SB

74

<TARGET><BILL>SB 74</BILL><SUBJECT>SB
74</SUBJECT><COMM>HHSS27</COMM></TARGET>

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

ALASKA STATE LEGISLATURE

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SENATOR JOHNNY ELLIS
RULES COMMITTEE CHAIR

MEMORANDUM

To: Representative Wes Keller, Chair of the House Health & Social Services Committee

From: Senator Johnny Ellis

Date: March 2nd, 2012

Re: Hearing Request for Senate Bill 74

I respectfully request that Senate Bill 74 be scheduled for a hearing in the House Health and Social Services Committee.

I am providing a background packet for Senate Bill 74 including a current version of the bill with 12 Senate co-sponsors and 15 House cross-sponsors, a sponsor statement, a sectional analysis, letters of support and background information about autism and autism treatment.

Please feel free to contact me, or my aide Amory Lelake, at 465-3704 with any questions.

Thank you for your consideration.

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SENATOR JOHNNY ELLIS
RULES COMMITTEE CHAIR

Table of Contents: Background Information for SB 74 Insurance Coverage for Autism Spectrum Disorders

r. "Insurance Coverage for Autism Treatment & Applied Behavior Analysis" State of Missouri Department of Insurance, Financial Institutions & Professional Registration

8. Letters of Support
    a. Alaska Mental Health Trust Authority
    b. Autism Speaks
    c. Letter from Dr. Gina Green concerning medically necessary treatment for autism
    d. Governor's Council on Disabilities and Special Education
    e. Key Campaign
    f. National Association of Social Workers, Alaska Chapter
    g. Stone Soup Group
    h. Alaska Primary Care Association
    i. Boys & Girls Club of Southcentral Alaska
    j. Alaska Women's Lobby
    k. Hope Community Resources, Inc.
    l. Alaska Nurses Association
    m. Alaska Association of Homes for Children
    n. National Federation of Independent Business

9. List of Invited Testimony

Rules Committee
•
Senate Finance Committee
•
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•
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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 around 0.39% of insured premiums across all markets or $1.34 per policy holder 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.

FISCAL NOTE

STATE OF ALASKA
2012 LEGISLATIVE SESSION

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

Identifier (file name): SB074-DCCED-INS-02-21-12
Title: Insurance Coverage for Autism Spectrum Disorder
Sponsor: Senator Ellis
Requester: Senate Rules

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.

	FY13 Appropriation Requested	Included in Governor's FY13 Request	Out-Year Cost Estimates				
OPERATING EXPENDITURES	**FY13**	**FY13**	**FY14**	**FY15**	**FY16**	**FY17**	**FY18**
Personal Services	0.0		0.0	0.0	0.0	0.0	0.0
Travel	0.0		0.0	0.0	0.0	0.0	0.0
Services	0.0		0.0	0.0	0.0	0.0	0.0
Commodities	0.0		0.0	0.0	0.0	0.0	0.0
Capital Outlay							
Grants, Benefits							
Miscellaneous							
TOTAL OPERATING	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

FUND SOURCE		(Thousands of Dollars)						
1002	Federal Receipts							
1003	GF Match							
1004	GF							
1005	GF/Prgm (DGF)							
1037	GF/MH (UGF)							
1178	temp code (UGF)							
TOTAL		**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

POSITIONS							
Full-time							
Part-time							
Temporary							

CHANGE IN REVENUES							

Estimated SUPPLEMENTAL (FY12) operating costs 0.0 *(separate supplemental appropriation required)*
(discuss reasons and fund source(s) in analysis section)

Estimated CAPITAL (FY13) costs 0.0 *(separate capital appropriation required)*
(discuss reasons and fund source(s) in analysis section)

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

Initial Version of SB 74 updated on the new form for the 2012 Legislative Session

Prepared by: Linda Hall, Division Director — Phone: 907-465-2560
Division: Division of Insurance — Date/Time: 12/8/11 9:00 AM
Approved by: Susan K. Bell, Commissioner — Date: 2/21/2012
Commerce, Community, and Economic Development

(Revised 11/28/2011 OMB)

FISCAL NOTE

STATE OF ALASKA
2012 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 a health care insurer. The Division does not expect a fiscal impact as a result of this legislation.

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
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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

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

(Continued on back side)

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GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

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.

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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:

Marc Lambright, FSA, MAAA

Contents

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.

[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.

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[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%

ABA Program Annual Number of Hours

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.

[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.

8

Cost – Benefit Analysis for ASD Treatments

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

Societal Costs of Autism- Ganz Report

One of the most often cited reports explaining the financial costs of ASD is *The Lifetime Distribution of the Incremental Societal Costs of Autism* by Michael Ganz, MS, PhD 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.

Appendix

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

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 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: Number of Persons Covered	Premium (Per Person)	Total Premium	Costs Excluding Administrative Expense: Costs	Costs (% of Premium)	Cost (Per Covered Person)	Premium Increase including Admin @ 15%: 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

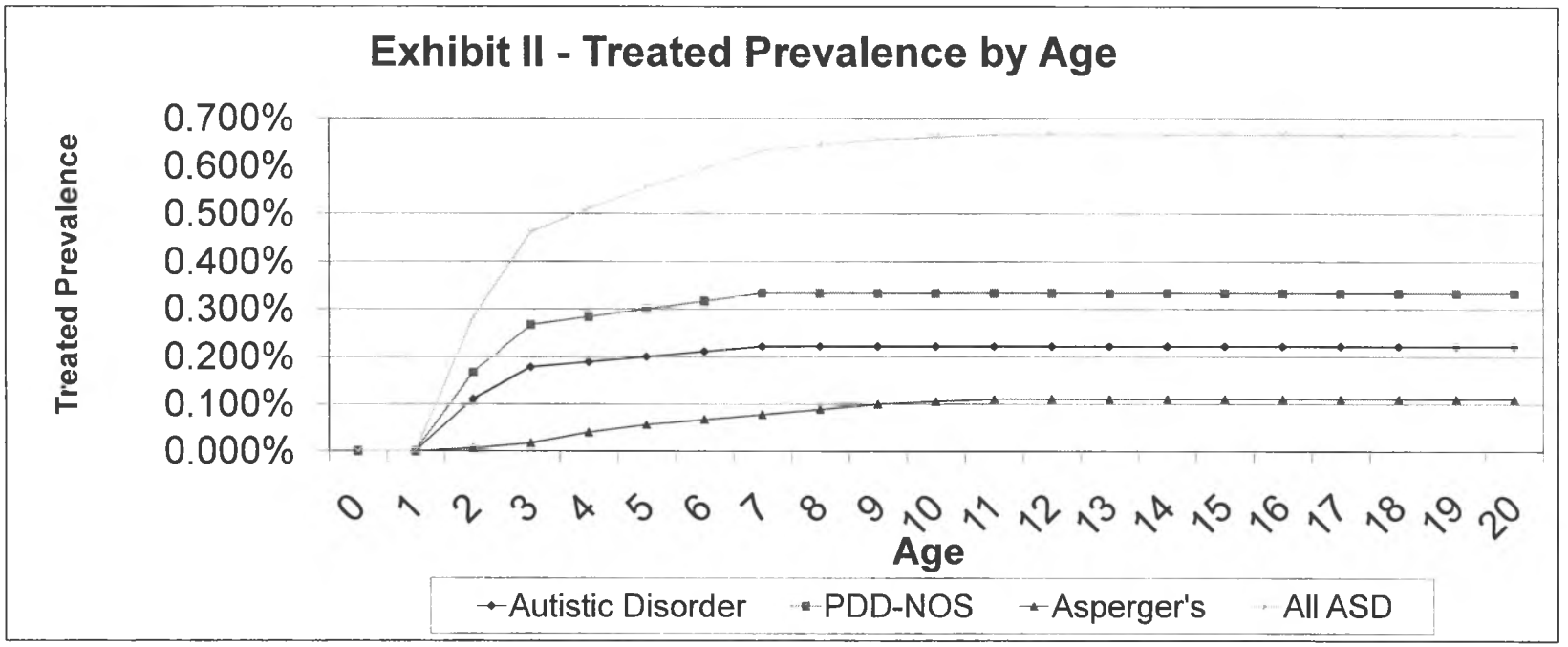
Exhibit II - Treated Prevalence by Age
Treated Prevalence
0.700%
0.600%
0.500%
0.400%
0.300%
0.200%
0.100%
0.000%
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
Autistic Disorder
PDD-NOS
Asperger's
All ASD

