cost
3-7	35 370	10 805	43 066	446 203
8-12	6013	15 708	41 138	314 297
13-17	5014	13 550	38 453	285 082
18-22	2879	10 720	36 090	248 446
23-27	1574	27 539	51 740	404 260
28-32	1454	23 755	35 757	304 828
33-37	1389	20 492	30 852	263 662
38-42	1283	17 676	29 132	240 457
43-47	1440	15 248	26 600	216 439
48-52	1447	13 152	24 531	195 650
53-57	1290	11 292	17 776	151 790
58-62	1218	9489	0	53 535
63-66	1027	7908	0	35 738
Total lifetime costs	305 956	978 761	1 875 667	3 160 384

*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.

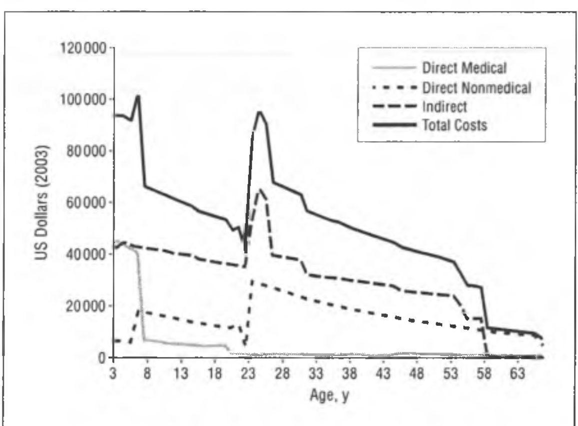

Figure 1. Age distribution of incremental societal costs of autism (present value).

CALCULATING COSTS

To the extent possible, cost estimates were derived for higher- and lower-functioning individuals as they were presented in the literature. Semidependent, independent, or those individuals described as having high-functioning autism were classified in the higher-functioning category. Dependent individuals or those not described as having high-functioning autism were classified in the lower-functioning category. Based on data presented in Fombonne,[42] the prevalence of higher-functioning autism is assumed to be 54%. The male-female ratio is assumed to be 4:1. Weighted average per capita costs were computed based on the assumed distribution of lower- and higher-functioning status and the male-female ratio. Age 3 years was considered to be the baseline age (age at diagnosis) and 2003 was the baseline year. Because there is some evidence that people with autism have reduced life expectancies,[43-46] costs were tabulated through age 66 years for males and through age 65 years for females. Costs were discounted to present value (to age 3 years) using a discount rate of 3% as recommended by the Panel on Cost-effectiveness in Health and Medicine.[8] Costs in future years were discounted, or deflated, to reflect the time value of money: a dollar today is worth more than a dollar in the future. In doing so, all costs were adjusted for the different periods in which they were incurred. In other words, dollars at different ages become comparable. Because health care resource investments, such as in the case of autism research and treatment budgets, incur costs in the present and potentially realize the benefits in the future, it is common to discount future flows of costs (and benefits) to present value. Although 3% is the currently used standard for a discount rate, this rate is varied in the sensitivity analyses described in the next subsection.

SENSITIVITY ANALYSES

In previous work, the robustness of the overall cost estimates was assessed using 1-way sensitivity analyses and conclusions were mostly robust to changes in many key parameters.[1] However, the total costs were found to be most sensitive to changes in the discount rate and to changes in the assumed level of indirect costs. Because variations in indirect costs will not substantially change the pattern of costs over the life cycle, herein focus is placed on the discount rate.[8] The discount rate is varied between 2% and 5% as suggested by Gold et al.[8]

DEFINITION OF AUTISM

Many of the sources of data simply used the term *autism* and did not differentiate between the different autism spectrum disorders. Reflecting the literature, the term *autism* herein is used in an inclusive manner to mean all disorders in the spectrum. Given the nature of many of the nonmedical and indirect costs, it is likely that those costs are more representative of more disabled individuals. Older sources[9] may have only included lower-functioning children and individuals in their definitions of autism. However, varying the proportions of lower- and higher-functioning individuals does not substantially change conclusions about overall lifetime costs.[1]

RESULTS

In the Tables that follow, the average per capita costs by category are presented in 5-year intervals (the full Tables

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Table 2. Age-Specific and Lifetime per Capita Incremental Societal Direct Costs of Autism*

Age Group, y	Average per Capita Cost per Age Group						
	Physician and Dental	Drugs	CAM Therapies	Behavioral Therapies	Emergency and Hospital	Home Health	Travel
3-7	1147	147	198	32 501	828	467	81
8-12	577	153	109	4033	768	303	70
13-17	435	131	50	3479	591	267	60
18-22	426	129	33	1254	852	132	52
23-27	496	124	28	0	774	106	45
28-32	507	114	25	0	682	87	39
33-37	547	98	21	0	598	93	33
38-42	540	84	18	0	522	90	29
43-47	765	72	16	0	426	137	25
48-52	845	61	14	0	352	154	21
53-57	851	52	12	0	292	65	18
58-62	810	44	10	0	323	14	16
63-66	632	34	9	0	301	39	14
Total lifetime costs	42 259	6180	2704	206 337	36 235	9738	2503

Abbreviation: CAM, complementary and alternative medicine.
*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.

Table 3. Age-Specific and Lifetime per Capita Incremental Societal Direct Nonmedical Costs of Autism*

Age Group, y	Average per Capita Cost per Age Group						
	Child Care	Adult Care	Respite Care	Home Improvements	Special Education	Supported Work	Other
3-7	4636	0	1100	161	4585	0	323
8-12	3999	0	948	139	10 343	0	278
13-17	3450	0	818	120	8922	0	240
18-22	2907	0	706	10	6247	0	851
23-27	0	25 064	0	9	0	836	1630
28-32	0	21 620	0	8	0	721	1406
33-37	0	18 650	0	7	0	622	1213
38-42	0	16 087	0	6	0	537	1046
43-47	0	13 877	0	5	0	463	903
48-52	0	11 970	0	4	0	399	778
53-57	0	10 326	0	4	0	291	672
58-62	0	8907	0	3	0	0	579
63-66	0	7423	0	3	0	0	483
Total lifetime costs	74 963	662 192	17 858	2388	150 483	19 349	51 528

*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.

are available as eTables 1-4 at http://archpediatrics.com). **Table 1** and **Figure 1** display the incremental societal direct medical, direct nonmedical, and indirect costs. Direct medical costs are quite high for the first 5 years of life (average of around $35 000), start to decline substantially by age 8 years (around $6000), and continue to decline through the end of life to around $1000. Direct nonmedical costs vary around $10 000 to approximately $16 000 during the first 20 years of life, peak in the 23- to 27-year age range (around $27 500), and then steadily decline to the end of life to around $8000 in the last age group. Indirect costs also display a similar pattern, decreasing from around $43 000 in early life, peaking at ages 23 to 27 years (around $52 000), and declining through the end of life to $0.

Table 2 displays the individual components of the incremental societal direct medical costs. Considered over the entire life span, direct medical costs make up 9.7% of total discounted lifetime costs. Behavioral therapies, which are the largest component of direct medical costs, make up 6.5% of total discounted lifetime costs.[1] However, behavioral therapies, as presented herein, are only relevant for children 19 years or younger. 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 $4000 in the 8- to 12-year age group to around $1250 for the 18- to 22-year age group. Physician and dental costs are initially high, then decrease, but increase again in later life. Prescription drugs, complementary and alternative therapies, and hospital and emergency services are also relatively

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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	43 066
8-12	0	41 138
13-17	0	38 453
18-22	0	36 090
23-27	32 703	19 036
28-32	32 620	3136
33-37	30 852	0
38-42	29 132	0
43-47	26 600	0
48-52	24 531	0
53-57	17 776	0
58-62	0	0
63-66	0	0
Total lifetime costs	971 072	904 595

*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.

high initially but steadily decline. Some costs decline less smoothly than others because of different availability of cost-by-age estimates in the literature.

Table 3 displays the individual components of the incremental societal direct nonmedical costs. Nonmedical costs, except during ages 3 to 7 years, are more expensive than direct medical costs and make up 31% of total discounted lifetime costs.[1] Different costs become relevant at different ages, which contributes to the dips and spikes in the direct nonmedical line in Figure 1. Child care and respite costs, which average about $5700 in early ages to around $3600 at ages 18 to 22 years, contribute far less (3% of total discounted lifetime costs) than adult care costs (21% of total discounted lifetime costs), which range from around $25 000 at ages 23 to 27 years to around $7400 at ages 63 to 66 years. Special education costs, which make up 4.8% of total discounted lifetime costs, range from around $12 000 at age 6 years (costs for ages 3-5 years are assumed to be zero) to around $6200 at ages 18 to 22 years, and supported employment costs range from around $800 at ages 23 to 37 years to around $300 at ages 53 to 57 years (age 57 years is the assumed end of working life).

Table 4 displays the components of the incremental societal indirect costs. Indirect costs are by far the largest component of the total incremental societal costs of autism (59.3% of total discounted lifetime costs).[1] Own indirect costs, which make up 30.7% of total discounted lifetime costs, range from around $33 000 at ages 23 to 27 years to around $18 000 at ages 53 to 57 years. Not own (assumed herein to be parents') indirect costs, which make up 28.6% of total discounted lifetime costs, range from around $43 000 at ages 3 to 7 years, when parents are assumed to be about 33 to 37 years of age, to around $19 000 at ages 23 to 27 years, when parents are assumed to be 53 to 57 years of age, to around $3000 per year for the next 5 years until the end of the average work life. Although total indirect costs spike at ages 23 to 27 years, because of the overlapping own and not own indirect costs, as **Figure 2** indicates, at any given time from age 3 years through age 57 years, there is a substantial and smoothly declining level of indirect costs. Figure 2 also dramatically illustrates, at least for this model, the transition from exclusive parental lost productivity almost immediately to lost own productivity.

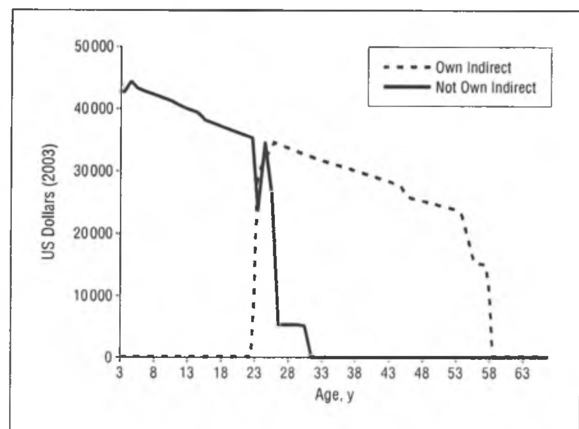

Figure 2. Age distribution of own and not own indirect incremental costs (present value).

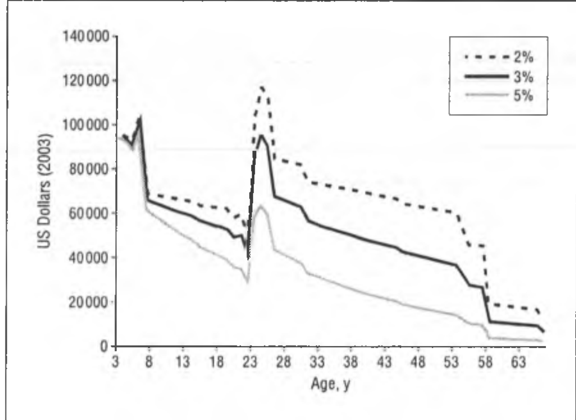

Figure 3. Age distribution of total incremental societal costs of autism computed at different discount rates.

SENSITIVITY ANALYSES

Sensitivity analyses using 2% and 5%, which are common upper and lower bounds, reveal that the patterns of age-specific expenditures are similarly shaped. **Figure 3** displays total costs using 2%, 3%, and 5% as the discount rates. There is an inverse relationship between the discount rate and the weight placed on future costs: lower discount rates place greater weight on future costs and higher rates place less weight on future costs. As a result, total present value costs will be larger the smaller the discount rate. The maximum difference in total costs between the 5% scenario and the 2% scenario (about $53 000) occurs at age 24 years and the average difference in costs between the 5% and 2% scenarios is about $31 000.

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COMMENT

This article presents the first description, to my knowledge, of the societal costs of autism in the United States across all ages of the life span and contributes not only to the literature on the costs of autism but also to the literature on age-specific health care costs in general. As was previously reported, the total annual societal per capita cost of caring for and treating a person with autism in the United States was estimated to be $3.2 million and about $35 billion for an entire birth cohort of people with autism.[1] Sensitivity analyses revealed that these lifetime costs could range from $13 billion to $76 billion depending on the underlying assumptions of the model. Although those estimates are highly conservative because they exclude a number of important elements (such as legal costs that families incur to secure services[47,48]; lost productivity of those other than parents; the costs of genetic testing; the full costs of alternative therapies, including diets; the costs of adverse outcomes of potentially dangerous treatment modalities; and costs associated with immunization-avoidance behaviors[48]), they are valuable because they add information to a relatively underdeveloped literature. As treatment and, perhaps prevention, strategies are developed, knowledge of when costs are incurred relative to when benefits are expected is important for clinical decision-making and cost-effectiveness analysis efforts.

Knowledge about age-specific per capita incremental societal costs is particularly important because, as opposed to the summary lifetime data presented previously,[1,25,47] age-specific data illuminate the relative magnitudes of different types of costs at different ages. Given that at different ages different segments of society are responsible for absorbing these costs, this detailed disaggregation of costs can provide even more valuable information to planners, policy makers, and even to families making decisions that can affect current and future financial health, especially as they consider the fact that at various points in the life cycle different costs are more germane than others.

Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. Adult care, which has the largest lifetime cost of all direct costs, is typically more than 5 times larger than the next 3 largest costs, which include care incurred during childhood (behavioral therapies, child/respite care, and special education). Alemayehu and Warner[49] reported that the typical American spends about $317 000 over his or her lifetime in direct medical costs, incurring 60% of those costs after age 65 years. In contrast, people with autism incur about $306 000 in incremental direct medical costs, implying 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.

These results, especially on the substantial costs resulting from lost productivity of both individuals with autism and their parents and from rather large adult care costs, have important implications for those aging members of the baby boom generation approaching retirement. As those individuals retire, many of their adult children with autism will be transitioning into adult care settings. Those costs, combined with very limited to nonexistent 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. Perhaps physicians and other care professionals should consider recommending that parents of children with autism seek financial counseling to help plan for the transition into adulthood.

Although this study is limited by a number of factors, it is the first of its kind, to my knowledge, and can shed insight into the lifetime distribution of autism costs and also motivate future, more rigorous studies. The cost model presented herein is based on a number of simplifying assumptions and relies on sometimes incomplete and old information. These caveats should be kept in mind when using these estimates for policy or practice decision making. The results presented herein for direct medical costs are consistent with recently published data on health care use and costs for children with autism. Gurney et al[50] reported that, relative to children without autism, children with autism, as reported by their parents, experience a significantly higher number of preventive visits and emergency and nonemergency hospital visits. Croen et al[51] reported, based on administrative data from the Northern California Kaiser Permanente Medical Care program, that children with autism incurred 2.5 times as much outpatient costs, 2.9 times as much inpatient costs, and 7.6 times as much medication costs as randomly selected children without autism. Pursuing a research agenda of both carefully and systematically documenting the costs of autism in the United States can be helpful in improving these estimates. Prospectively tracking the life experiences of individuals with autism and their families and obtaining a wide variety of data on the different sources of services for people with autism can provide this more complete picture. Prospectively collected clinical and quality-of-life data combined with cost data will be even more useful for understanding the societal costs, both financial and nonfinancial, of caring for those members of our society with autism at every age of the life course.