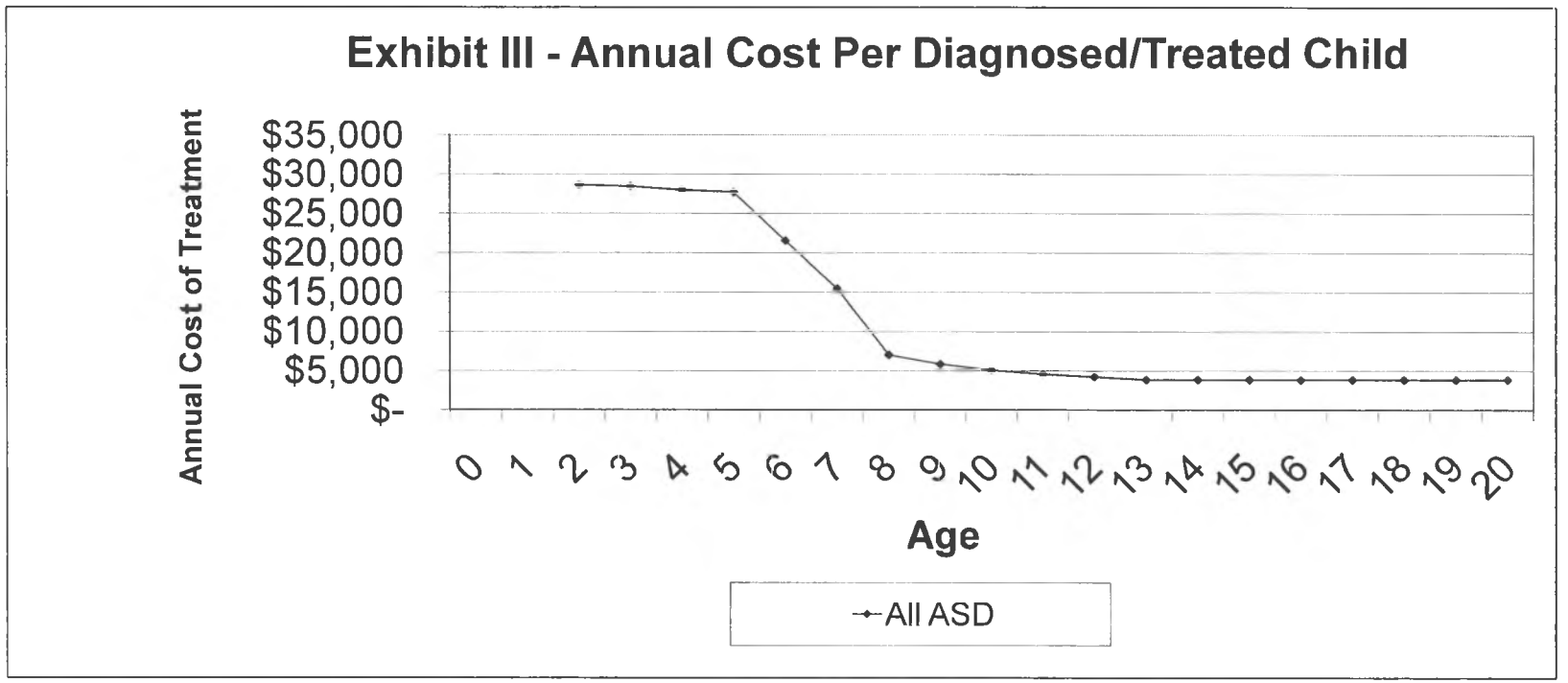
Exhibit III - Annual Cost Per Diagnosed/Treated Child
Annual Cost of Treatment
$35,000
$30,000
$25,000
$20,000
$15,000
$10,000
$5,000
$-
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
All ASD

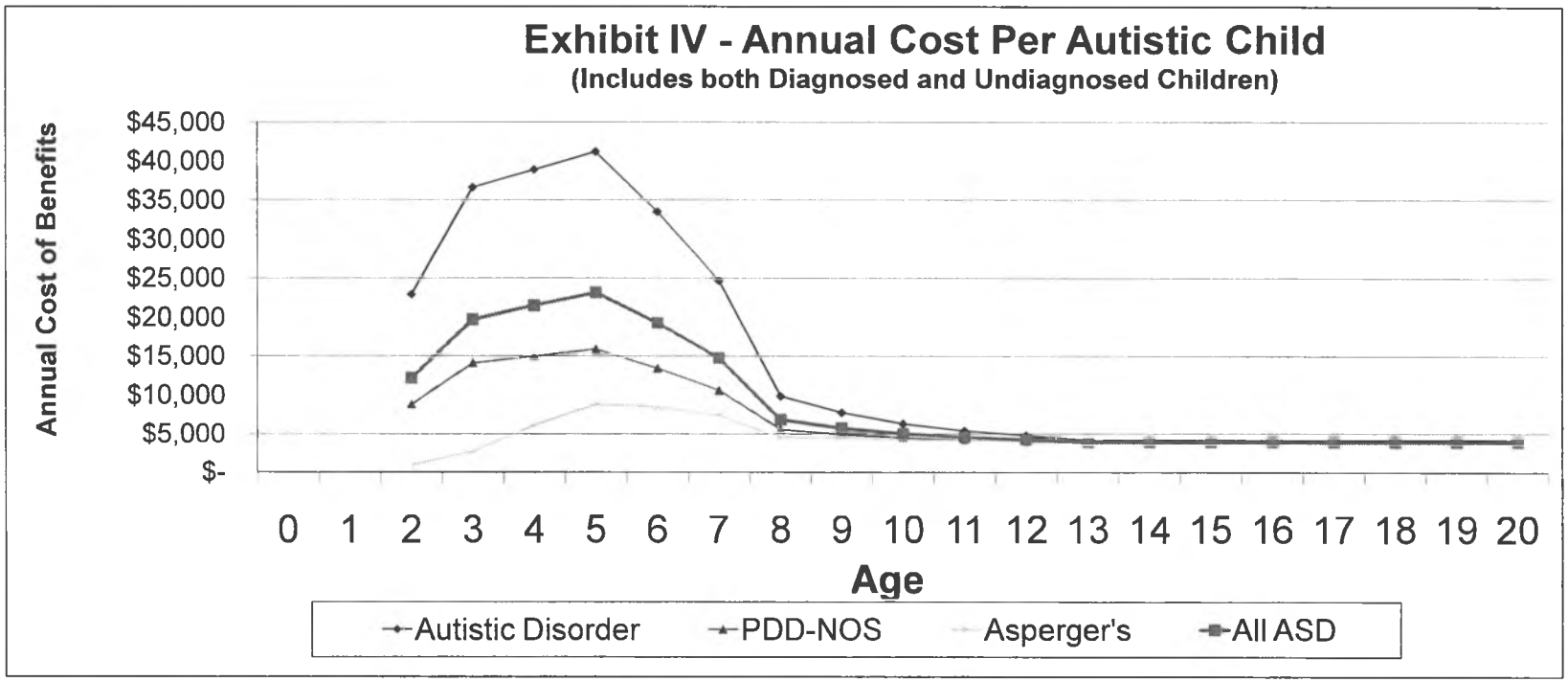
Exhibit IV - Annual Cost Per Autistic Child
(Includes both Diagnosed and Undiagnosed Children)
Annual Cost of Benefits
$45,000
$40,000
$35,000
$30,000
$25,000
$20,000
$15,000
$10,000
$5,000
$-
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
Autistic Disorder
PDD-NOS
Asperger's
All ASD

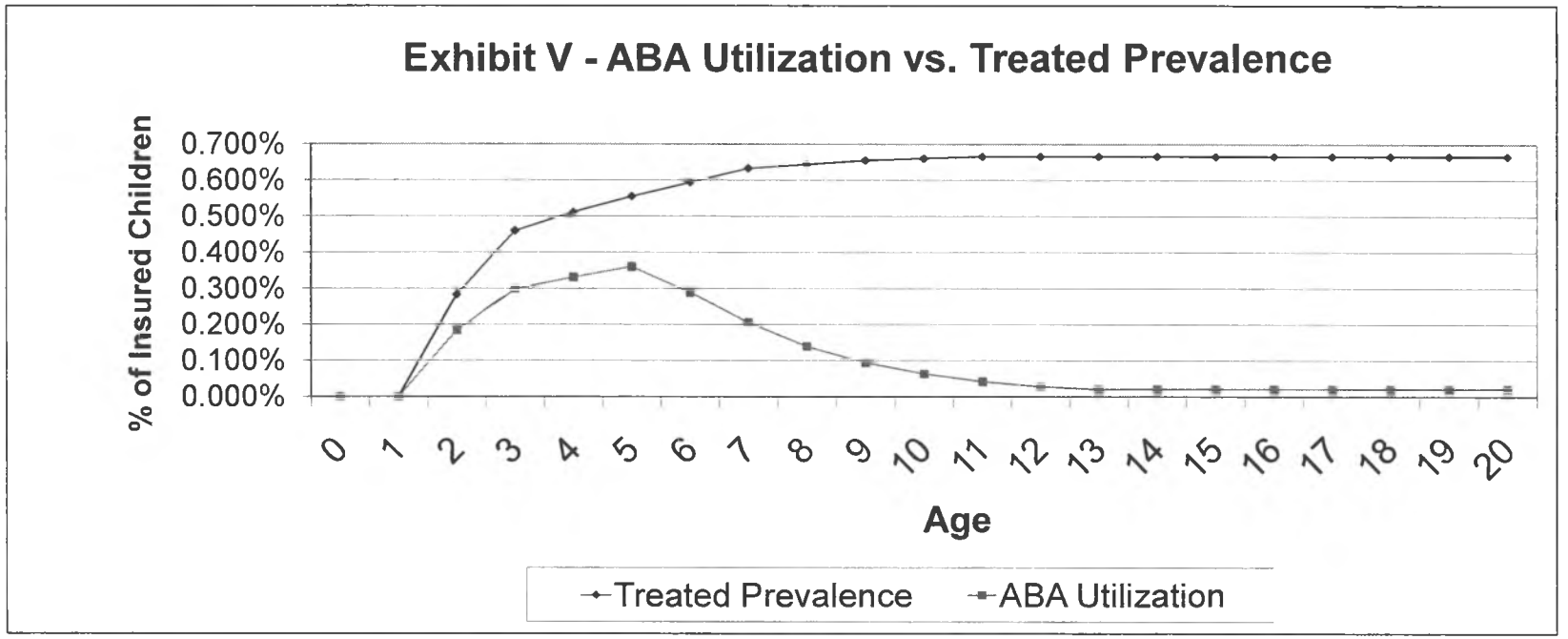
Exhibit V - ABA Utilization vs. Treated Prevalence
% of Insured Children
0.700%
0.600%
0.500%
0.400%
0.300%
0.200%
0.100%
0.000%
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
Treated Prevalence
ABA Utilization

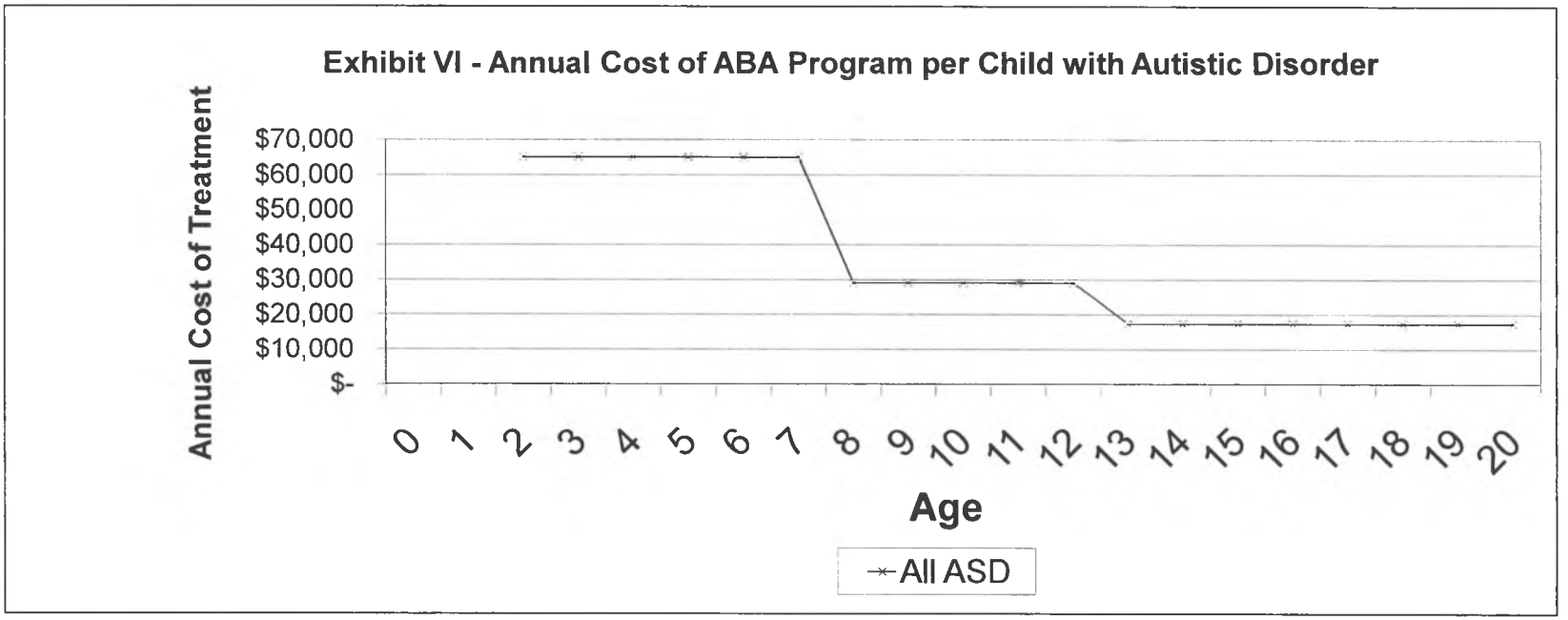
Exhibit VI - Annual Cost of ABA Program per Child with Autistic Disorder
Annual Cost of Treatment
$70,000
$60,000
$50,000
$40,000
$30,000
$20,000
$10,000
$-
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
All ASD

OLIVER WYMAN

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What Does Our Research Mean for Autism Early Intervention?

Pat Mirenda, Ph.D. and Karen D. Bopp, Ph.D. University of British Columbia

The following information is a summary of the implications of what recent UBC-based research -- funded by the Ministry of Children and Family Development, the Human Early Learning Partnership and the National Alliance for Autism Research/Autism Speaks -- might mean for early intervention designed for young children with autism spectrum disorders. This summary is based on the research described in five of the six webcasts—available via SET BC at http://www.setbc.org/—produced in October 2008.

Knowing what skills are related to development in children with autism spectrum disorder (ASD), can help us to understand why some children make a lot of progress in treatment and others, at present, do not. If we understand the relationship between the skills that children with ASD have before they start intervention and how they progress over time, we might be able to do something - for example, recommend that certain skills be targeted in early intervention which might ultimately lead to better outcomes for those children.

Overall, the research found that children who had the following skills before they started intervention had better outcomes over time.

Predicting Early Vocabulary Development in Children with Autism Spectrum Disorder

(with Veronica Smith, Ph.D., and Anat Zaidman-Zait, Ph.D.)

Synopsis:

- Early intervention programs should assess a child's ability to imitate sounds and words, use gestures to share and label (e.g., pointing, waving, etc.), and engage in pretend play (e.g., pretending a block is a car, or playing dress-up).
- These skills should be targets for early intervention if a child is not able to do them.

Early Word Learning in Children with Autism Spectrum Disorder and Early Predicate Development in Children with Autism Spectrum Disorder

(with Jenea Peralejo, M.A., and Judith Johnston, Ph.D.)

Synopsis:

- Children with autism learn words in the same sequence or pattern as typically developing children—they just learn words more slowly.
- Speech-language pathologists and other professionals can use typical vocabulary development to guide the goals they set during early intervention.
- Early treatment should focus on teaching action and descriptive words (also known as predicates – e.g., eat, love, hungry, big, red, under, yucky, out, etc.), and not just focus on object words (also known as nominals – e.g., ball, dog, mum, dad, school, etc.).

What Predicts General Language Development in Children with Autism?

Synopsis:

- The ability to engage in simple social or people games and other play routines and to point to objects and label them socially to another person are both important.
- These skills require children to be able to *take turns, imitate actions and words, and point in order to label and share information.*
- If young children with ASD do not have these skills, they should be included in early intervention programs.
- All of these skills occur during social play—not play with toys, but play with people—so lots of social play is important!

Are Problem Behaviors Related to Language Development in Children with ASD?

Synopsis:

- The ability to pay attention to people and activities and to interact socially with other people are both important for young children with ASD in order for them to learn language.

To teach children **better *attention* skills**, parents and professionals can:

- Use toys and activities that are motivating to the child. When something is motivating then a child is more likely to attend and they are also more likely to interact with another person.
- Structure or arrange the environment to gain the child's attention by reducing the number of distractions in a room. For example, taking down colourful mobiles from the ceiling, facing the child towards the walls of the room instead of toward an open area.
- Be predictable and teach within familiar routines – Doing something over and over in a predictable way allows the child to focus on the language involved within the routine rather than worrying about what comes next.
- Use visual/picture supports – pictures do not disappear like spoken words and so the child has a longer time to take in the information.
- Use visual schedules – visual schedules allow a child to see what is happening next – when there will be a break etc. – this allows them to concentrate more on the task at hand.
- Provide choices to give the child a sense of control.
- Get down to the child's eye level to help them focus.
- Use simple language with lots of expression to emphasize the key message.
- Teach or target attending skills directly within early intervention.

To teach children to ***interact socially***, parents and professionals can:

- Make sure that learning is fun!
- Provide activities that require social skills such as turn-taking, imitation, and sharing another person's attention to a favourite toy.
- Include person-to-person games and routines (e.g., tickle play, chase, songs with actions, peek-a-boo, horsey rides, etc.)

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Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model

Geraldine Dawson, Sally Rogers, Jeffrey Munson, Milani Smith, Jamie Winter, Jessica Greenson, Amy Donaldson and Jennifer Varley

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Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model

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KEY WORDS
autism, behavioral intervention, cognitive function, developmental outcomes, early intervention

ABBREVIATIONS
ASD—autism spectrum disorder
ESDM—Early Start Denver Model
ABA—applied behavior analysis
A/M—assess and monitor
PDD—pervasive developmental disorder
NOS—not otherwise specified
MSEL—Mullen Scales of Early Learning
ADOS—Autism Diagnostic Observation Schedule
VABS—Vineland Adaptive Behavior Scales
RBS—Repetitive Behavior Scale

This trial has been registered at www.clinicaltrials.gov (identifier NCT00090415).

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FINANCIAL DISCLOSURE: *Sally Rogers and Geraldine Dawson are authors of Early Start Denver Model for Young Children with Autism from which they receive royalties.*

WHAT'S KNOWN ON THIS SUBJECT: Previous studies on the efficacy of early behavioral intervention for improving outcomes for preschool-aged children with autism have yielded promising results. However, no randomized clinical trials of early developmental behavioral intervention designed for toddlers with autism have been conducted to date.

WHAT THIS STUDY ADDS: This study assessed the efficacy of the Early Start Denver Model, a comprehensive developmental behavioral intervention, for improving outcomes of toddlers with ASD. The intervention, which was initiated when children were less than 2½ years, resulted in significant improvements in IQ, language, adaptive behavior, and autism diagnosis.

abstract

OBJECTIVE: To conduct a randomized, controlled trial to evaluate the efficacy of the Early Start Denver Model (ESDM), a comprehensive developmental behavioral intervention, for improving outcomes of toddlers diagnosed with autism spectrum disorder (ASD).

METHODS: Forty-eight children diagnosed with ASD between 18 and 30 months of age were randomly assigned to 1 of 2 groups: (1) ESDM intervention, which is based on developmental and applied behavioral analytic principles and delivered by trained therapists and parents for 2 years; or (2) referral to community providers for intervention commonly available in the community.

RESULTS: Compared with children who received community-intervention, children who received ESDM showed significant improvements in IQ, adaptive behavior, and autism diagnosis. Two years after entering intervention, the ESDM group on average improved 17.6 standard score points (1 SD: 15 points) compared with 7.0 points in the comparison group relative to baseline scores. The ESDM group maintained its rate of growth in adaptive behavior compared with a normative sample of typically developing children. In contrast, over the 2-year span, the comparison group showed greater delays in adaptive behavior. Children who received ESDM also were more likely to experience a change in diagnosis from autism to pervasive developmental disorder, not otherwise specified, than the comparison group.