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March 4, 2011

Actuarial Cost Estimate: Alaska House Bill 79 and Senate Bill 74

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

OLIVER WYMAN

Prepared By:

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Contents

1. Executive Summary 1

2. Background 3

3. Scope and Limitations 4

4. Description of Key HB 79 / SB 74 Provisions and their Impact on Covered Benefits . 5

5. Modeling Methodology 7
   - Modeling Perspective 7
   - Emerging Cost Experience for Autism Coverage 8
   - General Modeling Process 9

6. Summary of Key Assumptions 10
   - Treated Prevalence and Age at Diagnosis 10
   - ABA Program Utilization and Cost 12
   - Other (than ABA) Medical Costs 15
   - Administrative Costs 15
   - Alaska Market Data 15

7. Cost Estimates 17
   - Long-Term Cost Estimates - "Middle" Cost Scenario 17
   - Scenario Estimates 18
   - Short-Term Cost Estimates by Scenario 18
   - Individual Market Comment 18

8. Cost – Benefit Analysis for ASD Treatments 19
   - Societal Costs of Autism- Ganz Report 19
   - Cost Savings to State and Local Governments 20

Appendix

Cost Assumptions – Illustrative Exhibits, and 22

HB 79 / SB 74 Text 22

1

Executive Summary

Oliver Wyman Actuarial Consulting, Inc. (Oliver Wyman) 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) under Alaska House Bill 79 and Senate Bill 74, which are identical bills that will be referred to as "HB 79 / SB 74" throughout this report.

The most significant class of treatments covered under HB 79 / SB 74 are behavioral health treatments, which are referred to as applied behavior analysis, or "ABA" throughout this document since ABA is one of the most common behavioral health treatments and the general approach and costs for ABA are assumed to be similar to those of other behavioral health treatments. The key provisions of HB 79 / SB 74 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 0.39% of premiums and premiums would increase about 0.45% should HB 79 / SB 74 be enacted. Our estimated range of long-term premium increases is 0.28% to 0.68% 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 79 / SB 74, with first year cost increases in the range of 0.09% to 0.45% 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 first covered. 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.

Long-Term Cost Estimates - "Middle" Cost Scenario

	Market			
	Individual	Small Group	Large Group	All
Covered Persons	25,000	39,000	52,000	116,000
Average Premium per Person	$2,800	$5,500	$4,700	$4,559
Annual Claim Cost per Covered Person	$17.60	$17.60	$17.60	$17.60
Claim Cost as a Percentage of Premium	0.63%	0.32%	0.37%	0.39%
Estimated Premium Increase with Admin @ 15%	$20.70	$20.70	$20.70	$20.70
Premium Increase as a Percentage of Premium	0.74%	0.38%	0.44%	0.45%

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	% Autistic Disorder Diagnosed Under Age 6 Starting ABA	Program Cost - Autistic Disorder (Ages 0-6)	Avg. Annual non-ABA Cost	Premium Increase per Covered	Premium Increase (% of Premium)
Low	50.0%	$50,000	$2,350	$12.80	0.28%
Middle	65.0%	$65,000	$3,525	$20.70	0.45%
High	80.0%	$83,718	$4,700	$30.90	0.68%

While this analysis focused primarily on estimating the insured costs of covered medical benefits associated with HB 79 / SB 74, 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.

Based on the results of several studies, we expect that the costs of ABA treatments covered under HB 79 / SB 74 could be recovered through reductions in educational and medical expenditures alone. We also expect that benefits associated with successful treatments would reduce future costs of caring for individuals with ASD, and improve both the productivity and the quality of life for individuals with ASD, as well as their family caregivers.

2

Background

Oliver Wyman Actuarial Consulting, Inc. (Oliver Wyman) has been engaged by Autism Speaks to develop a cost model in order to analyze and estimate the impact of legislation providing for additional 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 of HB 79 / SB 74 on insurance premiums, which provides coverage for the diagnosis and treatment of autism spectrum disorders.

Oliver Wyman is a part of the Marsh & McLennan 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 fourteen 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 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 79 / SB 74 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 incremental insured costs of the ASD benefits provided for in HB 79 / SB 74 and the associated premium impact on the individual, small group, and large group markets affected by HB 79 / SB 74. This analysis also identifies and partially quantifies identified offsetting cost savings associated with successful ASD treatment.

We note that cost estimates associated with autism coverage legislation have varied widely state to state based on state specific differences in legislation and the methods and assumptions used in estimating costs, though typically independent estimates show premium increases due to legislation covering additional autism benefits of less than 1%. A March 2009 report by 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 79 / SB 74 is due to the coverage of behavioral therapies, including applied behavior analysis (ABA), which is almost universally excluded from health coverage, and therefore very little mature 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 reflects the likely behavior of consumers, providers and insurers of ABA services in developing the assumptions underlying the cost estimates. Likewise, the additional costs for medical services other than ABA are uncertain. Insurance policies often cover some services for children diagnosed with an ASD, although the legislation could cause the insured costs for certain services to increase because ASD exclusions or limitations are common, and certain services that may have been initially denied or terminated following utilization review or benefit limitations might be covered due to HB 79 / SB 74.

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

4

Description of Key HB 79 / SB 74 Provisions and their Impact on Covered Benefits

Insurance Markets Covered by HB 79 / SB 74

The Bills state: *"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 our modeling we are assuming that this means that HB 79 / SB 74 applies to health insurance contracts in the individual, small group, and large group markets.

Covered Benefits

HB 79 / SB 74 provides for the diagnosis and treatment for autism spectrum disorders, where covered services are outlined in the following language:

"Covered treatment may include medically necessary pharmacy care, psychiatric care, psychological care, habilitative or rehabilitative care, and therapeutic care."

"'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"

The inclusion of applied behavior analysis (ABA), and other behavioral therapies is especially important, and the coverage of these types of programs has the most significant impact on the cost of covered benefits under HB 79 / SB 74.

ABA may include 30-40 hours of therapy a week, though many programs would not utilize that level of resources. Key assumptions underlying our ABA cost estimates which also consider costs of other intensive programs are outlined in Section 6.

5

Modeling Methodology

The following discussion 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 the Appendix.

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 ASD services and for parents of autistic children to aggressively seek treatment of their children's disorders.

In spite of these real limitations that will likely limit short-term costs associated with autism benefits covered due to HB 79 / SB 74, 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 following discussion outlining our cost estimates, we have included illustrative exhibits showing the possible progression of costs for additional covered 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.

Emerging Cost Experience for Autism Coverage

While actual cost experience is limited, there have been some examples of emerging experience reported in various forums that are indicative of the costs of autism insurance laws being modest. These examples of emerging experience are not inconsistent with the cost estimates in this report.

South Carolina State Health Plan – Calendar year 2010 costs of approximately $2 million for 350,000 to 390,000 members. This represents an increase of about 0.1% to 0.2% in medical costs.[2]

The Ohio State University[3]
Percentage of Claim Cost Experienced by OSU Managed Health Care Systems Inc. (MHCS) for Autism Treatment:
2006 0.15%
2007 0.15%
2008 0.12%

Aetna Texas- Comments to press indicated increased costs equal to approximately 0.1% of premium in the year after the Texas autism law was enacted. Aetna noted in December 2008 that it had tracked the cost of the autism coverage legislation 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 legislation might change after the first year.[4] While this is only first year experience for a single insurer, it illustrates that initial costs after the passage of autism insurance legislation are likely low. Aetna's Texas block of business is quite large (approximately $1.5 - 2.0 billion in premium[5]), so the statistics provided indicate a cost of less than 0.1% of premium.

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[2] APS Healthcare South Carolina state employees' plan experience.

[3] Robert Meier Ohio legislature testimony submitted March 17, 2009.

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

[5] NAIC Annual Statements for 2007.

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, and Asperger's Syndrome) were estimated separately, since diagnosis patterns and service utilization could reasonably be expected to vary by how severely affected an individual with ASD is and 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.[6]
4. The percentage of diagnosed children who could be expected to have an ABA program was estimated for each age based on assumptions regarding the percentage of children that 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 the potential increase in costs that could be expected due to HB 79 / SB 74 benefits.
8. Based on Census demographic data and the cost estimates associated with HB 79 / SB 74's coverage of ASD services by age as outlined in 1-7 above, an annual cost per covered person was developed.
9. The cost of services was increased to reflect administrative and other insurer costs or profit charges.
10. The estimated size of the covered market was developed based on Census, Medical Expenditure Panel Survey (MEPS) enrollment and premium information for Alaska, and Kaiser Family Foundation coverage data. These assumptions are further explained and documented in Section 6.
11. The incremental costs of the ASD 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.

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[6] IAN database. http://dashboard.ianexchange.org/StateStatsAdvanced.aspx?A1=OR&ADU=T. Accessed January 2011.

6

Summary of Key Assumptions

Key assumptions underlying the cost estimates for the proposed HB 79 / SB 74 covered 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[7] 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.*[8]

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.*[9] A prevalence rate of 9 per 1,000 is approximately 1 in 110.

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[7] Centers for Disease Control and Prevention. Morbidity and Mortality Weekly Report. December 18, 2009. http://www.cdc.gov/mmwr/PDF/ss/ss5810.pdf. Accessed February 2011.

[8] Ibid, p. 1.

[9] 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.*[10]

4. *Among all children meeting the ADDM ASD surveillance case definition, approximately 77% had a documented ASD classification in their records.*[11]

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.*[12]

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 meeting the ADDM ASD surveillance case definition 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 9.0/1,000 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 7.5/1,000, 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 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.

[10] Ibid, p. 7.

[11] Ibid, p. 9.

[12] Ibid, p.7.

Prevalence by diagnostic subtype was estimated based on an academic study published in the American Journal of Psychiatry.[13] 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,[14] 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 may have difficulty accessing a provider. We also note that the most severely affected children with the diagnostic subtype of Autistic Disorder will be more likely to have behavioral programs than those with PDD-NOS or Asperger's and will also, on the whole, have more intensive programs.

For this reason, we have assumed that 50% to 80% of children with Autistic Disorder (50% for "Low" scenario, 65% for "Middle" and 80% for "High") diagnosed under age six 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. As noted later, we make an adjustment to reflect lower cost estimates for PDD-NOS and Asperger's. Implicit in that adjustment is an expectation of lower ABA utilization for these two diagnostic subtypes.

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

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

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[15], which is lower than assumed in each 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 such that a program is no longer necessary or if the insurer or family sees no progress, as well as for other reasons.

The assumed percentage of children diagnosed with Autistic Disorder that have an ABA program by age for our "Middle" scenario is shown in the table below:

% of Diagnosed Children with Autistic Disorder with ABA	
Under 6	65.0%
6	48.8%
7	32.5%
8	21.7%
9	14.4%
10	9.6%
11	6.4%
12	4.3%
13 to 21	3.3%

<u>ABA Program Annual Number of Hours</u>

In developing the assumed annual ABA program hours, we discussed typical ABA programming with ABA providers, and reviewed benefit materials from one of the large self-insured employer who offers ABA benefits.[16] We developed a distribution of expected hours for a child with Autistic Disorder that resulted in the annual averages shown in the following table:

[15] 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.
[16] Autism Therapy Reference- Microsoft Corporation (administered by Premera Blue Cross).

Average Annual ABA Program Hours for a child with Autistic Disorder

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 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[17] health care wage data. The resulting average cost per hour of ABA therapy in Alaska is about $56 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. Costs will vary, as well, depending upon the degree of care management employed by a given payer.

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 for a child with Autistic Disorder being treated with an intensive ABA program as follows:

"Low" cost scenario - assumes average ABA program cost is $50,000 per year.
"Middle" cost scenario - assumes average ABA program cost is $65,500 per year.
"High" cost scenario - based on the assumptions outlined in this section for the continuance of ABA programming, 1,500 annual hours for ABA programming for children younger than age 8, and an hourly rate of slightly under $56, the calculated average annual cost for an ABA program for all ages is $83,718.

After developing cost estimates for ABA for children diagnosed with Autistic Disorder, we assumed that for children diagnosed with PDD-NOS or Asperger's, ABA costs would be one-third of the Autistic Disorder costs. The basis for this adjustment is that children with these two diagnoses can be expected to utilize ABA programs at a significantly lower rate than those with Autistic Disorder, and have less intensive programs (i.e., programs with fewer weekly and annual therapy hours). The one-third factor applied to overall costs reflects the combination of lower utilization and fewer therapy hours.

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[17] BLS wage data. http://www.bls.gov/guide/geography/wages.htm. Accessed January 2011.

Other (than ABA) Medical Costs

Based on several studies[18], 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 under HB 79 / SB 74 some services that an insurer could currently deny or exclude would now be covered. In our range of estimates, we assumed that this additional coverage would result in increased insured medical costs of 50% to 100% of the current level of estimated covered non-inpatient costs for services to all children diagnosed with an ASD, which we assumed are currently three times higher than the population costs in the absence of the benefits under HB 79 / SB 74 for children/dependents under age 21 diagnosed with an ASD.

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 HB 79 / SB 74 are shown for each scenario in the table below:

Scenario	Non-ABA Costs
Low	$2,350
Middle	$3,525
High	$4,700

(Amounts in 2011 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 2009[19], so we trended this data based on average recent employer premium increases provided in the Kaiser Family Foundation HRET[20] survey to estimate the 2011 average annual premium per member necessary to compute the cost of HB 79 / SB 74 benefits as a percentage of annual premiums.

To estimate average premiums for the individual market, we reviewed the 2009 individual premium and membership experience found in the regulatory filings for insurers in Alaska.

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

[19] MEPS state survey data. http://www.meps.ahrq.gov/mepsweb/data_stats/state_tables.jsp?regionid=-1&year=2009. Accessed January 2011.

[20] Kaiser Family Foundation and Health Research Educational Trust. Employer Health Benefits- 2010 Annual Survey.

We calculated the average individual premium for 2009 in Alaska, and again trended this amount to estimate 2011 premiums.

As part of our development of premiums and membership estimates, we completed reasonableness tests by reviewing Alaska insurer regulatory filings to ensure that the premium estimates were not unreasonable.

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 additional benefits provided by HB 79 / SB 74 would be about 0.45% of insured premiums across all markets. However, we expect that costs would be lower in the years immediately following the passage of HB 79 / SB 74 based on experiences in other states that have passed legislation providing for the coverage of additional ASD benefits, lags typically seen in accessing new benefits, and the limited supply of ABA providers.

The estimated cost increases by market are shown in the table below. The annual claim cost per covered person estimate of $17.60 and premium increase estimate of $20.70 are in 2011 dollars.