CONCLUSIONS: This is the first randomized, controlled trial to demonstrate the efficacy of a comprehensive developmental behavioral intervention for toddlers with ASD for improving cognitive and adaptive behavior and reducing severity of ASD diagnosis. Results of this study underscore the importance of early detection of and intervention in autism. *Pediatrics* 2010;125:e17–e23

Autism spectrum disorder (ASD) is characterized by impairments in social reciprocity and communication, and stereotyped and repetitive behaviors, with onset during early childhood. Intellectual disability is present in a large proportion of individuals.[1] With a prevalence of 1 per 150,[2] autism costs the United States $35 billion per year.[3] The lifetime per-capita societal cost of autism is $3.2 million, with lost productivity and adult care among the largest costs.[4] Thus, early-intervention methods that can improve outcome for individuals with ASD are of high importance.

The 1987 report by Lovaas[5] of an early behavioral intervention that resulted in 49% of children in the study being mainstreamed into regular classrooms and showing significant IQ gains created a groundswell of interest among parents and professionals in early intervention and raised questions about early plasticity in children with autism.[6] Although subsequent intervention studies, including a randomized, controlled trial,[7] have documented improvements in IQ for a subgroup of children, questions regarding the efficacy of early intervention have remained. Many of the studies lacked methodologic rigor. Authors of a recent meta-analysis of the efficacy of early behavioral intervention argued that stronger evidence that early behavioral intervention results in better outcomes than standard care is still needed.[8]

Our study was a randomized, controlled trial of early intensive behavioral intervention for young children with ASD that was funded by the National Institute of Mental Health (Dr Dawson, principal investigator). It was hypothesized that the early intervention would result in significant improvements in cognitive abilities of young children with ASD. The study differed from previous ones in several ways. First, we maintained a high level of methodologic rigor, including gold-standard diagnostic criteria, randomization, comprehensive outcome measures conducted by naive examiners, high retention rates, and measures of fidelity of implementation of a manualized intervention.

Second, to our knowledge, our study is the first randomized, controlled trial of intervention for toddlers with autism; all children were younger than 30 months at entry. Given the recent recommendation by the American Academy of Pediatrics that 18-month-old children be screened for ASD,[9] it is imperative that the efficacy of early-intervention models appropriate for toddlers with ASD be demonstrated.

Third, the intervention, the Early Start Denver Model (ESDM),[10] is a comprehensive early behavioral intervention for infants to preschool-aged children with ASD that integrates applied behavior analysis (ABA) with developmental and relationship-based approaches. The ESDM was designed to address the needs of toddlers with ASD as young as 12 months. The intervention is provided in a toddler's natural environment (the home) and is delivered by trained therapists and parents. In our study, children received structured intervention at high intensity, consistent with the National Research Council's recommendation.[11]

PATIENTS AND METHODS

Study Procedures

Forty-eight children between 18 and 30 months of age diagnosed with autistic disorder or pervasive developmental disorder (PDD), not otherwise specified (NOS), were randomly assigned to 1 of 2 groups: (1) the ESDM group received yearly assessments, 20 hours/week of the ESDM intervention from University of Washington clinicians, parent training, and parent delivery for 5 or more hours/week of ESDM, in addition to whatever community services the parents chose; and (2) the assess-and-monitor (A/M) group received yearly assessments with intervention recommendations and referrals for intervention from commonly available community providers in the greater Seattle region.

Children were evaluated by experienced examiners naive to intervention status at baseline (preintervention), 1 year after onset of the intervention, and at either 2 years after onset of the intervention or at 48 months of age, whichever yielded a longer time frame.

Participants

Participants were recruited through pediatric practices, Birth to Three centers, preschools, hospitals, and state and local autism organizations. Exclusion criteria included (1) a neurodevelopmental disorder of known etiology (eg, fragile X syndrome), (2) significant sensory or motor impairment, (3) major physical problems such as a chronic serious health condition, (4) seizures at time of entry, (5) use of psychoactive medications, (6) history of a serious head injury and/or neurologic disease, (7) alcohol or drug exposure during the prenatal period, and (8) ratio IQ below 35 as measured by mean age equivalence score/chronological age on the visual reception and fine motor subscales of the Mullen Scales of Early Learning (MSEL).[12] Children who developed seizures during the course of the study were not excluded. Inclusion criteria included age below 30 months at entry, meeting criteria for autistic disorder on the Toddler Autism Diagnostic Interview,[13] meeting criteria for autism or ASD on the Autism Diagnostic Observation Schedule,[14] and a clinical diagnosis based on *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) criteria[15] using all available information, residing within 30 minutes of the University of Washington,

and willingness to participate in a ≥2-year intervention. At baseline, 18 children in the A/M group and 21 in the ESDM group received a DSM-IV diagnosis of autistic disorder. Six children in the A/M group and 3 in the ESDM group received a diagnosis of PDD NOS. This difference was not significant (Fisher's exact test, $P = .231$). The ethnicities involved were Asian (12.5%), white (72.9%), Latino (12.5%), and multiracial (14.6%). The male-to-female ratio reflected the expected ratio in ASD of 3.5:1.

Retention rates were 100% (1-year) and 100% (2-year) for the ESDM group and 96% (1-year) and 88% (2-year) for the A/M group, which yielded a sample size of 24 in the ESDM and 21 in the A/M group at outcome. Figure 1 shows the participant flowchart.

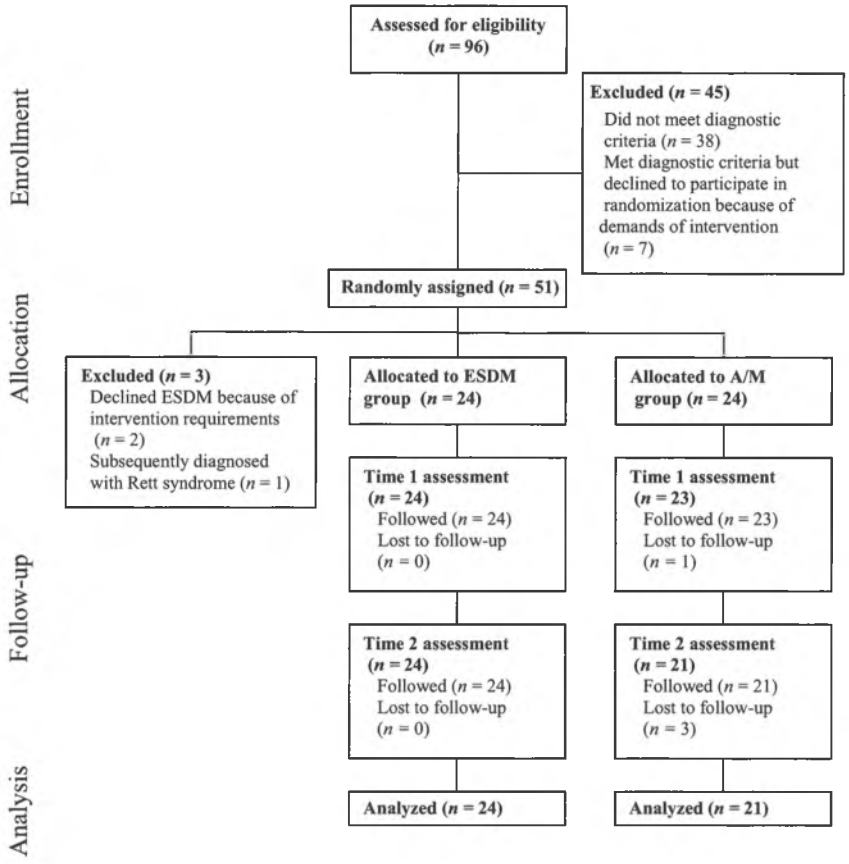

FIGURE 1
Participant flowchart.

Measures

Autism Diagnostic Interview–Revised

The toddler version of the Autism Diagnostic Interview–Revised[13] is a semistructured parent interview that assesses autism symptoms across 3 domains: social relatedness; communication; and repetitive, restricted behaviors.

Autism Diagnostic Observation Schedule

The Autism Diagnostic Observation Schedule (ADOS), WPS version,[14] is a semistructured standardized observation that measures autism symptoms in social relatedness, communication, play, and repetitive behaviors. A standardized severity score based on codes within these domains can be calculated to compare autism symptoms across modules.[16]

Mullen Scales of Early Learning (MSEL)

The MSEL[12] are a standardized developmental test for children from birth to 68 months of age. Four of the 5 subscales were administered: fine motor, visual reception, expressive language, and receptive language. *T* scores for subscales have a mean of 50 (SD: 10). The early-learning composite score is a standard score with mean of 100 (SD: 15).

Vineland Adaptive Behavior Scales

The Vineland Adaptive Behavior Scales (VABS)[17] are a parent interview that assesses social, communication, motor, and daily living skills. They provide age-equivalent and standard scores for several subscales, including expressive and receptive language and social adaptive functioning.

Repetitive Behavior Scale

The Repetitive Behavior Scale (RBS)[18] is a parent questionnaire that characterizes the severity of repetitive behaviors, yielding 6 subdomain scores (eg, sameness, self-injurious behavior) and a total score.

Randomization

Participants were stratified into 2 groups on the basis of composite IQ at entry (<55 and 55) and gender to ensure comparable IQ and gender ratios between groups. Within each of these strata, randomization was conducted by using random permuted blocks of 4. The intervention groups did not differ at baseline in severity of autism symptoms based on ADOS scores, chronological age, IQ, gender, or adaptive behaviors (see Table 1).