	Market			
	Individual	Small Group	Large Group	All
Covered Persons	25,000	39,000	52,000	116,000
Average Premium per Person	$2,800	$5,500	$4,700	$4,559
Annual Claim Cost per Covered Person	$17.60	$17.60	$17.60	$17.60
Claim Cost as a Percentage of Premium	0.63%	0.32%	0.37%	0.39%
Estimated Premium Increase with Admin @ 15%	$20.70	$20.70	$20.70	$20.70
Premium Increase as a Percentage of Premium	0.74%	0.38%	0.44%	0.45%

We expect that state government programs covering state employees would have claims costs and claims cost increases comparable to insured large groups.

Scenario Estimates

As discussed in Section 3, limited insurance data exists that can be used to directly estimate the costs of ABA benefits under HB 79 / SB 74. 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	% Autistic Disorder Diagnosed Under Age 6 Starting ABA	Program Cost - Autistic Disorder (Ages 0-6)	Avg. Annual non-ABA Cost	Premium Increase per Covered	Premium Increase (% of Premium)
Low	50.0%	$50,000	$2,350	$12.80	0.28%
Middle	65.0%	$65,000	$3,525	$20.70	0.45%
High	80.0%	$83,718	$4,700	$30.90	0.68%

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 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 79 / SB 74						
Scenario	Year 1	Year 2	Year 3	Year 4	Year 5	Years 6 and Beyond
Low	0.09%	0.13%	0.17%	0.21%	0.24%	0.28%
Middle	0.23%	0.27%	0.32%	0.36%	0.41%	0.45%
High	0.45%	0.50%	0.54%	0.59%	0.63%	0.68%

Individual Market Comment

Completing an assessment of the potential for anti-selection to increase premium rates in the individual market under HB 79 / SB 74 is complicated for several reasons. Notably, the recent passage of Federal health care reform legislation has guaranteed issue provisions that would impact the coverage of individuals with ASD in the individual market. Therefore, a detailed analysis of the individual market is complicated by several matters, and is beyond the scope of this review.

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 which 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.[21] 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 Health Care
- Travel

[21] 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[22]:

> *"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*

[22] 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:

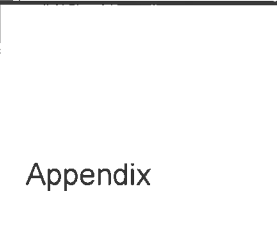
Table 3: Multiple Studies Demonstrate Children Who Receive Intensive Treatment Fare Better Than Those Who Receive Less Intensive Services

	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.

While a complete cost-benefit analysis is beyond the scope of this review, under the assumption that the costs of ASD services and efficacy of EIBI are in line with those indicated in the studies noted, we expect that the costs of ABA treatments covered under HB 79 / SB 74 could be recovered through reductions in educational and medical expenditures, alone.

We 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.



Cost Assumptions – Illustrative Exhibits and HB 79 / SB 74 Text

EXHIBIT I - SUMMARY OF House Bill 79/Senate Bill 74 "MIDDLE" SCENARIO ASSUMPTIONS AND COSTS

State Alaska

Age Limits for Autism Benefits

Minimum None

Maximum 20

Additional Annual Medical Costs for Non ABA Services

Up to age 21 $ 3,525 per person w/ ASD

Annual Limits by Covered Service

	Hours Limit	Max Hours	Dollar Limit	Max $s
ABA	No	-	No	No Cap

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 with Autistic Disorder with ABA

Age	%
Under 6	65.0%
6	48.8%
7	32.5%
8	21.7%
9	14.4%
10	9.6%
11	6.4%
12	4.3%
13 to 21	3.3%

Average Annual ABA Program Hours for a child with Autistic Disorder

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

Average cost of ABA Program (0-6 Year Olds): $65,000

Market	Coverage Estimates			Costs Excluding Administrative Expense			Premium Increase including Admin @ 15%		
	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	25,000	$ 2,800	$ 70,000,000	$ 440,000	0.63%	$ 17.60	$ 518,000	0.74%	$ 20.70
Small Group	39,000	$ 5,500	$ 214,500,000	$ 686,400	0.32%	$ 17.60	$ 808,000	0.38%	$ 20.70
Large Group	52,000	$ 4,700	$ 244,400,000	$ 915,200	0.37%	$ 17.60	$ 1,077,000	0.44%	$ 20.70
Total	116,000	$ 4,559	$ 528,900,000	$ 2,041,600	0.39%	$ 17.60	$ 2,402,000	0.45%	$ 20.70

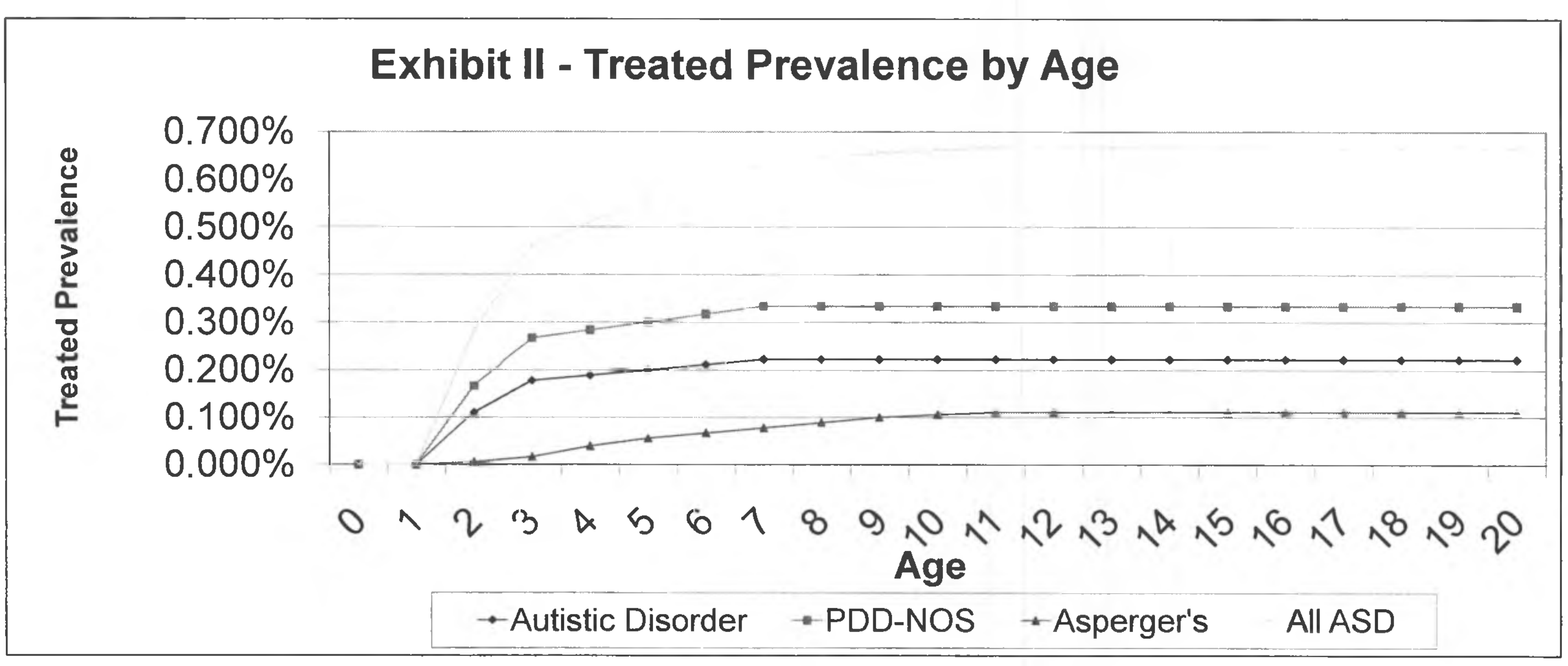


Exhibit II - Treated Prevalence by Age
Treated Prevalence
0.700%
0.600%
0.500%
0.400%
0.300%
0.200%
0.100%
0.000%
0
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
Age
Autistic Disorder
PDD-NOS
Asperger's
All ASD

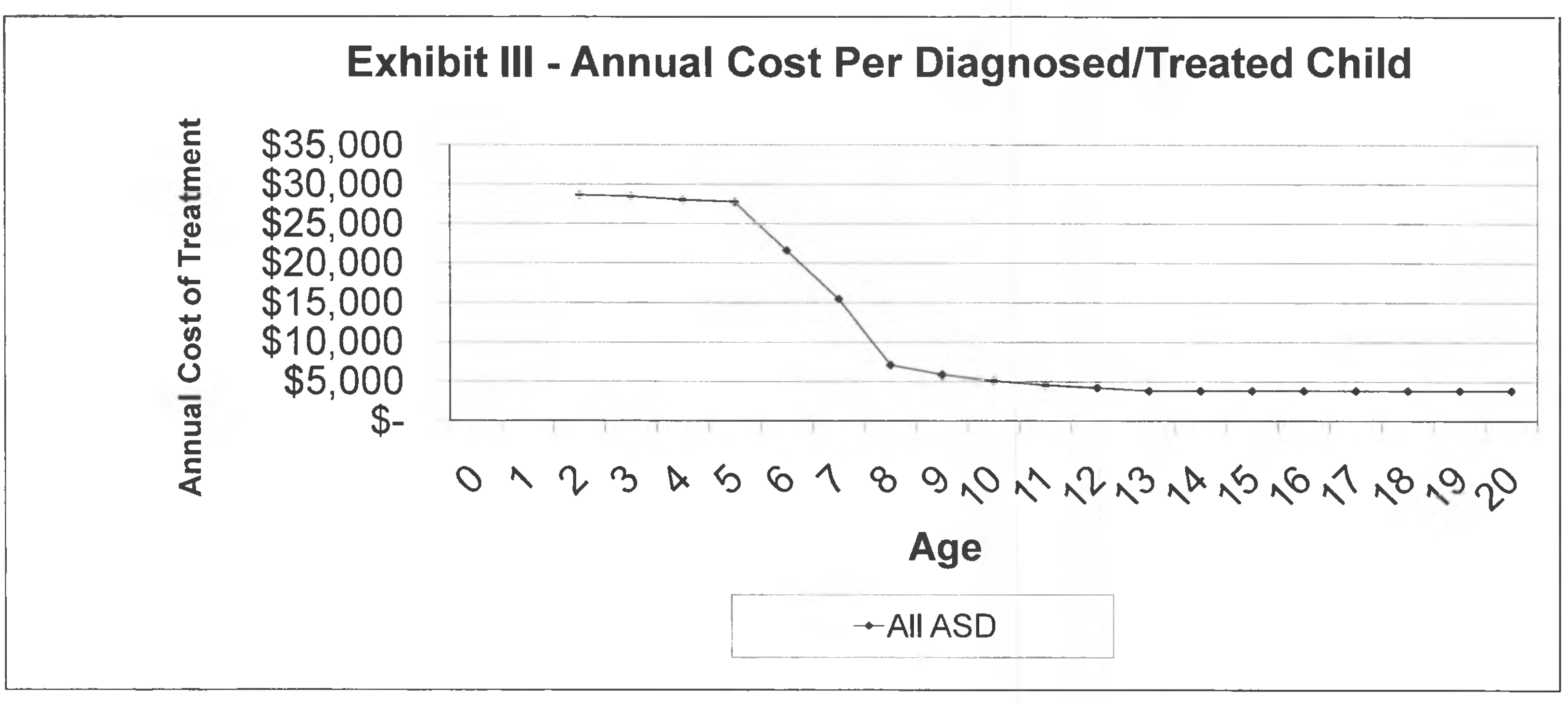


Exhibit III - Annual Cost Per Diagnosed/Treated Child
Annual Cost of Treatment
$35,000
$30,000
$25,000
$20,000
$15,000
$10,000
$5,000
$-
0
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
Age
All ASD

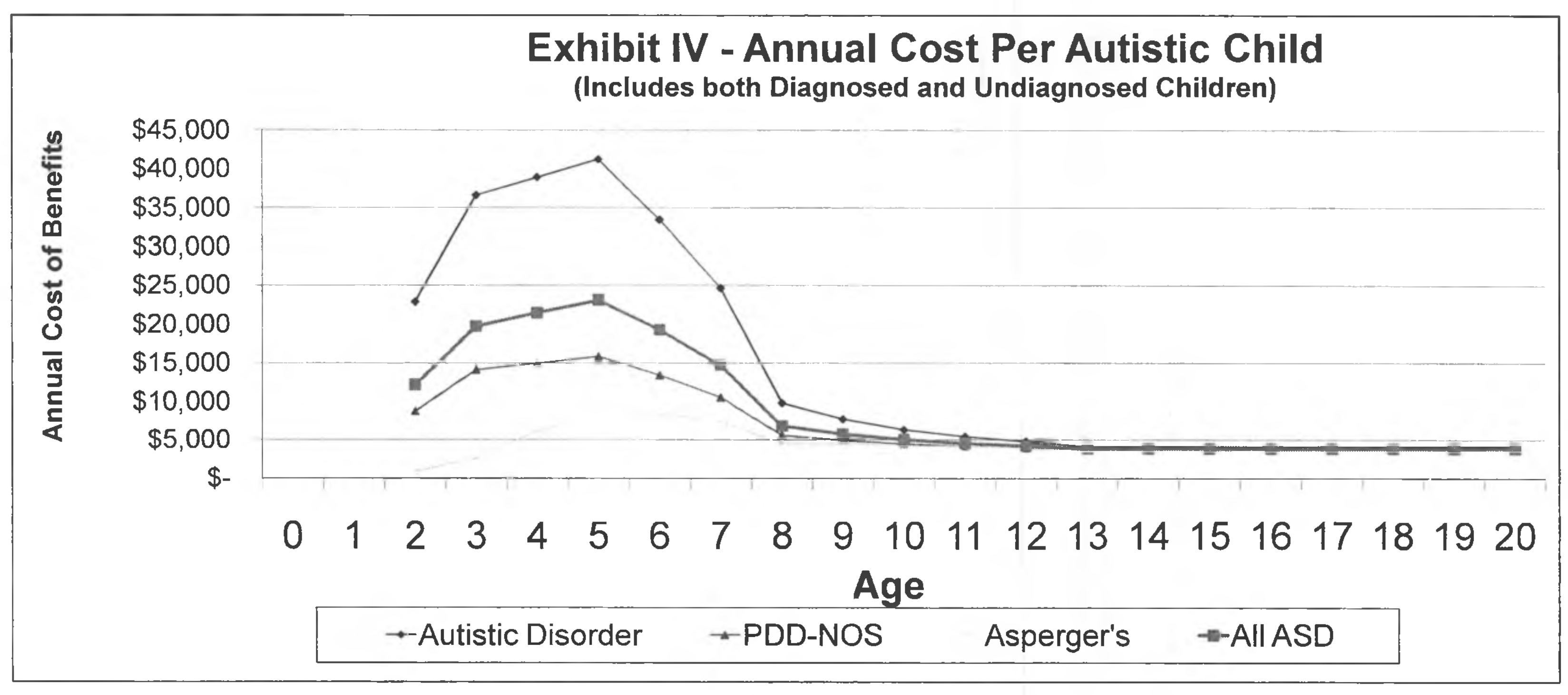


Exhibit IV - Annual Cost Per Autistic Child
(Includes both Diagnosed and Undiagnosed Children)
Annual Cost of Benefits
$45,000
$40,000
$35,000
$30,000
$25,000
$20,000
$15,000
$10,000
$5,000
$-
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
Autistic Disorder
PDD-NOS
Asperger's
All ASD

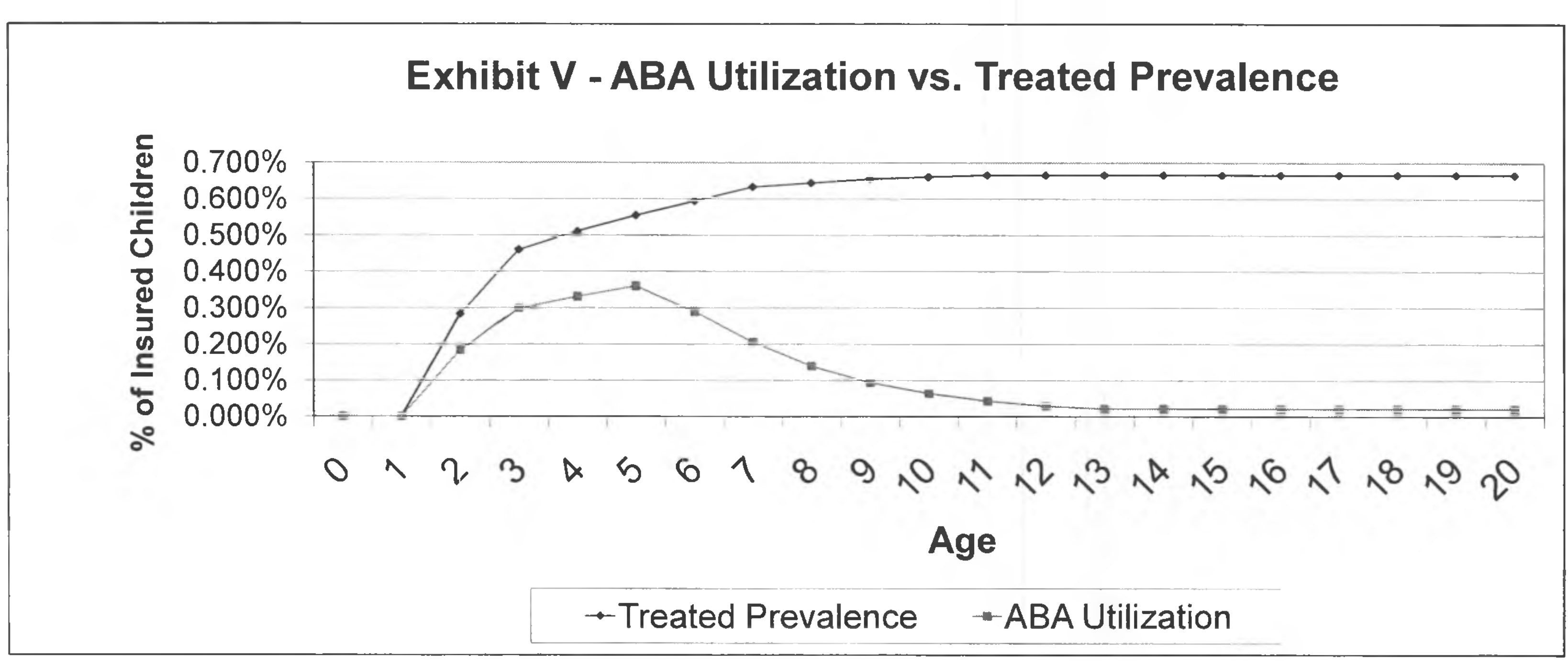


Exhibit V - ABA Utilization vs. Treated Prevalence
% of Insured Children
0.700%
0.600%
0.500%
0.400%
0.300%
0.200%
0.100%
0.000%
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
Treated Prevalence
ABA Utilization

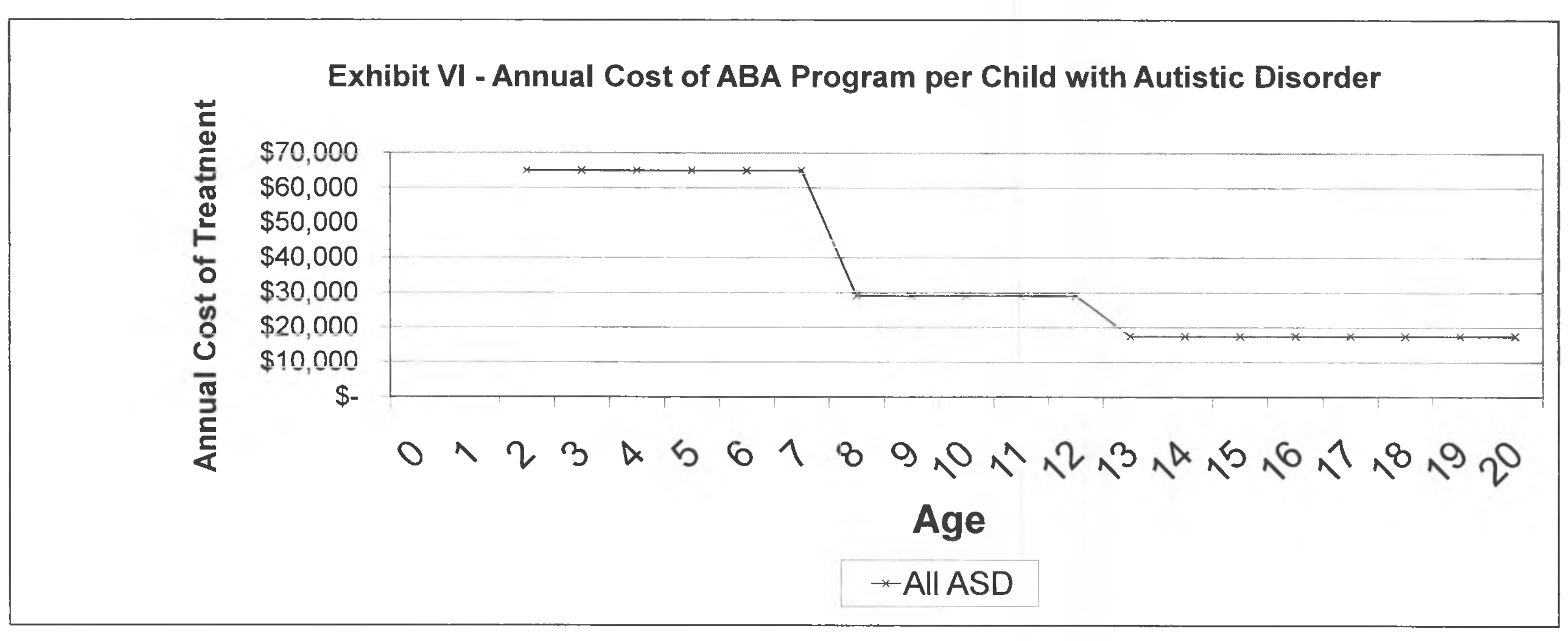


Exhibit VI - Annual Cost of ABA Program per Child with Autistic Disorder
Annual Cost of Treatment
$70,000
$60,000
$50,000
$40,000
$30,000
$20,000
$10,000
$-
0
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
Age
All ASD

HOUSE BILL NO. 79

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-SEVENTH LEGISLATURE - FIRST SESSION

BY REPRESENTATIVES PETERSEN AND KAWASAKI, Gruenberg, Gara, Kerttula, Holmes

Introduced: 1/18/11
Referred: Health and Social Services, Labor and Commerce

A BILL

FOR AN ACT ENTITLED

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

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

5 * **Section 1.** AS 21.42 is amended by adding a new section to read:
6 **Sec. 21.42.397. Coverage for autism spectrum disorders.** (a) Except for a
7 fraternal benefit society, a health care insurer that offers, issues for delivery, delivers,
8 or renews a health care insurance plan in this state shall provide coverage for the costs
9 of the diagnosis and treatment of autism spectrum disorders. Coverage required by this
10 subsection must include treatment prescribed by a licensed physician or psychologist,
11 provided by or supervised by an autism service provider, and as identified in a
12 treatment plan developed following a comprehensive evaluation. Covered treatment
13 may include medically necessary pharmacy care, psychiatric care, psychological care,
14 habilitative or rehabilitative care, and therapeutic care. In this subsection,

1 (1) "habilitative or rehabilitative care" means professional counseling,
2 guidance services, and treatment programs, including applied behavior analysis or
3 other structured behavioral therapies necessary to develop, restore, and maintain the
4 functioning of an individual to the maximum extent practicable; in this paragraph,
5 "applied behavior analysis" means the design, implementation, and evaluation of
6 environmental modifications, using behavioral stimuli and consequences, including
7 direct observation, measurement, and functional analysis of the relationship between
8 environment and behavior, to produce socially significant improvement in human
9 behavior or to prevent the loss of an attained skill or function;
10 (2) "therapeutic care" means services provided by or under the
11 supervision of a speech-language pathologist licensed under AS 08.11 or an
12 occupational therapist or physical therapist licensed under AS 08.84.
13 (b) Coverage under this section
14 (1) is required to be provided only to individuals under 21 years of
15 age;
16 (2) may not limit the number of visits to an autism service provider for
17 treatment;
18 (3) is subject to copayment, deductible, and coinsurance provisions,
19 and other general exclusions or limitations included in a health insurance policy to the
20 same extent as other health care services covered by the policy; and
21 (4) must cover medically necessary treatment that is coordinated with
22 an education program, but may not be contingent on the coordination of treatment
23 with an education program.
24 (c) This section does not limit benefits that are otherwise available to an
25 individual under a health care insurance plan.
26 (d) A health care insurer may not refuse to deliver, execute, issue, amend, or
27 renew coverage to an individual or terminate coverage because the individual is
28 diagnosed with or received treatment for autism spectrum disorders.
29 (e) In this section,
30 (1) "autism service provider" means an individual who is licensed,
31 certified, or registered by the applicable state licensing board or by a nationally

1 recognized certifying organization and who provides direct services to an individual
2 with an autism spectrum disorder;
3 (2) "autism spectrum disorders" means pervasive developmental
4 disorders, or a group of conditions having substantially the same characteristics as
5 pervasive developmental disorders, as defined in the American Psychiatric
6 Association's Diagnostic and Statistical Manual of Mental Disorders-IV-TR, as
7 amended or reissued from time to time;
8 (3) "health care insurance plan" has the meaning given in
9 AS 21.54.500;
10 (4) "health care insurer" has the meaning given in AS 21.54.500;
11 (5) "medically necessary" means any care, treatment, intervention,
12 service, or item prescribed by a licensed physician or psychologist in accordance with
13 accepted standards of practice that will, or is reasonably expected to,
14 (A) prevent the onset of an illness, condition, injury, or
15 disability;
16 (B) reduce or ameliorate the physical, mental, or developmental
17 effects of an illness, condition, injury, or disability;
18 (C) assist to achieve or maintain maximum functional capacity
19 in performing daily activities, taking into account both the functional capacity
20 of the individual and the functional capacity of other persons of the individual's
21 age.
22 * **Sec. 2.** The uncodified law of the State of Alaska is amended by adding a new section to
23 read:
24 APPLICABILITY. AS 21.42.397, enacted by sec. 1 of this Act, applies to a health
25 insurance policy that is offered, issued for delivery, delivered, or renewed on or after
26 January 1, 2012.
27 * **Sec. 3.** This Act takes effect immediately under AS 01.10.070(c).

From: **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 79 Would End Health Care Discrimination Against Children with Autism by Requiring Coverage of Diagnosis and Treatment

NEW YORK, NY (January 27, 2011) – Autism Speaks, the nation's largest autism advocacy organization, today announced its support for House Bill 79, 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).

Sponsored in the Alaska State House by State Representative Pete Petersen, HB 79 includes coverage of behavioral health treatments, such as Applied Behavior Analysis (ABA), an evidence-based, medically-necessary autism therapy, for individuals with autism under the age of 21. HB 79 has been referred to the House Health & Social Services Committee, which may hear the bill next month.

"We applaud and thank Representative Petersen for his leadership again this year on this issue of critical concern to thousands of Alaska's families," said Peter Bell, Autism Speaks executive vice president for programs and services. "Autism Speaks joins Alaska's autism community in calling on the legislature to pass HB 79 and join the growing number of states that have ended healthcare discrimination against children with autism."

Many 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.

To date, twenty-three states – Arizona, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, Pennsylvania, South Carolina, Texas, Vermont, and Wisconsin – have enacted autism insurance reform legislation. Several other state legislatures will introduce similar legislation during the current 2011 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 neurobiological 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 110 children in the United States, affecting four times as many boys as girls. The prevalence of autism increased 57 percent from 2002 to 2006. 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 North America's largest autism science and advocacy organization. Since its inception only five short years ago, Autism Speaks has made enormous strides, committing over $142.5 million to research and developing innovative new resources for families through 2014. The organization is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. In addition to funding research, Autism Speaks also supports the Autism Treatment Network, Autism Genetic Resource Exchange and several other scientific and clinical programs. Notable awareness initiatives include the establishment of the annual United Nations-sanctioned World Autism Awareness Day on April 2 and an award-winning "Learn the Signs" campaign with the Ad Council which has received over $210 million in donated media. Autism Speaks' family resources include the Autism Video Glossary, a 100 Day Kit for newly-diagnosed families, a School Community Tool Kit, a community grant program and much more. Autism Speaks has played a critical role in securing federal legislation to advance the government's response to autism, and has successfully advocated for insurance reform to cover behavioral treatments. Each year *Walk Now for Autism Speaks* events are held in more than 80 cities across North America. To learn more about Autism Speaks, please visit www.autismspeaks.org.

About the Co-Founders
Autism Speaks 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. He also serves on the boards of the Polo Ralph Lauren Corporation, RAND Corporation and the New York Presbyterian Hospital. Suzanne Wright has an extensive history of active involvement in community and philanthropic endeavors, mostly directed toward helping children. She serves on the boards of several non-profit organizations and is also Trustee Emeritus of Sarah Lawrence College, her alma mater. Suzanne has received numerous awards such as

the CHILD Magazine Children's Champions Award, Luella Bennack Volunteer Award, Spirit of Achievement award by the Albert Einstein College of Medicine's National Women's Division and the Weizmann Institute of Science. In 2008, the Wrights were named to the *Time* 100 list of the most influential people in the world for their commitment to global autism advocacy.

###

Sean Parnell, Governor
State of Alaska

GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

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

March 24, 2011

Senator Johnny Ellis
State of Alaska
Alaska State Legislature
State Capitol, Room 119
Juneau, AK 99801

Re: SB 74 Insurance Coverage for Autism Spectrum Disorders

Dear Senator Ellis:

Thank you for sponsoring SB 74, which provides private insurance coverage for Autism Spectrum Disorders. The Governor's Council on Disabilities and Special Education strongly supports SB 74, which will provide coverage for the diagnosis and treatment of autism spectrum disorders, including but not limited to applied behavioral analysis, the leading evidence-based intervention for autism.

As you know, many families struggle when their child is diagnosed as being on the spectrum, because many insurance policies specifically exclude treatments for Autism Spectrum Disorders (even if those treatments are routinely covered otherwise). This bill would put services for people with autism on the same footing as other health issues when it comes to insurance coverage of treatment and prevention services. Otherwise, families often go into debt in order to secure needed services, or go without them.