Intervention Groups

ESDM Group

The ESDM group was provided with intervention by trained therapists for

TABLE 1 Baseline Measures for ESDM and A/M Groups

	A/M Group			ESDM Group			F	MS	P
	Mean	SD	N	Mean	SD	N			
Age at study entry, mo	23.1	3.9	24	23.9	4.0	24	0.48	7.52	.490
MSEL									
Early-learning composite[a]	59.4	8.6	24	61.0	9.2	24	0.40	31.69	.530
Receptive language[b]	21.2	3.8	24	21.1	4.7	24	0.01	0.19	.920
Expressive language[b]	26.0	8.6	24	24.5	7.2	24	0.48	30.08	.492
Visual reception[b]	30.8	8.9	24	33.2	11.0	24	0.70	70.08	.406
Fine motor[b]	30.6	10.7	24	33.9	11.9	24	1.02	130.02	.318
VABS									
Adaptive behavior composite[a]	69.9	7.3	24	69.5	5.7	24	0.04	1.69	.844
Communication[a]	69.6	7.3	24	68.4	7.6	24	0.32	17.52	.577
Socialization[a]	72.4	9.4	24	73.8	7.7	24	0.29	21.33	.594
Daily living skills[a]	86.8	10.0	24	87.3	11.4	24	0.03	3.52	.381
Motor skills[a]	72.5	6.5	24	70.9	6.2	24	0.78	31.69	.862
ADOS severity score	6.9	1.7	24	7.2	1.7	24	0.35	1.02	.557
RBS total	21.5	19.2	24	15.2	10.8	24	1.93	468.75	.171

No significant differences among baseline measures were found ($P > .10$ on all measures).
[a] Standard score (mean: 100 [SD: 15]).
[b] T score (mean: 50 [SD: 10]).

2-hour sessions, twice per day, 5 days/week, for 2 years. A detailed intervention manual and curriculum were used.[19] One or both parents were provided with parent training from the primary therapist during semimonthly meetings, during which the principles and specific techniques of ESDM were taught. Parents were asked to use ESDM strategies during daily activities and to keep track of the number of hours during which they used these strategies. ESDM uses teaching strategies that involve interpersonal exchange and positive affect, shared engagement with real-life materials and activities, adult responsivity and sensitivity to child cues, and focus on verbal and nonverbal communication, based on a developmentally informed curriculum that addresses all developmental domains. Teaching strategies are consistent with the principles of ABA, such as the use of operant conditioning, shaping, and chaining. Each child's plan is individualized. There is a strong parent-family role responsive to each family's unique characteristics. Parents are taught the basic ESDM strategies and asked to use them during everyday activities such as feeding, bath time, and play. Parents chose teaching objectives from the curriculum that they viewed as high priority.

Intervention programs were supervised by a graduate-level, trained lead therapist who had a minimum of 5 years' experience providing early intervention to young children with autism, with ongoing consultation from a clinical psychologist, speech-language pathologist, and developmental behavioral pediatrician. An occupational therapist provided consultation as needed. Intervention objectives and strategies were reviewed, and the intervention was observed at least biweekly by the lead therapist and every 3 months by the speech-language pathologist. Intervention was delivered by therapists who typically held a baccalaureate degree, received 2 months of training by the lead therapist, and met weekly with the lead therapist. Therapists were trained to competence, defined as completing coursework, passing tests, mastering the intervention, demonstrating fidelity of 85% of maximum scores on the fidelity instrument, and maintaining ongoing fidelity.[20]

ESDM intervention hours were systematically recorded. Although 20 therapist-delivered intervention hours per week were made available, the actual mean was 15.2 hours (SD: 1.4) because of illnesses, vacations, and so on. Parents reported spending an average of 16.3 hours/week (SD: 6.2) using ESDM strategies. The ESDM group reported an average of 5.2 hours/week (SD: 2.1) in other therapies (eg, speech therapy, developmental preschool) over the study enrollment period. Other therapies were documented by using an intervention history interview administered every 6 months.

A/M Group

Children who were randomly assigned to the A/M group received comprehensive diagnostic evaluations, intervention recommendations, and community referrals at baseline and again at each of the 2 follow-up assessments. Families were given resource manuals and reading materials at baseline and twice yearly throughout the study. The A/M group reported an average of 9.1 hours of individual therapy and an average of 9.3 hours/week of group interventions (eg, developmental preschool) across the 2-year period during which the intervention study was conducted. In the greater Seattle area, there are a number of Birth to Three centers that provide interventions, speech and language therapy, and occupational therapy. Developmental preschool programs vary but typically include special education and related services. There are a number of private ABA providers in the community.

Data Analysis

The effect of ESDM intervention was assessed by using repeated-measures analysis of variance, with a priori contrasts that compared baseline scores with 1- and 2-year outcome scores. The primary outcome measures were the MSEL composite standard score and the VABS composite standard score.

TABLE 2 Child Outcomes After 1 and 2 Years of Study Participation

	1-y Outcome						2-y Outcome						Group × Time (Baseline vs 1-y)			Group × Time (Baseline vs 2-y)		
	A/M ($N = 23$)			ESDM ($N = 24$)			A/M ($N = 21$)			ESDM ($N = 24$)								
	Mean	SD	Δ	Mean	SD	Δ	Mean	SD	Δ	Mean	SD	Δ	F	MS	*P*	F	MS	*P*
Chronological age, mo	38.1	3.8	15.3	38.8	4.4	14.9	52.1	4.3	29.3	52.4	3.4	28.5	0.95	2.18	.334	1.27	6.91	.266
MSEL																		
Early-learning composite	64.0	13.8	4.4	76.4	23.4	15.4	66.3	15.3	7.0	78.6	24.2	17.6	5.99	1416.90	.018	4.31	1264.38	.044
Receptive language	31.1	11.1	9.8	38.9	15.4	17.8	31.5	10.6	10.2	40.0	16.3	18.9	4.00	745.21	.051	4.14	843.56	.048
Expressive language	33.0	11.5	6.7	36.1	14.2	11.6	30.0	9.2	4.0	36.6	13.6	12.1	1.99	290.43	.165	4.88	748.07	.033
Visual reception	29.0	10.7	−1.7	38.8	16.4	5.6	34.5	13.0	4.5	41.0	17.9	7.8	4.22	621.97	.046	0.63	126.23	.433
Fine motor	26.1	8.6	−5.0	32.7	11.7	−1.3	28.5	9.5	−2.8	33.5	12.2	−0.4	1.32	161.35	.256	0.46	63.81	.503
VABS	63.7	8.8	−6.3	65.7	9.8	−3.8	59.1	8.8	−11.2	68.7	15.9	−0.8	0.85	71.61	.360	7.05	1181.82	.011
Communication	71.0	13.0	1.2	73.5	11.7	5.0	69.4	15.8	−0.7	82.1	21.8	13.7	1.38	175.69	.246	6.38	2300.98	.015
Socialization	68.9	12.1	−3.5	70.0	9.9	−3.8	63.1	9.3	−8.9	69.2	11.6	−4.6	0.01	1.15	.934	1.29	204.57	.263
Daily living skills	65.3	7.1	−7.4	65.6	8.6	−5.3	58.0	8.1	−14.5	64.7	12.4	−6.2	0.89	51.78	.350	6.73	773.34	.013
Motor skills	70.7	12.2	−15.9	75.1	14.4	−12.2	64.1	12.3	−23.1	77.4	19.8	−9.9	0.99	157.43	.326	7.40	1881.65	.009
ADOS severity score	7.3	2.1	0.4	6.5	1.5	−0.7	7.3	1.8	0.3	7.0	1.9	−0.2	3.38	13.15	.072	0.66	3.29	.422
RBS total	23.3	17.5	1.0	15.5	12.3	0.9	22.0	16.3	−0.6	16.7	13.1	2.5	0.001	0.19	.976	0.37	92.50	.545

Δ indicates mean change from baseline.

Secondary outcome measures were the ADOS severity score,[16] the RBS,[18] MSEL, and VABS subscale scores, and changes in diagnostic status (autistic disorder, PDD NOS, and no diagnosis).

RESULTS

No serious adverse effects related to the intervention were reported during the 2-year period.

1-Year Outcome

Table 2 displays statistics for 1- and 2-year outcomes, change scores relative to baseline, and group comparisons for primary and secondary measures. Significant intervention effects were found for cognitive ability after 1 year on the MSEL composite standard scores. The ESDM group demonstrated an average IQ increase of 15.4 points (>1 SD) compared with an increase of 4.4 points in the A/M group. The visual reception subscale was the only individual subscale on the MSEL on which the groups significantly differed at the 1-year outcome. The ESDM group gained 5.6 *T*-score points, whereas the A/M group declined 1.7 points. The ESDM group improved 17.8 points on receptive language compared with a 9.8-point improvement in the A/M group, a difference that fell just short of statistical significance.

As a whole, children gained raw score points in the daily living skills subscale of the VABS; however, progress was much slower in relation to the VABS normative sample between baseline and 1 year. The groups did not differ in terms of adaptive behavior, measured by the VABS composite standard score, after 1 year (the ESDM group showed a 3.8-point decline, and the A/M group showed a 6.3-point decline). The groups did not differ in terms of their ADOS severity scores or RBS total score after 1 year of intervention.

2-Year Outcome

Two years after the baseline assessment, the ESDM group showed significantly improved cognitive ability, measured by MSEL composite standard scores, which increased 17.6 points compared with 7.0 points in the A/M group. The bulk of this change seems to have been a result of receptive and expressive language, which showed increases of 18.9 and 12.1 points, respectively, for the ESDM group, whereas the A/M group improved 10.2 and 4.0 points, respectively.

The ESDM and A/M groups significantly differed in terms of their adaptive behavior as measured by the VABS composite standard scores at the 2-year outcome (see Fig 2). The ESDM group showed similar standard scores at the 1- and 2-year outcomes, indicating a steady rate of development, whereas the A/M group, on average, showed an 11.2-point average decline. Thus, the A/M group's delays in overall adaptive behavior became greater when compared with the normative sample. The A/M group showed average declines in standard scores that were twice as great as those in the ESDM group in the domains of socialization, daily living skills, and motor skills. The groups did not differ in terms of their ADOS severity scores or RBS total score after 2 years of intervention.