In addition, 40 years of research clearly shows that 50 percent of children with severe autism who receive early intervention and treatment do not require lifelong services and supports. According to a study conducted by Michael Ganz, a Harvard University Economist, with treatment, the state will see savings of $208,500 per person in avoided or reduced special education costs and lifetime savings of $1.8 million. Without treatment it is estimated lifetime costs to the State of Alaska will exceed $3.2 million per person.

Thank you again for your support on this important issue.

Respectfully,

Donna Swihart

Donna Swihart, Chair

Key Campaign XXIV Priority IV:

Autism Insurance Reform

BACKGROUND:

Autism is a disorder affecting at least 1 in 110 children with approximately 1 in 500 requiring significant clinical treatment. Alaska currently has around 1,512 children and youth under the age of 21 who have autism; approximately 454 need significant clinical treatment.

It is recommended that private, state employee and university employee insurance policies provide coverage for the diagnosis and treatment of autism spectrum disorders, including, but not limited to applied behavior analysis, the leading evidence-based intervention for autism.

URGENCY:

- Most insurance policies specifically exclude coverage for treating autism, even when the services are otherwise covered by the health plan.
- 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 j\much as $50,000 per year or more; in some instances, bearing this burden results in divorce or bankruptcy.
- Autism is treatable. Ro years of research shows that with treatment, many children overcome the severe symptoms of their disorder.
- The earlier the diagnosis, the more effective the treatment.
- Treatment equals savings. Without treatment it is estimated that it will cost the state $3.2 million per capita.
- Coverage of medically necessary autism treatment in Alaska will enable many children to access the services they need and live more productive lives.
- The costs of this insurance reform are small and will have very little impact on the cost of health insurance premiums for the individual consumer.

ACTION REQUESTED

The Key Coalition of Alaska asks the Alaska State Legislature to:

Pass HB79 and SB94 requiring insurance coverage for autism spectrum disorders.

From: David Flynn <dflynn@tdxpower.com>
Date: March 25, 2011 4:03:20 PM AKDT
To: "Sen. Bettye Davis" <Senator_Bettye_Davis@legis.state.ak.us>
Cc: "Sen. Dennis Egan" <Senator_Dennis_Egan@legis.state.ak.us>, "Sen. Johnny Ellis" <Senator_Johnny_Ellis@legis.state.ak.us>, "Sen. Kevin Meyer" <Senator_Kevin_Meyer@legis.state.ak.us>, "Sen. Fred Dyson" <Senator_Fred_Dyson@legis.state.ak.us>
Subject: SB 74: Autism Insurance Coverage

My family and I live in Delta Junction , AK.

Our 3.5yr old son has autism and it is a struggle for him...and our family...to cope with the challenges of this condition.

I can be contacted as an advocate for these children and families and believe that anything that we can do to assist these special people and their families is worth doing. This bill's passing would be one way to help.

Please do what you can to see that this Bill passes.

Much appreciation in advance for your efforts in this regard...

David J. Flynn, P.Eng
TDX Project Engineer
907-865-4806 TDX
907-590-7775 cell

On Mar 27, 2011, at 5:26 PM, "Joanne Healy" <jhealy7@alaska.edu> wrote:

By supporting this now you will be saving the states millions over the long run. Early Intervention WORKS!!!!

The Council supports this bill with the intent to better support and treat Alaskans experiencing autism. The Centers for Disease Control estimates that one in every 110 children, with one in every 70 boys, are diagnosed annually. These children require extensive services from medical professionals and other providers. Most insurance policies specifically exclude coverage for treating autism, even when the services are otherwise covered by the health plan.

--

Joanne Healy
Assistant Professor Special Education
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(907) 474-1557 (907) 474-5451 fax
jhealy7@alaska.edu * www.uaf.edu

On Mar 27, 2011, at 1:12 PM, "Paul & Robin Barrett" <robinbarrett@gci.net> wrote:

Please support this bill. Money spent for early autism treatment will be a mere drop in the bucket when compared to the later cost of lifetime institutionalism. Our son is age 10 and severely autistic. Our insurance does not pay for the therapy he desperately needs. We have been selling our retirement assets to pay for his treatment. In the past 5 years we are out-of-pocket more than $136,000.00. Most families cannot afford such expenses (nor can we, over time) so their children are untreated and likely doomed to a lifetime of dependence on society. Again, please support this bill.

Paul and Robin Barrett

Autism Insurance Reform

(The Council supports HB 79, Requiring Insurance Coverage for Autism Spectrum Disorders)

- **The earlier the diagnosis, the more effective treatment is.** The diagnostic process involves a comprehensive assessment (neuro-developmental 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.
  - ✓ Habilitative 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.

- **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.**

- **The costs of this insurance reform are small and will have very little impact on the cost of health insurance premiums for the individual consumer.**
  - ✓ **According to a February 9, 2010 actuarial study conducted by Oliver Wyman Actuarial Consulting, Inc.** the "Middle" estimate is that, in the long-term, the premium increase associated with the mandated benefits for private insurance plans would be about 0.39% of insured premiums across all markets or $1.34 per policyholder per month. **Note:** the original estimate was 0.02% or $3.60 per policyholder per month; it was revised based on the actual experiences of states that have enacted autism insurance reform.
  - ✓ **The Council estimates** government programs such as the State of Alaska and/or the university system would have cost increases comparable to large insured groups. This would translate into an increased cost to the State of Alaska of $1.34 per state employee per month. **Note:** the Division of Insurance's actuarial consultants, Buck Consultants, estimated a rate of 1-3% or $3.20 per member per month based on the nationwide trends of children being diagnosed with autism over the past 10 years. However, the actual experiences of government insurance programs that implemented autism insurance reform were closer to the $1.34 per member per month figure cited above.
  - ✓ South Carolina's State Employee Health Plan experience has been far less than $1.34. In year one it was 20 cents per member per month and in year two it was 44 cents per member per month.

GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

Autism Insurance Reform

(The Council supports HB 79, Requiring Insurance Coverage for Autism Spectrum Disorders)

WHAT:

- **Autism is a disorder affecting at least 1 in 110 children with approximately 1 in 500 requiring significant clinical treatment.** Alaska currently has around 1,512 children and youth under the age of 21 who have autism; approximately 454 need significant clinical treatment.

RECOMMENDED INSURANCE REFORM

- **The Governor's Council on Disabilities and Special Education recommends that private, state employee and university employee insurance policies provide coverage for the diagnosis and treatment of autism spectrum disorders, including but not limited to applied behavior analysis, the leading evidence-based intervention for autism.**
  - ✓ 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.

WHY:

- **Most insurance policies specifically exclude coverage for treating autism, even when the services are otherwise covered by the health plan.**

- **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.** 40 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

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APPLIED BEHAVIOR ANALYSIS (ABA)-BASED INTERVENTIONS FOR YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDERS

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

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

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

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

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

Provided By: Millie Ryan 5 April 2009
The Governor's Council on Disabilities and Special Education

- 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

AUTISM SPECTRUM DISORDERS

Treatment

There is no single best treatment for all children with ASDs. However, well-planned, structured teaching of specific skills is very important. Some children respond well to one type of treatment while others have a negative response or no response at all to the same treatment. Before deciding on a treatment program, it is important to talk with the child's health care providers to understand all the risks and benefits.

It is also important to remember that children with ASDs can get sick or injured just like children without ASDs. Regular medical and dental exams should be part of a child's treatment plan. Often it is hard to tell if a child's behavior is related to the ASD or is caused by a separate health condition. For instance, head banging could be a symptom of the ASD, or it could be a sign that the child is having headaches. In those cases, a thorough physical exam is needed. Monitoring healthy development means not only paying attention to symptoms related to ASDs, but also to the child's physical and mental health, as well.

Early Intervention Services

Research shows that early intervention treatment services can greatly improve a child's development.[1],[2] Early intervention services help children from birth to 3 years old (36 months) learn important skills. Services include therapy to help the child talk, walk, and interact with

others. Therefore, it is important to talk to your child's doctor as soon as possible if you think your child has an ASD or other developmental problem.

Even if your child has not been diagnosed with an ASD, he or she may be eligible for early intervention treatment services. The Individuals with Disabilities Education Act (IDEA) says that children under the age of 3 years (36 months) who are at risk of having developmental delays may be eligible for services. These services are provided through an early intervention system in your state. Through this system, you can ask for an evaluation.

In addition, treatment for particular symptoms, such as speech therapy for language delays, often does not need to wait for a formal ASD diagnosis. While early intervention is extremely important, intervention at any age can be helpful.

Types of Treatments

The National Institute of Mental Health and the Autism Society of America suggest a list of questions parents can ask when planning treatments for their child.

There are many different types of treatments available. For example, auditory training, discrete trial training, vitamin therapy, anti-yeast therapy, facilitated communication, music therapy, occupational therapy, physical therapy, and sensory integration.

The different types of treatments can generally be broken down into the following categories:

- Behavior and Communication Approaches
- Dietary Approaches
- Medication
- Complementary and Alternative Medicine

Behavior and Communication Approaches

According to reports by the American Academy of Pediatrics and the National Research Council, behavior and communication approaches that help children with ASDs are those that provide structure, direction, and organization for the child in addition to family participation.

Applied Behavior Analysis (ABA)

A notable treatment approach for people with an ASD is called applied behavior analysis (ABA). ABA has become widely accepted among health care professionals and used in many schools and treatment clinics. ABA encourages positive behaviors and discourages negative behaviors in order to improve a variety of skills. The child's progress is tracked and measured.

There are different types of ABA. Following are some examples:

- **Discrete Trial Training (DTT)**
  DTT is a style of teaching that uses a series of trials to teach each step of a desired behavior or response. Lessons are broken down into their simplest parts and positive reinforcement is used to reward correct answers and behaviors. Incorrect answers are ignored.

- **Early Intensive Behavioral Intervention (EIBI)**
  This is a type of ABA for very young children with an ASD, usually younger than five, and often younger than three.

- **Pivotal Response Training (PRT)**
  PRT aims to increase a child's motivation to learn, monitor his own behavior, and initiate communication with others. Positive changes in these behaviors should have widespread effects on other behaviors.

- **Verbal Behavior Intervention (VBI)**
  VBI is a type of ABA that focuses on teaching verbal skills.

Other therapies that can be part of a complete treatment program for a child with an ASD include:

Developmental, Individual Differences, Relationship-Based Approach (DIR; also called "Floortime")
Floortime focuses on emotional and relational development (feelings, relationships with caregivers). It also focuses on how the child deals with sights, sounds, and smells.

Treatment and Education of Autistic and related Communication-handicapped CHildren (TEACCH)

TEAACH uses visual cues to teach skills. For example, picture cards can help teach a child how to get dressed by breaking information down into small steps.

Occupational Therapy
Occupational therapy teaches skills that help the person live as independently as possible. Skills might include dressing, eating, bathing, and relating to people.

Sensory Integration Therapy
Sensory integration therapy helps the person deal with sensory information, like sights, sounds, and smells. Sensory integration therapy could help a child who is bothered by certain sounds or does not like to be touched.

Speech Therapy
Speech therapy helps to improve the person's communication skills. Some people are able to learn verbal communication skills. For others, using gestures or picture boards is more realistic.

The Picture Exchange Communication System (PECS)
PECS uses picture symbols to teach communication skills. The person is taught to use picture symbols to ask and answer questions and have a conversation.

Visit the Autism Speaks or Easter Seals website to read more about these therapies.

Dietary Approaches

Some dietary treatments have been developed by reliable therapists. But many of these treatments do not have the scientific support needed for widespread recommendation. An unproven treatment might help one child, but may not help another.

Many biomedical interventions call for changes in diet. Such changes include removing certain types of foods from a child's diet and using vitamin or mineral supplements. Dietary treatments are based on the idea that food allergies or lack of vitamins and minerals cause symptoms of ASDs. Some parents feel that dietary changes make a difference in how their child acts or feels.

If you are thinking about changing your child's diet, talk to the doctor first. Or talk with a nutritionist to be sure your child is getting important vitamins and minerals.

Medication

There are no medications that can cure ASDs or even treat the main symptoms. But there are medications that can help some people with related symptoms. For example, medication might help manage high energy levels, inability to focus, depression, or seizures. Also, the U.S. Food and Drug Administration approved the use of risperidone (an antipsychotic drug) to treat 5- to 16-year-old children with ASDs who have severe tantrums, aggression, and cause self-injury.

To learn more about medications and ASDs go to National Institute of Mental Health autism website.

Complementary and Alternative Treatments

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To relieve the symptoms of ASDs, some parents and health care professionals use treatments that are outside of what is typically recommended by the pediatrician. These types of treatments are known as complementary and alternative treatments (CAM). They might include special diets, chelation (a treatment to remove heavy metals like lead from the body), biologicals (e.g., secretin), or body-based systems (like deep pressure).[3]

These types of treatments are very controversial. Current research shows that as many as one third of parents of children with an ASD may have tried complementary or alternative medicine treatments, and up to 10% may be using a potentially dangerous treatment.[4] Before starting such a treatment, check it out carefully, and talk to your child's doctor.

-

Additional Treatment Resources

The National Institute on Deafness and Other Communication Disorders has a website to help individuals with an ASD who have communication challenges.

The National Institute of Dental and Craniofacial Research has a website to help health professionals with the oral health care needs of patients with an ASD.

Clinical Trials.Gov lists federally funded clinical trials that are looking for participants. If you or someone you know would like to take part in an autism study, go to the website and search "autism."

The Autism Treatment Network (ATN) seeks to create standards of medical treatment that will be made broadly available to physicians, researchers, parents, policy makers, and others who want to improve the care of individuals with autism. ATN is also developing a shared national medical database to record the results of treatments and studies at any of their five established regional treatment centers.

References

1. Handleman, J.S., Harris, S., eds. Preschool Education Programs for Children with Autism (2nd ed). Austin, TX: Pro-Ed. 2000.
2. National Research Council. Educating Children with Autism. Washington, DC: National Academy Press, 2001.
3. Gupta, Vidya Bhushan. Complementary and Alternative Medicine. New York Medical College and Columbia University, 2004. Pediatric Habilitation, volume 12.
4. Levy, S. Complementary and Alternative Medicine Among Children Recently Diagnosed with Autistic Spectrum Disorder; Journal of Developmental and Behavioral Pediatrics, December 2003; vol 24: pp 418-423. News release, Health Behavior News Service.

Learn the Signs. Act Early.

Overview of Autism Spectrum Disorders

- Autism spectrum disorders are a group of developmental disabilities that can cause social, communication and behavioral challenges for affected children and adults. Autism's effects vary person to person, so these challenges can be mild or significant.

- About 1 percent of all babies born in Alaska each year will develop an autism spectrum disorder, according to CDC nationwide estimates. In other words, about 11,000 Alaskans will be born this year, and 110 of them will be diagnosed with an autism disorder by the age of eight.

- In 2008, more than 600 children were receiving services related to an autism diagnosis in Alaska schools.

- Current research indicates that autism spectrum disorders are present at birth and last throughout a person's life, although symptoms can improve over time. Some children with autism disorders show hints of future problems within the first few months of life. In others, symptoms might not develop until 24 months or later. In still others, the children may develop normally until 18 months or 24 months, and then they stop gaining new skills or they lose the skills they once had.

A person with an autism spectrum disorder may exhibit some or all of the following:

- Not respond to his or her name by 12 months old
- Not point at objects to show interest by 14 months old (such as pointing at an airplane flying overhead)
- Not play "pretend" games by 18 months old (such as pretend to feed a doll)
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about his or her own feelings
- Have delayed speech and/or language skills
- Repeat words or phrases over and over (often called "echolalia")
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap hands, rock his or her body or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look or feel

Types of Autism Spectrum Disorders

There are three types of autism spectrum disorders:

Autistic Disorder

This is sometimes called "classic" autism. It is what most people think of when hearing the word "autism". People with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests. Many people with autistic disorder also have intellectual disability.

Asperger Syndrome

People with Asperger syndrome usually have milder symptoms of autistic disorder. They might have social challenges and unusual behaviors and interests. However, they typically do not have problems with language or intellectual disability.

Pervasive Developmental Disorder – Not Otherwise Specified

This is sometimes called "atypical autism," or PDD-NOS. People who meet some of the criteria for autistic disorder or Asperger syndrome, but not all, may be diagnosed with atypical autism. These people usually have fewer and milder symptoms than those with autistic disorder. The symptoms might cause only social and communication challenges

GO

Issues & Research » Health » Autism and Insurance Coverage State Laws Go 18246 Share Comment

Insurance Coverage for Autism

November 2010

The Centers for Disease Control and Prevention (CDC) estimate that an average of one in 110 children have an autism spectrum disorder (ASD). More children than ever before are being classified as having autism spectrum disorders. The CDC estimates that up to 730,000 people between the ages of 0 and 21 have an ASD.

There is no cure for autism, but it is a treatable condition. Most health professionals agree that early intervention treatment programs are important. Treatment options may include behavioral and educational interventions, complementary and alternative medicine, dietary changes or medications to manage or relieve the symptoms of autism. These treatments may be costly. Some families may spend more than $50,000 per year on autism-related therapies, such as applied behavior analysis. A study in 2006 by the Harvard School of Public Health estimated that it costs $3.2 million to take care of an individual with autism over his or her lifetime and that it costs society an estimated $35 billion each year to care for all individuals with autism.

Some states require insurers to provide coverage for the treatment of autism. However, opponents to this approach argue that care for individuals with autism is the responsibility of parents and/or the responsibility of school systems. Others have raised concerns that mandating coverage for autism will significantly increase insurance premiums. According to the Council for Affordable Health Insurance, an autism mandate increases the cost of health insurance by about 1 percent. However, if the incidence of autism continues to increase and as more services are covered, the cost of insurance may increase 1 to 3 percent. This debate has intensified in recent years and states are taking a variety of approaches to meet the needs of children and adults with autism.

Additional NCSL Resources

- NCSL's Autism Policy Issues Overview webpage
- NCSL's State Autism Legislation Database
- NCSL's Mandated Health Insurance Coverage webpage
- NCSL's State Laws Mandating or Regulating Mental Health Benefits webpages

A total of 35 states and the District of Columbia have laws related to autism and insurance coverage. At least 23 states—Arizona, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, Pennsylvania, South Carolina, Texas, Vermont and Wisconsin—specifically require insurers to provide coverage for the treatment of autism. Other states may require limited coverage for autism under mental health coverage or other laws.

In the past few years, the debate over autism and insurance coverage has heated up in state legislatures. Most of the legislation to provide coverage for autism has been enacted in the last three years.

During the 2007-2008 legislative session, nine states passed legislation related to autism and insurance coverage. Arizona, Florida, Illinois, Louisiana, Pennsylvania, South Carolina and Texas enacted legislation specifically requiring coverage for autism. In addition, Massachusetts enacted legislation in 2008 to specify that autism shall be covered under mental health parity laws on a nondiscriminatory basis. Connecticut enacted legislation in 2008 that requires insurers to provide coverage for physical, speech and occupational therapy services for the treatment of autism spectrum disorders to the extent that such services are a covered benefit for other diseases and conditions under such policy. A summary of this legislation is included in the two tables below.

In 2009, Colorado, Connecticut, Montana, Nevada, New Jersey, New Mexico and Wisconsin enacted legislation requiring insurance coverage for autism. Illinois enacted legislation requiring insurance coverage for habilitative services for children with a congenital or genetic disorder, including autism.

In 2010, Iowa, Kansas, Kentucky, Maine, Massachusetts, Missouri, New Hampshire and Vermont enacted legislation requiring insurance coverage for autism. In addition, in April 2010, Oklahoma enacted legislation to specify that health insurance policies must provide the same coverage and benefits to children who have been diagnosed with autism as children who have not been diagnosed with the disorder.

In 2009, the Federal Autism Treatment Acceleration Act of 2009 (S 819 and HR 2413), was introduced which provides for enhanced treatment, support, services and research for individuals with autism spectrum disorders and their families. One component of the bill requires health insurance coverage for the diagnosis and treatment of autism spectrum disorders under group health plans.

Additional Resources:

National Association of Insurance Commissioners

The Council for Affordable Health Insurance

Health Insurance Mandates in the States, 2010
Mandate Benefit Definition Memo, 2009
The Growing Trend Toward Mandating Autism Coverage, March 2009

America's Health Insurance Plans

Autism Votes: An Autism Speaks Initiative

Actuarial Cost Estimate: Virginia House Bill No. 303 and Senate Bill 464- Bills Relating to Health Insurance Coverage for Autism Spectrum Disorder, January 15, 2010

Early Intensive Intervention Services for Alaska Children with Autism: A Policy Analysis
The Governor's Council on Disabilities and Special Education, August 2007

Statutes specifically requiring insurance coverage of autism

State	Statute Summary
Arizona	Ariz. Rev. Stat. Ann. § 20-826.04, § 20-1057.11, § 20-1402.03 and § 20-1404.03 (2008 Ariz. Sess. Laws, Chap. 4; HB 2847 of 2008) Require policies issued by certain health insurers, beginning July 1, 2009, to provide coverage for the diagnosis and treatment of autism spectrum disorders, with some limitations. Coverage for autism treatment may not be excluded or denied and dollar limits, deductibles and coinsurance cannot be imposed based solely on the diagnosis of an autism spectrum disorder. Coverage for medically necessary behavioral therapy services may not be excluded or denied and is subject to a $50,000 maximum benefit per year for an eligible person up to the age of 9 and a $25,000 maximum benefit per year for an eligible person who is between the ages of 9 and 16 years.
Colorado	Colo. Rev. Stat. § 10-16-104 (1.3)(g), § 10-16-104 (1.4) and § 25.-5-8-107 (a)(IV) (2009 Colo., Sess. Laws, Chap. 391; SB 244 of 2009, Fiscal Note, Commission on Mandated Health Insurance Benefits Review of SB 244) Require that all health benefit plans provide coverage for the assessment, diagnosis and treatment of autism spectrum disorders for a child. Treatment for autism spectrum disorders is defined to include treatments that are medically necessary, appropriate, effective or efficient and shall include evaluation and assessment services; behavior training and management and applied behavior analysis; habilitative or rehabilitative care, including occupational, physical or speech therapy; pharmacy care and medication; psychiatric care; psychological care; and therapeutic care. Colo. Rev. Stat. §10-16-104.5 (1993 Colo., Sess. Laws, Chap. 211, amended by 2009 Colo., Sess. Laws, Chap. 391; SB 244 of 2009) Specified sickness and accident insurance policies providing indemnity for disability due to sickness and specified individual policies that provide coverage for autism shall provide such coverage in the same manner as for any other accident or sickness, other than mental illness, otherwise covered under such policy.
Connecticut	Conn. Gen. Stat. § 38a-514b (2009 Conn. Acts, P.A. 115; SB 301 of 2009, Summary, Fiscal Note) Requires specified group health insurance policies to provide coverage for the diagnosis and treatment of autism spectrum disorders. Treatments shall be medically necessary and identified and ordered by a licensed physician, psychologist or clinical social worker in accordance with a treatment plan. Treatments may include behavioral therapy, prescription drugs, psychiatric services, psychological services, physical therapy, speech and language pathology services and occupational therapy. This law repealed the previous version of § 38a-514b (2008 Conn. Acts, P.A. 132; HB 5696, Fiscal Note), which specified that each individual and group health insurance policy is required to provide coverage for physical, speech and occupational therapy services for the treatment of autism spectrum disorders to the extent such services are a covered benefit for other diseases and conditions under such policy.
Florida	Fla. Stat. § 627.6686 and § 641.31098 (2008 Fla. Laws, Chap. 30; SB 2654 of 2008, Bill Analyses) Requires health insurance plans and health maintenance contracts to provide coverage to eligible individuals for well-baby and well-child screening for diagnosing the presence of autism spectrum

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	disorders, treatment of autism spectrum disorders through speech, occupational and physical therapy and applied behavior analysis. Coverage is limited to treatment that is prescribed by the insured's treating physician in accordance with a treatment plan and is limited to $36,000 annual and may not exceed $200,000 in total lifetime benefits.
Illinois	Ill. Rev. Stat. ch. 215, § 5/356z.14 (2008 Ill. Laws, P.A. 95-1005, SB 934 of 2008; and 2009 Ill. Laws, P.A. 95-1049, SB 101 of 2008) Requires all individual and group accident and health insurance or managed care plans to provide coverage for the diagnosis and treatment of autism spectrum disorders for individuals less than 21 years of age. Coverage is to include applied behavioral analysis and other treatments with a maximum benefit of $36,000 per year. The law was amended in 2009 by 2009 Ill. Laws, P.A. 95-1049 (SB 101 of 2008) to require insurance coverage for habilitative services for children less than 19 years of age with a congenital, genetic or early acquired disorder, including autism spectrum disorders. Habilitative services includes occupational therapy, physical therapy, speech therapy and other services prescribed by the insured's treating physician pursuant to a treatment plan to enhance the ability of a child to function with a congenital, genetic or early acquired disorder. ▶ For more information, please see Illinois' fact sheet on insurance coverage for autism.
Indiana	Ind. Code § 27-8-14.2-1 et seq. and § 27-13-7-14.7 (HB 1122 of 2001; Fiscal Impact Statement) Requires an accident and sickness insurance policy that is issued on a group basis and a group contract with a health maintenance organization to provide coverage for the treatment of a pervasive developmental disorder. Coverage is limited to treatment that is prescribed by the insured's treating physician in accordance with a treatment plan. An insurer may not deny or refuse to issue coverage, or otherwise terminate or restrict coverage on an individual under an insurance policy solely because the individual is diagnosed with a pervasive developmental disorder. An insurer that issues an accident and sickness insurance policy on an individual basis or a health maintenance organization that enters into an individual contract that provides basic health care services must offer to provide coverage for the treatment of a pervasive developmental disorder of an enrollee. ▶ For additional information about the law, please visit the Indiana Resource Center for Autism's webpage.
Iowa	Iowa House File 2531 of 2010 (Fiscal Analysis) Requires state employee health care plans to provide coverage for the diagnosis and treatment of autism spectrum disorders for individuals under 21 years of age. Treatment is defined as pharmacy care, psychiatric care, psychological care, rehabilitative care and therapeutic care. The law also establishes a $36,000 annual maximum benefit on coverage for children with autism spectrum disorder. The coverage plan cannot limit the number of visits to an autism service provider for treatment. Coverage must be provided in coordination with requirements established in Iowa Code § 514c.22. Iowa Code § 514c.22 (2005 Iowa Acts, Chap. 91; HF 420 of 2005) Requires specified insurers to provide coverage benefits for treatment of a biologically based mental illness, including pervasive developmental disorders and autistic disorders.
Kansas	2010 Kan. Sess. Laws, Chap. 120 (HB 2160 of 2010; Supplemental Note) Requires state employee health insurance plans to provide coverage for the diagnosis and treatment of autism spectrum disorder for any covered individual up to 19 years old. Covered services are defined to include applied behavioral analysis and evidence-based services. The annual benefit cap for children up to age 7 is $36,000 and for children at least 7 years old and up to age 19, the annual cap is $27,000. The law also requires the state employees health care commissioner to submit a report to the legislature that includes information on the impact of the mandated coverage for autism spectrum disorder on the state health care benefits program, data on the utilization of coverage and the cost of providing such coverage, and recommendations for whether such coverage should continue. 2009 Kan. Sess. Laws, Chap. 136 (HB 2214 of 2009) The law amends Kan. Stat. Ann. § 40-2,105a (HB 2033 of 2001) to require any group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization, which provides medical, surgical or hospital expense coverage to include coverage for the diagnosis and treatment of mental illness. The law re-defines mental illness to include any disorder defined in the DSM-IV.

Statutes specifically requiring insurance coverage of autism

State	Statute Summary
Kentucky	2010 Ky. Acts, Chap. 150; (HB 159 of 2010) Requires large group health benefit plans to provide coverage for the diagnosis and treatment of autism spectrum disorders for individuals between the ages of one through 21 years of age. For individuals between the ages of one through their seventh birthday, the maximum annual benefit amount is $50,000, and the maximum benefit for individuals between the ages of seven through 21 is $1,000 per month. Coverage may not be subject to any limits on the number of visits an individual may make to an autism services provider. Treatment of autism spectrum disorders is defined to include medical care, pharmacy care (if covered by the plan), psychiatric care, psychological care, therapeutic care, applied behavior analysis, and rehabilitative and habilitative care. This law also amends Ky. Rev. Stat. § 304.17A-143 (1998 Ky. Acts, Chap. 106; SB 63 of 1998), to require individual and small group market health benefit plans to provide coverage for pharmacy care (if covered by the plan), psychiatric care, psychological care, applied behavioral analysis, and habilitative care for the treatment of autism spectrum disorders, in addition to the law's existing coverage for therapeutic and rehabilitative care. The law increases the maximum benefit per month from $500 to $1000. Additional definitions related to this law are included in Kentucky Regulations 806 KAR 17:460. The law also amends Ky. Rev. Stat. § 18A.225 to require state employee health benefit plans to provide coverage for the diagnosis and treatment of autism spectrum disorder consistent with the requirement for coverage under large group health benefit plans.
Louisiana	La. Rev. Stat. Ann. § 22:1050 (2008 La. Acts. P.A. 648; HB 958 of 2008: Fiscal Note) Requires health insurance policies, including health maintenance organizations, to provide coverage for the diagnosis and treatment of autism spectrum disorders in individuals less than 17 years of age. Coverage is subject to a maximum benefit of $36,000 per year and a lifetime maximum benefit of $140,000. Treatment of autism spectrum disorders is defined to include habilitative or rehabilitative care (including applied behavior analysis), pharmacy, psychiatric, psychological and therapeutic care. 2009 House Bill 406 amended the statute (La. Acts. P.A. 419) to exclude individually, underwritten, guaranteed renewable limited benefit health insurance policies from the provisions in this law.
Maine	2010 Me. Laws. Chap. 635 (LD 1198; SB 446 of 2010; Fiscal Note) Requires all individual health insurance policies and contracts, group health insurance policies, and all individual and group health maintenance organization contracts to provide coverage for the diagnosis and treatment of autism spectrum disorders for individuals five years of age and under. Treatment is defined as habilitative or rehabilitative care, applied behavior analysis, counseling services and therapy services, including speech, occupational and physical therapy. The policy or contract may limit coverage for applied behavior analysis to $36,000 per year, and the insurance policy or contract may not include any limits on the number of visits. The law also requires the Department of Professional and Financial Regulation, Bureau of Insurance to review and evaluate the financial and social impact and medical efficacy of this mandated health insurance benefit, and submit a report to the Legislature by February 1, 2015. Me. Rev. Stat. Ann. tit. 24 § 2325-A; tit. 24-A § 2749-C, § 2843 and § 4234-A Requires specified group contracts to provide, at a minimum, benefits for a person receiving medical treatment for specified mental illnesses, including pervasive developmental disorders. Other specified individual and group insurance contracts or policies must make available benefits for the treatment and diagnosis of specified mental illnesses, including pervasive developmental disorder or autism, under terms and conditions that are no less extensive than the benefits provided for medical treatment for physical illnesses. 2009 Me. Acts. Chap. 33 (SB 226 of 2009) Requires the Department of Health and Human Services to amend the rules of reimbursement for the provision of supervisory services by board-certified behavior analysts in the MaineCare programs for home and community benefits for persons with mental retardation or autistic disorders, developmental and behavioral clinical services, day habilitation services for persons with mental retardation, early intervention services, community support benefits for persons with mental retardation or autistic disorders, day treatment services, intermediate care facilities for persons with mental retardation and school-based rehabilitative services. The law also requires the Department of Health and Human Services to pursue amendment to the federally approved Medicaid state plan on a timely basis and, after approval, amend the MaineCare rules to provide for reimbursement of board-certified behavior analysts for supervision only.