Diagnosis

At baseline, the diagnoses in each group were not significantly different (Fisher's exact test, $P = .461$) and were distributed as follows:

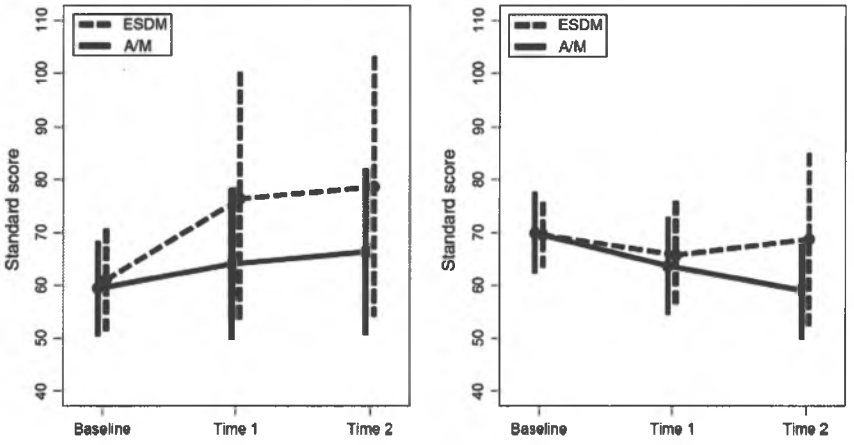

FIGURE 2

Mean scores on the MSEL (left) and the VABS composite (right) for children in the ESDM and A/M groups 1 and 2 years after entering study. Error bars indicate ±1 SD.

ESDM, 21 with autistic disorder and 3 with PDD NOS; A/M, 18 with autistic disorder and 6 with PDD NOS. At the 2-year outcome, 15 (62.5%) children in the ESDM group had the same diagnosis (14 with autistic disorder, 1 with PDD NOS) and 15 (71.4%) children in the A/M group had the same diagnosis (all 15 with autistic disorder). Diagnosis improved (baseline autistic disorder to PDD NOS at year 2) for 7 (29.2%) children in the ESDM group but for only 1 (4.8%) child in the A/M group. However, the diagnosis changed from PDD NOS at baseline to autistic disorder at year 2 for 2 (8.3%) children in the ESDM group and 5 (23.8%) children in the A/M group. Thus, children who received ESDM were significantly more likely to have improved diagnostic status at the 2-year outcome compared with children in the A/M group, as assessed by using Fisher's exact test 2 (intervention groups) × 2 (improved versus worsened diagnosis) contingency table ($P = .041$). Fisher's exact test for the 2 (intervention groups) × 3 (diagnostic change: no change versus improved versus worsened diagnosis) contingency table was just short of significance ($P = .060$).

DISCUSSION

Recommendations by the American Academy of Pediatrics[9] that all children be screened for autism at 18 months of age oblige the development of interventions that are appropriate for toddlers with ASD. To our knowledge, this study is the first to demonstrate the efficacy of an intensive intervention designed for toddlers with ASD as young as 12 months of age. After 2 years of intervention, children provided with the ESDM[19] showed significant improvements in IQ, adaptive behavior, and diagnostic status compared with children who received community interventions. Consistent evidence of improvement in communicative abilities in the ESDM group was found, as demonstrated by gains in receptive and expressive language scores on the MSEL subscales and the VABS communication subscale. Significant improvement for the ESDM group was found for overall adaptive behavior, communication, daily living skills, and motor skills. Specifically, the ESDM group, although still significantly delayed in adaptive behavior, was able to keep pace with the rate of change of the VABS normative sample, whereas the community-based intervention group continued to fall farther behind in adaptive behavior. Given the importance of adaptive behavior for everyday functioning at home and school, the fact that the ESDM group did not continue to fall farther behind is likely to affect ability to function in less-restrictive environments. This demonstrates that the ESDM intervention accelerates overall development and is generalizing to everyday life. Whereas 71% of the children in the group that received community-based intervention retained their diagnosis of autistic disorder over the 2-year period, only 56% of children in the ESDM group did so. The diagnosis of 7 children (30%) in the ESDM group changed from autistic disorder to PDD NOS, whereas this only occurred for 1 child (5%) in the community-intervention group. These diagnostic assessments were conducted by experienced clinicians who were naive with respect to intervention-group status. However, this change in diagnostic severity was not reflected in significant differences in the ADOS severity scores. This lack of correspondence between measures is difficult to interpret, because the child's performance in the ADOS contributes to clinical diagnosis. However, other behaviors, including parental report, also contribute to overall clinical diagnosis. The repetitive-behavior scores also did not change over time in either group.

CONCLUSIONS

The outcomes of this study, which involve an increase in IQ scores of 17 points (>1 SD) and significant gains in language and adaptive behavior, compare favorably with other controlled studies of intensive early intervention (eg, Smith et al [2000],[7] which delivered discrete trial intervention for >2

years for 25–40 hours/week). The group differences reported from our study are larger than those produced by other comparative trials of developmental behavioral approaches, which were conducted for briefer periods of time and with fewer hours of delivery per week.[21,22] Whether the children will sustain their gains over a longer term is an important question that will require follow-up study.

The results of this study suggest that the ESDM model,[19] an intervention approach that uses teaching strategies of ABA that are delivered within an affectively rich, relationship-focused context, can be effective for improving outcomes of young children with autism. Parents' use of these strategies at home during their daily activities likely was an important ingredient of its success.

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Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model

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Early Intervention in Autism

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We now know that professionals can diagnose children with autism when they are as young as 2 years of age (Lord, 1995). Screening and the role of the pediatrician have become even more critical as we have recognized the stability of early diagnosis over time and the importance of early intervention. At this point, experts working with children with autism agree that early intervention is critical. There is professional consensus about certain crucial aspects of treatment (intensity, family involvement, focus on generalization) and empirical evidence for certain intervention strategies. However, there are many programs developed for children with autism that differ in philosophy and a lack of research comparing the various intervention programs. Most of the programs for children with autism that exist are designed for children of preschool age, and not all are widely known or available. While outcome data are published for some of these programs, empirical studies comparing intervention programs are lacking. In this review, existing intervention programs and empirical studies on these programs will be reviewed, with a particular emphasis on the birth to 3 age group. **Key words:** *autism, early intervention, treatment*

BACKGROUND

Autism is a developmental disorder that was first described by Leo Kanner in 1943, in a classic article that included case studies of 11 children. Since that time, the diagnostic criteria have evolved based on continued observations and research, resulting in the current criteria in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition or DSM-IV* (American Psychiatric Association, 1994) and the *International Classification of Diseases or ICD-10* (World Health Organization, 1993). At the present time, ***autistic disorder*** is defined in terms of qualitative impairments in social interaction and communication, and restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities, with impairments in one of these areas prior to the age of 3 years.

In addition to autistic disorder, there are 4 other specific diagnoses included within the autistic spectrum disorders (ASD) category, which is a term now preferred by most parents and professional organizations (Filipek et al., 2000; Lord & McGee, 2001). Included among them are 2 disorders that are defined by a regression in skills: Rett syndrome and childhood disintegrative disorder. These will not be the focus of this article. Recently, a specific gene has been linked with Rett syndrome (Cheadle et al, 2000). Childhood disintegrative disorder is a very rare disorder, with reported prevalence rates of 0.6 per 100,000 (Chakrabarti & Fombonne, 2001). This disorder involves a period of normal development in the first 2 years of life, followed by a regression in a number of skill areas prior to the age of 4 years, resulting in autistic symptoms.

The other 2 ASD diagnoses are Asperger's disorder and pervasive developmental disorder – not otherwise specified (PDD-NOS). Asperger's disorder, like Autistic disorder, includes qualitative impairments in reciprocal social interactions, and restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities. However, unlike Autistic disorder, it does not require qualitative impairments in communication. In addition, this diagnosis requires that there is no clinically significant language delay prior to 3 years of age, no cognitive delays, and that the criteria for another specific PDD have not been met. If children who have ever met criteria for autistic disorder are ruled out, the diagnosis

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of Asperger's disorder is very rare (Miller & Ozonoff, 1997). Nevertheless, the diagnosis of Asperger's disorder is often used for milder cases of high-functioning autism. The final diagnosis within this general category is PDD-NOS. This disorder is characterized by qualitative impairments in social interaction, accompanied by either qualitative impairments in communication or restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities. There is still controversy about this diagnosis, including whether it is "almost autism" or "atypical autism" (Towbin, 1997).

Recent epidemiological studies have reported rates of ASDs as high as 66 per 10,000 (Fombonne, 2002), which is a surprising increase over rates reported in the past. Early identification has increased in importance, as many studies have found that children with ASDs who receive services prior to 48 months of age make greater improvements than those who enter programs after 48 months of age (Harris & Weiss, 1998; Sheinkopf & Siegel, 1998).

Over the past 10 to 15 years, there has been evidence that children with ASDs can be reliably diagnosed as young as 2 years of age (Lord, 1995). One of the largest errors in diagnoses of 2-year-olds referred for autism is underdiagnosing children on the basis of clinical impression when their scores on standardized measures are consistent with a diagnosis of autism (Lord & Risi, 1998). Possible contributors to this bias are the variability in behaviors of 2-year-olds who have ASDs (Lord, 1995) and the lack of repetitive behaviors in autism that are often present in 3-year-olds, but may not be present in 2-year-olds with autism (Cox et al., 1999; Lord, 1995; Stone et al., 1999).

In this review, early intervention programs and empirical studies available on each of the programs (Table 1) will be reviewed, with a specific focus on the birth to 3 age group. When reviewing empirical support and programs, it is important to differentiate program outcome studies, which are designed to determine if a program is having the desired effect, from controlled empirical studies, which are designed to determine if the program or specific aspects of the program are clearly responsible for the changes observed.

When reviewing research on intervention for children with ASDs, there are several important considerations. These include the age groups included in the study, the control group, the control condition, and the outcome measures (Table 1). When reviewing programs, there are several components to cover, including method of intervention, the format, the setting, who implements the program, and whether it is child- or adult-directed (Table 2). Within this review, we will first focus on issues relevant to early intervention, followed by a review of programs and empirical support for programs, and suggested next steps with regard to intervention with very young children.