Statutes specifically requiring insurance coverage of autism

State	Statute Summary
Massachusetts	2010 Mass. Acts, Chap. 207 (HB 4935 of 2010) Requires specified individual, group and state employee health plans and health maintenance contracts to provide benefits on a nondiscriminatory basis for the diagnosis and treatment of autism spectrum disorder. Treatment is defined to include habilitative or rehabilitative, pharmacy, psychiatric, psychological and therapeutic care. The health plan may not contain an annual or lifetime dollar or unit of service limitation on coverage for autism which is less than the limitations imposed on coverage for physical conditions. The plan may not limit the number of visits an individual may make to an autism services provider. The law allows for exemptions from providing coverage under certain circumstances. Mass. Gen. Laws Ann. ch. IV § 32A-22 (2008 Mass. Acts, Chap. 256; HB 4423) Requires an individual policy and a group blanket or general policy of accident and sickness insurance or a health maintenance contract that provides hospital and surgical insurance to provide mental health benefits on a nondiscriminatory basis for the diagnosis and treatment of specified biologically-based mental disorders, including autism. Requires the group insurance commission to provide to any active or retired employee of the commonwealth who is insured under the group insurance commission coverage on a nondiscriminatory basis for the diagnosis of treatment of specified biologically-based mental disorders, including autism.
Missouri	Missouri House Bill 1311 and House Bill 1341 of 2010 (HB 1311 Fiscal Note) Requires all group health benefit plans to provide coverage for the diagnosis and treatment of autism spectrum disorders. Coverage is limited to medically necessary treatment that is ordered by the insured's treating physician or psychologist, in accordance with a treatment plan. Treatment for autism spectrum disorder is defined to include psychiatric, psychological, habilitative or rehabilitative care, applied behavior analysis, therapeutic care and pharmacy care. Coverage for applied behavior analysis is subject to a maximum benefit of $40,000 per year for individuals through 18 years of age. However, this limit may be exceeded, with approval by the health benefit plan, if the applied behavior analysis services are medically necessary for an individual. The health benefit plan may not place limits on the number of visits an individual makes to an autism service provider. The law requires the department of insurance and other institutions to submit a report to the legislature regarding the implementation of this coverage, including specified costs of this coverage.
Montana	Mont. Code Ann. § 33-22-515 (2009 Mont. Laws, Chap. 359, SB 234 of 2009, Fiscal Note) Requires specified disability policies, certificates of insurance and membership contracts to provide coverage for the diagnosis and treatment of autism spectrum disorders for a covered child 18 years of age or younger. Coverage must include habilitative or rehabilitative care, medications, psychiatric or psychological care, therapeutic care and other specified care. Coverage for treatment of autism spectrum disorders may be limited to a maximum benefit for $50,000 per year for a child 8 years of age and younger and to $20,000 per year for a child 9 years of age through 19 years of age. Mont. Code Ann. § 33-22-706 Requires a policy or certificate for health insurance or disability insurance to provide a level of benefits for the necessary care and treatment of severe mental illness, including autism, that is no less favorable than that level provided for other physical illness generally. Benefits for treatment of severe mental illness include but are not limited to inpatient services, outpatient services, rehabilitative services, medication and other specified treatments. The law was amended in 2009 by Mont. Laws, Chapter 359 to specify that coverage for a child with autism who is 18 years of age or younger must comply with § 33-22-515.
Nevada	Nev. Rev. Stat. § 689A.0435 (2009 Nev. Stats., Chap. 331, AB 162 of 2009, Health and Human Services Fiscal Note | Public Employees' Benefits Program Fiscal Note) Requires an individual health benefit plan to provide the option of coverage for screening, diagnosis, and treatment of autism spectrum disorders for persons covered by the policy under the age of 18, or if enrolled in high school, until the person reaches the age of 22. Requires health insurance for small employers and group and blank health insurance benefit plans and health care plans issued by a health maintenance organization to provide coverage for screening, diagnosis and treatment of autism spectrum disorders to persons covered by the policy of group health insurance under the age of 18, or if enrolled in high school until the person reaches the age of 22. Treatment of autism spectrum disorders must be identified in a treatment plan and may include medically necessary habilitative or rehabilitative care, prescription care, psychiatric care, psychological care or behavior therapy.

Statutes specifically requiring insurance coverage of autism

State	Statute Summary
New Hampshire	2010 N.H. Laws, Chap. 363 (House Bill 569 of 2010) Clarifies and defines treatment of pervasive developmental disorder or autism, as required under N.H. Rev. Stat. Ann. § 417-E:1, to include professional services and treatment programs, including applied behavioral analysis, prescribed pharmaceuticals (subject to the terms and conditions of the policy), direct or consultative services provided by specified licensed professionals, and services provided by licensed speech, occupation or physical therapists. The policy, contract or certificate may limit coverage for applied behavior analysis to $36,000 per year for children 0 to 12 years of age, and $27,000 from ages 13 to 21. N.H. Rev. Stat. Ann. § 417-E:1 Requires specified insurers that provide benefits for disease or sickness to provide benefits for treatment and diagnosis of certain biologically-based mental illness, including pervasive developmental disorder or autism, under the same terms and conditions and which are no less extensive than coverage provided for any other type of health care for physical illness.
New Jersey	N.J. Rev. Stat. § 17:48-6ii, § 17:48A-7ff, § 17:48E-35.33, § 17B:26-2.1cc, § 17B:27-46.1ii, § 17B:27A-7.16, § 17B:27A-19.20, § 26:2J-4.34, § 52:14-17.29p and § 52:14-17.46.6b (2009 N.J. Laws, Chap. 115, AB 2238 of 2009) Require specified health insurance policies and health benefit plans to provide coverage for expenses incurred in screening and diagnosing autism or another developmental disability. When the covered person's primary diagnosis is autism or another developmental disability, coverage must be provided for expenses incurred for medically necessary occupational therapy, physical therapy, and speech therapy, as prescribed through a treatment plan. When the covered person is under 21 years of age and the person's primary diagnosis is autism, coverage must be provided for expenses incurred for medically necessary behavioral interventions based on the principles of applied behavioral analysis and related programs, as prescribed through a treatment plan. N.J. Rev. Stat. § 17:48-6v, § 17:48A-7u, § 17:48E-35.20, § 17B:26-2.1s, § 17B:27-46.1v, § 17B:27A-7.5, § 17B:27A-19.7 and § 26:2J-4.20 Require specified insurers that provide hospital or medical expense benefits to provide coverage for biologically-based mental illness, including pervasive developmental disorder or autism, under the same terms and conditions as provided for any other sickness under contract.
New Mexico	N.M. Stat. Ann. § 59A-22-49, § 59A-23-7.9, § 59A-46-50 and § 59A-47-45 (2009 N.M. Laws, Chap. 74, SB 39 of 2009, Fiscal Impact Report) Requires specified insurance policies, health care plans, certificates of health insurance or contracts to provide coverage to an eligible individual who is 19 years of age or younger, or an individual who is 22 years of age or younger and is enrolled in high school for well-baby and well-child screening for diagnosing the presence of autism spectrum disorder and the treatment of autism spectrum disorder through speech therapy, occupational therapy, physical therapy and applied behavioral analysis. Coverage is limited to $36,000 annually and shall not exceed $200,000 in total lifetime benefits.
Pennsylvania	Pa. Cons. Stat. tit. 40, § 764h (Pa. Laws, Act 2008-62; HB 1150 of 2008; Mandated Benefits Review by the Pennsylvania Health Care Cost Containment Council; Autism Spectrum Disorders Mandated Benefits Review Panel Report by Abt Associates Inc.; Pennsylvania Department of Public Welfare "Where to Get Help with PA's Autism Insurance Law" webpage) Requires a health insurance policy or government program to provide coverage for individuals less than 21 years of age for the diagnostic assessment and treatment of autism spectrum disorders. Maximum benefit of $36,000 per year.
South Carolina	S.C. Code Ann. § 38-71-280 (2007 S.C. Acts, Act 65; SB 20 of 2007: Fiscal Impact Statement) Requires a health insurance plan to provide coverage for the treatment of autism spectrum disorders. Coverage is limited to treatment that is prescribed by the insured's treating medical doctor in accordance with a treatment plan. To be eligible for coverage, an individual must be diagnosed with autism spectrum disorder at age eight or younger and be less than 16 years of age.
Texas	Tex. Insurance Code § 1355.015 (2007 Tex. Gen. Laws, Chap. 877; HB 1919 of 2007:, Fiscal Note) Requires a health benefit plan to provide coverage for all generally recognized services prescribed in relation to autism spectrum disorder by the enrollee's primary care physician in the treatment plan recommended by the physician. The law defines "generally recognized services" to include applied

Statutes specifically requiring insurance coverage of autism

State	Statute Summary
	behavior analysis; speech, occupational and physical therapy; medications or nutritional supplements; and other treatments. This coverage may be subject to annual deductibles, copayments and coinsurance that are consistent with annual deductibles, copayments and coinsurance required for other coverage under the health benefit plan. 2009 Tex. Gen. Laws, Chap. 1107 (House Bill 451) amended the law to specify that a health benefit plan must provide coverage to an enrollee who is diagnosed with autism spectrum disorder from the date of diagnosis until the enrollee completes nine years of age. The law previously required coverage to an enrollee older than two years of age and younger than six years of age.
Vermont	2010 Vt. Acts, Act 127 (SB 262 of 2010, Vermont Legislative Joint Fiscal Office Analysis) Requires health insurance plans to provide coverage for the diagnosis and treatment of autism spectrum disorders, including applied behavior analysis for children beginning at 18 months of age and continuing until the child reaches age six or enters first grade, whichever occurs first. Treatment of autism spectrum disorders is defined to include habilitative or rehabilitative care, pharmacy care, psychiatric care, psychological care and therapeutic care. A plan may not limit the number of visits an individual may have with an autism services provider. The law requires specified agencies to evaluate the feasibility and budget impacts of requiring health insurance plans, including Medicaid and the Vermont health access plan, to provide coverage for autism spectrum disorders for children under the age of 18.
Wisconsin	Wis. Stat. § 632.895(12m) and Wis. Stat. § 609.87 (Assembly Bill 75 of 2009; 2009 Wis. Laws. Act 28) Requires specified disability insurance policies and self-insured health plans to provide coverage for treatment for autism spectrum disorder if the treatment is prescribed by a physician, including specified therapies. The statute defines intensive-level and nonintensive-level services. The law was amended in 2010 by Wis. Laws, Act 282 (SB 667) to create Wis. Stat. § 632.895 (12m) (b) 3m, which adds behavior analysts licensed under § 440.312 to the list of professionals qualified to provide intensive-level and nonintensive-level services. Wis. Stat. § 51.01(5a) Defines autism as a developmental disability. Admin. Code, Insurance Commissioner 6.54(3)(a) et seq. specifies that no insurance company may refuse, cancel or deny insurance coverage solely on the basis of the applicant's or insured's physical condition or developmental disability.

Statutes that may require limited insurance coverage of autism

State	Statute Summary
California	Cal. Insurance Code § 10144.5 Requires every policy of disability insurance that covers hospital, medical, or surgical expenses in this state to provide coverage for the diagnosis and medically necessary treatment of severe mental illnesses, including autism, for a person of any age under the same terms and conditions applied to other medical conditions. A March 2009 letter issued by the California Department of Managed Health Care clarifies that health plans must cover all basic health care services required under the Knox-Keene Act, including speech, physical and occupational therapies for persons with autism spectrum disorders, when those health care services are medically necessary.
District of Columbia	D.C. Code Ann. § 31-3271 and § 31-3272 (2007 D.C. Stat., Act 16-0493; B16-711 of 2007) Defines habilitative services as occupational, physical and speech therapy for the treatment of a child with a congenital or genetic birth defect to enhance the child's ability to function. Congenital or genetic birth defect is defined as a defect existing at or from birth, including a hereditary defect; includes autism or an autism spectrum disorder. Requires health insurers to provide habilitative services for children less than 21 years of age. The coverage shall not be more restrictive than coverage provided for any other illness, condition or disorder. A health insurer shall not be required to provide reimbursement for habilitative services delivered through early intervention or school services.

Statutes that may require limited insurance coverage of autism	
State	**Statute Summary**
Georgia	Ga. Code § 33-24-59.10 (HB 565 of 2001) An insurer that provides benefits for neurological disorders shall not deny providing benefits for neurological disorders because of a diagnosis of autism.
Maryland	Md. Insurance Code Ann. § 15-835 (2002 Md. Laws, Chap. 382; HB 692) Requires insurers, nonprofit health service plans and health maintenance organizations to provide coverage of habilitative services for children less than 19 years of age. Habilitative services include occupational, physical and speech therapy for the treatment of a child with a congenital or genetic birth defect to enhance the child's ability to function. The definition of congenital or genetic birth defect includes autism spectrum disorder.
New York	N.Y. Insurance Law § 3216 Requires every policy that provides coverage for hospital, surgical or medical care coverage to not exclude coverage for the diagnosis and treatment of medical conditions otherwise covered by the policy solely because the treatment is provided to diagnose or treat autism spectrum disorder.
Oklahoma	2010 Okla. Sess. Laws, Chap. 166 (SB 2045 of 2010) Requires all individual and group health insurance policies that provide medical and surgical benefits to provide the same coverage and benefits to any individual under the age of 18 years who has been diagnosed with an autistic disorder as it would provide coverage and benefits to an individual who has not been diagnosed with an autistic disorder.
Oregon	Or. Rev. Stat. § 743A.190 (2007 Or. Laws, Chap. 872; HB 2918) Requires specified health benefit plans to provide coverage for an enrolled child less than 18 years of age who is diagnosed with a pervasive developmental disorder or autism all medical services, including medical and rehabilitative services, that are medically necessary and are otherwise covered under the plan. Rehabilitative services include physical, occupational or speech therapy services to restore or improve function.
Tennessee	Tenn. Code Ann. § 56-7-2367 (2006 Tenn. Pub. Acts, Chap. 894; SB 2719) Defines autism spectrum disorder as a neurological disorder. Requires that contracts and policies that provide benefits for neurological disorders to provide benefits and coverage for treatment of children less than 12 years of age with autism.
Virginia	Va. Code § 38.2-3412.1:01 (1999 Va. Acts, Chap. 941; SB 430) Requires specified insurers that provide coverage for health care services to provide coverage for biologically based mental illnesses, including autism. Va. Code § 2.2-2818 and § 2.2-2818.2 (2009 Va. Acts, Chap. 317, SB 1351, Fiscal Impact Statement and 2009 Va. Acts, Chap. 247, HB 2557, Fiscal Impact Statement) Require the Department of Human Resource Management to establish a plan for providing health insurance coverage for state employees and retired state employees. The plan is required to include coverage for biologically based mental illness, including autism.

Sources: Health Insurance Mandates in the States 2009, The Council for Affordable Health Insurance; The National Association of Insurance Commissioners, 2006; State Autism Profiles, Easter Seals, 2008; The National Conference of State Legislatures, 2010.

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The Alaska Mental Health Trust Authority

February 7, 2011

Senator Johnny Ellis
Room #119
State Capitol
Juneau, AK 99801

RE: **SB 74 – Private Autism Insurance Coverage**

Dear Senator Ellis,

I am writing in support of **SB 74 – Private Autism Insurance Coverage**

The Alaska Mental Health Trust Authority (The Trust) appreciates your efforts to ensure that children in Alaska who experience autism receive the supports they need to be active members of our Alaskan communities. The Trust supports SB 74, which mandates that private insurance companies include coverage for treatment of autism spectrum disorders.

The Trust advocates for a robust continuum of healthcare opportunities for its beneficiaries, those experiencing developmental disabilities, mental illness, Alzheimer's disease and other related dementias and chronic alcoholics with psychosis. In Alaska today 1,512 children and young people have autism, approximately 454 of whom need significant clinical treatment. In response to these numbers, The Trust has partnered with the *Governor's Council on Disabilities and Special Education* to identify and develop treatment options for persons diagnosed with a disorder on the autism spectrum.

Thirty years of research demonstrates that with intensive early intervention, children on the autism spectrum could gain a significant number of IQ points, and half of them could achieve normal functioning within 2-3 years of treatment. With early intervention and treatment, Alaska will see a savings of $208,500 per capita in avoided special education costs and a lifetime savings of $1.08 million per capita. According to economists, without treatment it is estimated it will cost the state $3.2 million per capita. Requiring that private insurance policies include coverage for treating autism, we can help many children access the services they need, and live more productive lives.

We appreciate your advocacy on behalf of Trust beneficiaries; specifically, beneficiaries diagnosed with autism and their families, and look forward to continuing to work with you on this issue.

Sincerely,

Jeff Jessee, CEO

3745 Community Park Loop, Suite 200 Anchorage, Alaska 99508 **Tel:** 907-269-7960 **Fax:** 907-269-7966 www.mhtrust.org

The Honorable Johnny Ellis
State Capitol, Room 119
Juneau, Alaska 99801

March 28, 2011

RE: SB 74 Insurance Coverage: Autism Spectrum Disorder

Dear Senator Ellis:

The Alaska Primary Care Association (APCA) recognizes that insurance coverage often dictates access to health care for individuals. And because access greatly increases the likelihood of positive health outcomes, the APCA is supportive of efforts to expand access. In fact, the mission of the APCA is to work to promote access to health care for all Alaskans. With this goal in mind, the APCA supports access to services for Alaskans experiencing autism. SB 74 would empower these Alaskans to receive services and help ensure early identification of challenges and appropriate intervention. As a result, SB 74 would promote both a higher quality of life for these individuals and a savings to the State of Alaska and to families.

While it is difficult to predict the long term costs or consequences of the bill to the overall health system in Alaska, the positive impact the bill would have on individual Alaskans with autism and on the costs specific to these individuals is clear. The Alaska Primary Care Association thus supports SB 74 as it pertains to access to care and services for Alaskans with autism.

The Centers for Disease Control estimates that one in every 110 children is diagnosed with autism annually, and estimates a higher rate for boys at one in 70. Although these children require services from medical professionals and other providers specific to this condition, most insurance policies specifically exclude coverage for treating autism, even when the services are otherwise covered by the health plan. SB 74 would help to address this disparity in coverage and help ensure that these Alaskans receive necessary services.

Thank you for your work on behalf of Alaskans and your work on this specific issue.

Sincerely,

MMasmar

Marilyn Kasmar
Executive Director

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supporting Alaskans' health care homes

March 29, 2010

Alaska Senators and Representatives,

Please add my support for the Autism Insurance Coverage Bill. I have a 16 year old son with autism who was diagnosed when he was 4 years old by Dr. Brennan in Anchorage. When he was little my pediatrician told me to expect nothing from him, he would never be functional. Fortunately, a mother does not always listen to such advice.

He started receiving services before he was three at the Infant Learning Program. They gently guided me to the special ed preschool program at the school district. They set me up with a private speech therapist who came to the house twice a week. Speech therapy cost $150/hour and occupational therapy (we used it for sensory therapy) cost $57.50/15 minutes. Our private insurance had a maximum lifetime limit of $10,000 for these therapies. Caleb was maxed out by age 5 on our insurance.

We were able to gain coverage through TEFRA which is a part of Medicaid that covers autism if they have another physical disability. It was always iffy if he was going to qualify because he was a healthy child, other than the autism. I appealed several times through TEFRA to keep his services. At times in his young life he received therapy almost daily. The bill would have been over $500/week without state help.

With the help of Fairbanks Resource Agency (respite care, who because my part time therapists), TEFRA help, family help, school help, church help, adaptive rec help, speech and OT help, my son now goes to Lathrop High School on his own. He has one special ed class – study skills. We are approaching the end of his high school life and we have so much more to go.

Autism is a medical disability. It should be covered by insurance. The state can no longer afford to shoulder the entire bill for autism. This disability affects all of us. We should all pay.

Sincerely,

Amber Cheney
1015 Galena St.
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907-452-7294
cheneyamber@yahoo.com

Stone Soup GROUP

Supporting families who care for children with special needs

March 7, 2011

Senator Johnny Ellis
Alaska State Legislature
State Capitol Room 119
Juneau AK, 99801

Dear Sen. Ellis,
I'm writing on behalf of families served by Stone Soup Group to thank you for your leadership in sponsoring Senate Bill 74, the Autism Insurance Reform Bill. Stone Soup Group is a nonprofit agency that provides support services to families caring for children and youth with special health care needs and disabilities. With the increased incidents of autism and related disorders in the past decade, Stone Soup Group has grappled with how to assist families in accessing therapeutic interventions not covered by private insurance programs. The ability to use private insurance to access those services opens doors for thousands of families.

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 one in every 110 children, with one in every 70 boys are diagnosed annually. 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.

Stone Soup Group full supports Senate Bill 74 and the companion House Bill 79 sponsored by Rep. Petersen. Thank you for all of your hard work for Alaska's families.

Respectfully,

K Donnelly

Kelly Donnelly
Executive Director

March 30, 2011

Jack C. McRae
Senior Vice President

Senator Bettye Davis
State Capitol Room 30
Juneau, AK 99801-1182

Dear Senator Davis:

On behalf of Premera Blue Cross Blue Shield of Alaska, I am writing to you to express our concerns with SB 74 which mandates coverage for autism spectrum disorders (ASD) for children up to age 21.

We are concerned with the challenges faced by children with autism and want to approach this issue in a manner that is in their best interest balanced by the interests of all the members we serve. Our concerns relate to the coverage of predominantly educational therapies under health insurance and increased costs, particularly for specific segments of health insurance purchasers- individuals and small employers.

Coverage for Educational and Unproven Therapies under a Medical Plan

Health insurance is a means to pay for effective healthcare services and treatments, not educational therapies or unproven interventions. Under SB 74, applied behavior analysis (ABA) treatment would be required to be covered under the medical plan. The outcomes expected from ABA therapy more closely mirror social programs than medical coverage and may be considered investigational when applied to the treatment of autism.

Coverage for autism services should be considered in a comprehensive manner that accounts for the responsibilities of the public education system and should not shift the cost burden to purchasers of private health coverage. Provisions in the federal Individuals with Disabilities in Education Act (IDEA) which guarantees "free and appropriate public education" require school districts to conduct outreach to pre-school children who may be disabled and need special services. IDEA requires districts to establish individual education programs for disabled children ages 3-21 and provide special services to such children. Insurance coverage should not duplicate services that are provided through such programs, and any private coverage should not result in schools shifting responsibilities under federal and state laws to insurers.

Increased Costs for Members

Of serious concern to us is the cost impact of this benefit mandate on employers and families who are struggling to afford coverage. Our analysis of this mandate projects a premium increase of at least 3% to Alaska consumers. Excluded from this are children of employees in a self-funded plan as these plans are exempt from state mandates.

A very similar bill to mandate autism benefits was before the Washington State Legislature this session. The fiscal impact to the state as prepared by the Office of Financial Management was estimated at over $140 million for the biennium, growing to over $200 million in subsequent years. The bill has not advanced this session.

Every benefit mandate adds to the overall cost of healthcare and insurance premiums. We believe employers should have the flexibility to choose their own benefit plans without the burden of additional state mandates. An increasing load of mandates may force employers to drop health insurance altogether. We urge you to strongly consider the financial impacts for this benefit mandate proposal, especially given the current economic conditions, and in light of additional benefit requirements resulting from federal healthcare reform.

March 30, 2011

While this 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.

Children with a diagnosis of autism spectrum disorder receive the same comprehensive medical coverage under Premera plans available to any other member. This proposal will add to the overall cost of healthcare and would be borne by insured members.

Thank you for considering our concerns on this issue.

Sincerely,

Jack C. McRae

Jack C. McRae
Senior Vice President

Sen. Bettye Davis

From: Joanne Healy [marshallhealy@gmail.com]
Sent: Wednesday, March 30, 2011 8:24 AM
To: Sen. Bettye Davis; Sen. Dennis Egan; Sen. Johnny Ellis; Sen. Kevin Meyer; Sen. Fred Dyson
Subject: SB 74

I urge you to support SB 74 This is a classic example of pay a little now and save a millions in the future for our state. Early intervention works for children who are affected by autism and helps them become contributing members of our community. 37 other states support autism insurance bills for a reason it saves them money it is fiscally responsible and makes a huge difference in the lives of the families involved.

Thanks for your support,

Joanne Healy
1280 Jones Road
Fairbanks, AK 99709

Sen. Bettye Davis

[illegible]m:	Linda Robertson [stepinbcba@yahoo.com]
[illegible]t:	Wednesday, March 30, 2011 6:05 AM
To:	Sen. Bettye Davis
Subject:	Autism Insurance Bill

Dear Senator Davis:

I am a Board Certified Behavior Analyst, recently retired special educator (after over 35 years teaching preschool, infant learning, resource, intensive resource and admininistrative work), and half owner of a new business, "Step-In Autism Services of Alaska". While we are a for-profit business, since my young partner (a Board-Certified Assistant Behavior Analyst working on her Masters and BCBA) and I, need to pay our bills and support or help support our families, we are primarily concerned about providing effective, and quality services that can make a real difference to children with autism and their families.

We know, as evidenced by many, many, years of research, that behavior based programs can truly make a difference in the lives of both families and their autistic children. We are working with a number of children referred to us through Tri-West, military insurance. We have several children referred by local service agencies who currently work with us to provide services paid for through Medicaid. This is a lengthy, and sometimes fruitless process for families who are already stressed beyond what most of us would consider our "stress capacity" despite the best intentions of our local non-profit service providers.

Please, please do anything you can to support the services these families so desperately need. They need to [illegible]ore easily access the Medicaid funding or private insurance necessary to provide the services that their [illegible]ldren and young adults require to allow them to become independent or as independent as possible. This is absolutely a case where if we pay early up front we will pay much less later as these individuals will be able to assume all or more of their own care and are allowed to become contributing members of society.

Thank you so much for your attention to this very important matter,

Linda Robertson, M.Ed, BCBA
Step-In Autism Services of Alaska, LLC
3504 Industrial Avenue
Fairbanks, Alaska, 99709
Phone: (907) 378-8411
www.stepinautismalaska

Sen. Bettye Davis

m:	JayeKeener [jaye.keener@gmail.com]
nt:	Monday, March 28, 2011 9:31 AM
To:	Sen. Bettye Davis
Subject:	Please support SB 74: Autism Insurance Coverage

Dear Senator Davis,

Please support SB 74 with the intent to better support and treat Alaskans experiencing autism. The Centers for Disease Control estimates that one in every 110 children, with one in every 70 boys, are diagnosed annually. These children require extensive services from medical professionals and other providers. Most insurance policies specifically exclude coverage for treating autism, even when the services are otherwise covered by the health plan. Thank you for you time and consideration. Sincerely,

Jaye Keener

726-1001
16510 Centerfield Dr. # B-202
Eagle River, AK 99577
jaye.keener@gmail.com

Sen. Bettye Davis

From: Paul & Robin Barrett [robinbarrett@gci.net]
Sent: Sunday, March 27, 2011 1:12 PM
To: Sen. Bettye Davis
Subject: SB 74

Please support this bill. Money spent for early autism treatment will be a mere drop in the bucket when compared to the later cost of lifetime institutionalism. Our son is age 10 and severely autistic. Our insurance does not pay for the therapy he desperately needs. We have been selling our retirement assets to pay for his treatment. In the past 5 years we are out-of-pocket more than $136,000.00. Most families cannot afford such expenses (nor can we, over time) so their children are untreated and likely doomed to a lifetime of dependence on society. Again, please support this bill.

Paul and Robin Barrett

Sen. Bettye Davis

From:	David Flynn [dflynn@tdxpower.com]
Sent:	Friday, March 25, 2011 4:03 PM
To:	Sen. Bettye Davis
Cc:	Sen. Dennis Egan; Sen. Johnny Ellis; Sen. Kevin Meyer; Sen. Fred Dyson
Subject:	SB 74: Autism Insurance Coverage

My family and I live in Delta Junction , AK.

Our 3.5yr old son has autism and it is a struggle for him...and our family...to cope with the challenges of this condition.

I can be contacted as an advocate for these children and families and believe that anything that we can do to assist these special people and their families is worth doing. This bill's passing would be one way to help.

Please do what you can to see that this Bill passes.

Much appreciation in advance for your efforts in this regard...

David J. Flynn, P.Eng
TDX Project Engineer
907-865-4806 TDX
907-590-7775 cell