INTERVENTIONS

Over the years, there have been many treatments developed for children with autism, evolving from different philosophies. These include behavioral interventions, developmental interventions, and cognitive-behavioral interventions. While each program is based on a different philosophy and uses unique intervention strategies, there is also considerable overlap in components of the programs.

Two aspects of intervention that are common to most intervention programs designed for ASDs and have empirical support include the intensity of the program and the age at which children should begin intervention. Dawson and Osterling (1997), based on a review of programs for children with autism, report that most programs involve 15 to 25 hours of intervention a week. There is also empirical evidence that children who enter programs at younger ages make greater gains than those who enter programs at older ages (Harris & Handleman, 2000; Sheinkopf & Siegel, 1998). These studies generally compare children who are older than 4 or 5 years

Table 1. Intervention studies*

Method	Authors	Subjects/groups	Age, mo	Outcome measure	Findings
TEACCH Home Program	Ozonoff & Cathcart (1998)	11 TEACCH 11 control	31–69	PEP-R	TEACCH had significant gains in PEP-R scores when compared with controls
Discrete Trial	Lovaas (1987)	19 for 40 h 19 for 10 h 21 no treatment	$M = 32$ $M = 35$	IQ score Educational placement Educational support	Intense intervention group: 47% in regular education 31 point IQ gain
Discrete Trial	McEachin, Smith, & Lovaas (1993)	19 for 40 h 19 for 10 h	$M = 32$ $M = 35$	IQ score Adaptive behavior score	Intense intervention group: IQ higher Vineland score higher
Discrete Trial	Smith, Groen, & Wynn (2000)	15 for 30 h 13 for 5 h by parents, 15 h special classes	18–42	IQ Language Behavioral measure Adaptive measure Class placement	27% in regular education 16 point IQ gain Little difference in behavior Little difference in adaptive scores
Discrete Trial & Incidental Teaching	Luiselli, Cannon, Ellis, & Sisson (2000)	8 younger than 3 y 8 older than 3 y	$M = 2.63$ y $M = 3.98$ y	ELAP or LAP	Duration of treatment was only predictor of change
Applied Behavior Analysis	Harris & Handleman (2000)	27 subjects No control group	31–65	Class placement	IQ and age predicted class placement
Incidental Teaching	McGee, Morrier, & Daly (1999)	28 subjects No control group	29	Verbal sample Peer proximity	82% using meaningful words 71% improved in peer proximity
LEAP	Strain & Hoyson (2000)	6 subjects No control group	30–53	Class placement LAP CARS	Improvements in all areas

*PEP-R, Psychoeducational Profile – Revised; M, mean; ELAP, Early Learning Accomplishment Profile; LAP, Learning Accomplishment Profile; IQ, intelligence quotient; LEAP, Lifeskills and Education for Students with Autism and other Pervasive Developmental Disorders; CARS, Childhood Autism Rating Scale; mo, months; and h, hours.

Table 2. Intervention programs

Method	Authors/program	H/wk	Format	Setting	Implementer	Adult- or child-directed
Incidental Teaching	Walden Infant Toddler Program	30+	Group	Child care center	Parents	Child
			1 to 1	Home	Educational staff	
Social Pragmatic Developmental Approach	Wetherby & Prizant	Variable	1 to 1	Home	Parent Therapist Teacher	Child
Structured Teaching	TEACCH	Variable	Group	Classroom Home	Parents School staff	Adult
Discrete Trial	Lovaas (1987)	40	1 to 1	Home	Student therapists Trained consultants	Adult
Discrete Trial	Douglass Developmental Disabilities Center	35-45	1 to 1 Small group	Class Home	School staff Parents Student therapists	Adult
Pivotal Response Intervention	Koegel, Koegel, & Harrows (1999)	Variable	1 to 1 Group	Inclusive setting	Highly skilled specialists Family Consultants	Child
				Home Preschool	School staff	
Behavioral and Inclusion	LEAP*	15	Group	Integrated classroom	Teacher	Adult and child
Developmental	Greenspan	Variable	1 to 1	Home	Parents, educational staff	Child
Developmental	Denver Model	22	Group	Classroom	Trained staff	Child

*LEAP indicates Lifeskills and Education for Students with Autism and other Pervasive Developmental Disorders.

with those who are younger than 4 or 5 years. One study comparing children younger than 3 years with those older than 3 years did not find age differences in improvement (Luiselli, Cannon, Ellis, & Sisson, 2000), which may suggest that 4 years of age is young enough to lead to significant gains. A potentially complicating factor is that children tend to make intelligence quotient (IQ) gains regardless of intervention at the younger ages (Gabriels, Hill, Pierce, & Wehner, 2001; Lord & Schopler, 1989). This also leads to difficulties in interpreting changes in IQ scores, which are often used as an outcome measure.

Most early intervention programs are designed for preschool-aged children, although they may include younger children in their programs as well. It is only more recently that we have been able to identify children with autism as young as 2 years of age. There are a few programs that are specifically designed for children between birth and 3 years of age. We will first cover the programs designed specifically for the birth to 3 age group, followed by widely available preschool programs, and finally preschool programs that are less widely available.

EARLY INTERVENTION PROGRAMS DESIGNED FOR TODDLERS

Walden Toddler program

The Walden Toddler Program (McGee, Morrier, & Daly, 2001) is a program designed specifically for toddlers with autism. The program is based on a typical daycare model, with a focus on using incidental teaching and social inclusion. Incidental teaching is a method of applied behavior analysis (ABA) that uses behavioral principles within natural learning contexts. The environment includes toys and activities that are appealing to young children, and the adult expands on requests and activities that the child initiates. The program is very structured and works on individual goals within planned activities. The program includes typical toddlers and toddlers

with autism, between the ages of 15 and 36 months. There are no controlled empirical studies of this program, but program evaluation data found that 82% of the toddlers used meaningful words when they left the program and 71% of the children showed improvements in their proximity to other children.

Social pragmatic communication approach

Amy Wetherby (Wetherby & Prizant, 1999) has also developed strategies for teaching communication to young children with ASDs, based on a pragmatic communication developmental approach. She has not developed a comprehensive intervention program; however, she has focused her intervention strategies on social pragmatic communication development for children younger than 3 years. Within this approach, the importance of teaching in naturalistic contexts, using a facilitative rather than a directive style, providing opportunities for communication, and consistently and contingently reinforcing communication attempts are emphasized (Wetherby & Prizant, 1999). Other strategies used in teaching communication to young children include incorporating environmental supports to create a predictable environment and teaching peers to initiate and respond to children with ASDs.

COMPREHENSIVE PROGRAMS

There are many comprehensive programs for children with ASDs, among the most widely known are the Developmental Intervention Model or Greenspan approach (Greenspan & Wieder, 1997), the TEACCH Model (Marcus, Lansing, Andrews, & Schopler, 1978; Mesibov, 1997; Schopler, Mesibov, & Baker, 1982), the UCLA Young Autism Project (Lovaas, 1987), the LEAP (Lifeskills and Education for Students with Autism and other Pervasive Developmental Disorders) Program, and the Denver Model. Most of these programs have been developed for children of preschool age or older. The Walden Toddler Program is an exception, as it was designed specifically for toddlers. Most of the research on the available models is descriptive rather than based on empirical studies. Currently, there is no empirical evidence that one program is superior to another.

There are many common elements of these programs, although they differ considerably in philosophy. All of these programs include young children (mean ages between 30 and 47 months), active family involvement, and are intensive in hours (12–36 hours a week). In addition, in most of the model programs, staff is well trained and experienced in working with children with autism and the physical environment is supportive. It is important to note, however, that level of experience and training can vary considerably, particularly when adapting or incorporating model programs into the public domain. All of the programs focus on developmental skills and goals, and contain ongoing objective assessment of progress. The programs also use teaching strategies designed for the generalization and maintenance of skills, individualized intervention plans based on a child's strengths and needs, and planned transitions from preschool to school age. While there are many similarities, each program also has a different emphasis and defining features. Each of the programs will be reviewed below.

The TEACCH program

The TEACCH program is a statewide, community-based intervention program that emphasizes environmental organization and visual supports, individualization of goals, and the teaching of independence and developmental skills. The setting in which the program is implemented varies, depending on the abilities and needs of each child (self-contained classroom, included classroom, home). Teaching strategies are designed to be meaningful to the child with autism, and are therefore taught within the natural environment and within context. The TEACCH program views ASDs as lifelong. From the beginning, it emphasizes skills that are important for future independence. One of the strengths

of the TEACCH program is a focus on the lifespan and community-based intervention. One of the weaknesses is the lack of empirical studies of the program.

While the TEACCH program has been in existence for more than 30 years, there are relatively few empirical studies of the program. Two studies, comparing TEACCH interventions with only public education intervention, found significant differences in scores on the Psychoeducational Profile - Revised on follow-up testing (Ozonoff & Cathcart, 1998; Panerai, Ferrante, & Zingale, 2002). Only one of these studies focused on younger children (Ozonoff & Cathcart, 1998) and compared a TEACCH home program, involving 10 sessions, in addition to services provided by the public school, to solely public school services for children between 2 and 6 years of age. Children in the TEACCH group had significantly higher scores on the PEP-R than the children in the control group following 4 months of intervention. The groups in this study were small, but were matched on age, PEP-R pretest scores, and severity of autism and not randomly assigned.

Applied behavioral analysis programs

One of the most widely known and sought-after types of intervention is applied behavior analysis (ABA). Parents and professionals frequently associate the name Ivar Lovaas and the discrete trial format of instruction with ABA intervention. The popularity of the Lovaas intervention is partly the result of his 1987 study (Lovaas, 1987) and Catherine Maurice's (Maurice, 1993) book, both of which provide accounts of remarkable improvements and use the term "normal functioning" in the best outcome group of children with autism who received discrete trial intervention.

In reality, discrete trials and the Lovaas method is only one specific type of ABA intervention. Applied Behavior Analysis includes a number of other intervention strategies and programs that are based on behavioral principles. Many treatment studies are based on behavioral interventions, which is the case not only in autism but also in psychology in general.

The UCLA Young Autism Project uses the Lovaas method of intervention, specifically discrete trial intervention, implemented in a one-to-one setting by trained ABA therapists, supervised by trained professionals. The focus of the first year is on imitation, interaction, play, and response to basic requests. In the second year, the focus shifts to continued work on language, descriptions of emotions and preacademic skills. To teach generalization, the children practice the skills in other situations and with other people, once they have mastered them in a one-to-one setting.

The UCLA Young Autism Project has been empirically studied, and the most commonly cited article is Lovaas' article (Lovaas, 1987). At the time treatment began, the children had a mean age of 35 months in the experimental group and 41 months in the control group. The experimental group received one-to-one intervention 40 hours a week, and the control group received intervention 10 hours a week for 2 to 3 years. It was this article that started the belief that autistic children required intervention at least 40 hours a week. Lovaas (1987) used the term "normal functioning" in this article (p. 9), and he used IQ and class placement as outcome variables in this study. Understandably, parents have been quite influenced by this study. In a follow-up study of the children, between 9 and 19 years of age, the experimental group continued to have significantly higher IQs and Vineland scores than the control group (McEachin, Smith, & Lovaas, 1993).

There have been numerous criticisms of this study, including nonrandom selection of groups (the age restriction was lower for children without language and children had to achieve a certain mental age to be included), nonrandom assignment to groups, and a large discrepancy between the number of hours of intervention between the control and experimental groups. However, it was one of the first empirical studies of an intervention program for children with autism.

More recently, another study on the Lovaas method of intervention has been published and addresses some of the concerns of the original article (Smith, Groen, & Wynn, 2000). In this study, the experimental group received approximately 25 hours a week of intervention while the control group received 5 hours a week of parent training. In the parent-training condition, the parents were asked to work with the children 5 hours a week at home, and they were enrolled in special education classrooms for 10 to 15 hours a week. The children with ASDs in this study had IQ scores between 35 and 75, and an age range of 18 to 42 months at the time of enrollment in the program.

As in the Lovaas study, the experimental group had higher IQs than the control group on follow-up. At the time of follow-up, between the ages of 7 and 8 years, 27% of the children in the experimental group were in regular education and had made a 16-point IQ gain. There were little differences in Child Behavior Checklist (CBCL) scores and Vineland scores between the 2 groups. The outcome was not as impressive as in Lovaas' original study, as only 27% of the children in this study were defined as best outcome (IQ > 85 and in regular education without support) as opposed to 47% in the McEachin (McEachin et al., 1993) study. The average IQ gain was half that reported in the McEachin study, and the behavior and adaptive skills ratings were still reported as problematic in the experimental group in the Smith study. Clearly, children made gains in this program, but not the same degree of progress described in the original Lovaas and McEachin studies. The Smith study, with better controls and design, suggests that children improve more than they would with early education and focused parent support or education, but do not recover when they receive approximately 25 hours a week of intensive one-to-one ABA intervention.

Another model ABA program is the Douglass Developmental Center at Rutgers in New Jersey. This program has different levels, starting with a one-to-one format for the youngest children, then moving to a small classroom with a 2:1 ratio and then to a class with typical peers, using a model similar to the LEAP program, which is described later in this article. A follow-up study of the children in the program reported that age and IQ predicted outcome (Harris & Handleman, 2000). Approximately 33% of the children had average IQs upon discharge from the program. It is important to note that 22% of the children (6 out of 27) had IQ changes from the range of mental retardation to average. Of these 6 children, 4 (67%) were between 3 and 4 years of age and 2 (33%) were between 4 and 5 years of age at the time they started the program. Upon exit from the program, 3 of these children were in special education, 2 were in integrated classrooms with support, and 1 child was fully included without support.

More recently, embedded trials, pivotal response training, and incidental teaching have emerged from the ABA literature. These techniques are less well known and less widely available at the present time, but hold some promise for intervention for very young children with autism. Contemporary ABA strategies include naturalistic teaching methods, such as natural language paradigms (Koegel, O'Dell, & Koegel, 1987), incidental teaching (Hart, 1985; McGee, Krantz, & McClannahan, 1985; McGee, Morrier, & Daly, 1999), time delay and milieu intervention (Charlop, Schriebman, & Thibodeau, 1985; Charlop & Trasowech, 1991; Hwang & Hughes, 2000; Kaiser, 1993; Kaiser, Yoder, & Keetz, 1992), and pivotal response training or teaching core behaviors, with the idea that they will lead to changes in other behaviors and skills (Koegel, 1995; Koegel, Camarata, Koegel, Ben-Tall, & Smith, 1998). These methodologies have commonalities, including teaching within natural contexts (during play, snack, work, within the classroom, at home), the use of natural reinforcers (reinforcing children for requesting by giving them what they are asking for), and systematic trials that are initiated by the child (the child makes the initial attempt).

Contemporary behavioral approaches have resulted in good outcomes for teaching language content, including single word

vocabulary, describing objects and pictures, responding to questions, and increasing the intelligibility of speech (Goldstein, 1999; Koegel et al., 1998; Krantz, Zalewski, Hall, Fenski, & McClannahan, 1981). McGee and colleagues (1999) also reported good outcomes through natural reinforcers of vocalization, speech shaping, and incidental teaching. Contemporary behavioral approaches have also been applied with some success to teach broader communication skills, such as functional communication, that may lead to decreases in challenging behaviors (Horner et al., 1990; Horner, Carr, Strain, Todd, & Reed, 2000; Koegel, Koegel, & Surratt, 1992). Spontaneous language is more difficult to teach and requires a number of naturalistic as well as developmental methods of instruction (Watson, Lord, Schaffer, & Schopler, 1989). Children who use more spontaneous language earlier in treatment have more favorable language outcomes.

Very few intervention strategies have demonstrated success using behavioral interventions in teaching skills, such as joint attention and symbolic abilities, that focus on what are considered core deficits to children with autism. However, there are a few studies that documented some success in teaching symbolic play skills through pivotal response training (Stahmer, 1995; Thorp, Stahmer, & Schreibman, 1995). Other studies that have demonstrated some improvements in these skills include increase in gaze to regulate social interactions, joint attention, shared positive affect, and the use of conventional gestures. Recently, there has also been documentation that naturalistic teaching of communication skills leads to improvements in joint attention in children with autism (Buffington, Krantz, McClannahan, & Poulson, 1998; Hwang & Hughes, 2000; Pierce & Schreibman, 1995).

The LEAP program

There is an emphasis on including peers in intervention programs, because children with autism have difficulty generalizing skills learned with adults to interactions with peers (Bartak & Rutter, 1973). Including typical peers is an essential component of both the LEAP program and the Walden Toddler program. The LEAP program includes 10 typical children and 6 children with autism between the ages of 3 and 5 years in each classroom. The children are in class for 15 hours a week. The classroom is structured and incorporates incidental teaching and other ABA methods of intervention. Interventions are both child- and adult-directed. Peers are considered to be an essential element of the program (Harris & Handleman, 1994). Peer-mediated techniques for increasing interactions involve teaching peers to be "play organizers." These strategies have been shown to be effective in increasing social interactions, which have generalized to some extent and been maintained over time (Goldstein, Kaczmarek, Pennington, & Shafer, 1992; Hoyson, Jamieson, & Strain, 1984; Strain, Kerr, & Ragland, 1979; Strain, Shores, & Timm, 1977).

DEVELOPMENTAL INTERVENTIONS

Developmental intervention is a specific term used to describe a philosophy and specific strategies for working with children with autism. One common feature of developmental interventions is that they are child-directed. In developmental interventions, the environment is organized to encourage or facilitate communicative and social interactions. The child initiates and the adult responds. There is limited empirical support for developmental approaches, but there is some support for language outcomes using such strategies (Hwang & Hughes, 2000; Lewy & Dawson, 1992; Rogers & Lewis, 1989) and many case studies (Greenspan & Wieder, 1997) using these approaches. Rogers and Lewis (1989) have documented improvements in symbolic play as a result of structured, development-based programs, and Lewy and Dawson (1992) also demonstrated improvements in gaze, turn taking, object use, and joint attention with a child-directed imitation strategy.

There are some limitations to developmental interventions. Because the intervention approach is child-directed, it requires that

the child engage in behaviors to which the adult can respond. Many children with autism do not explore the environment in the way that typical children might. They may become stuck on certain activities or not play with the toys present in their environment. Developmental methods require considerable effort and skill on the part of the teacher or therapist, as she or he must know what child behaviors to respond as well as how to respond. When the child engages in behaviors that the therapist can respond to, and the therapist is skilled, it may be an effective intervention.

The Greenspan model

One of the most well-known developmental approaches is the Greenspan approach, also known as the Developmental Individual Difference (DIR) Model (Greenspan & Wieder, 1997). The Greenspan model is described as a "relationship-based model," in which the goal is to help the child develop interpersonal connections that will lead to the mastery of cognitive and developmental skills, including (1) attention and focus, (2) engaging and relating, (3) nonverbal gesturing, (4) affect cuing, (5) complex problem solving, (6) symbolic communication, and (7) abstract and logical thinking. The program is based on following the child's lead and looking for opportunities to "close the circle of communication" or respond in a way that leads to expanding a skill or interaction. Within this model, it is recommended that a child spend at least 4 hours a day in spontaneous play interactions with an adult, at least 2 hours a day in semistructured skill building activities with an adult, and at least 1 hour a day in sensory-motor play activities. The Greenspan program is supplemented by time in an inclusive preschool program, speech and occupational therapy.

The DIR method of intervention is highly dependent on the skills of the parent or professional implementing the program. It requires that the adult recognizes when and how to respond to a child's actions and behaviors, which can make it difficult to implement the program in the community. This differs from many behavioral approaches, which have a prescribed pattern of responses and adult-initiated teaching trials. There are currently no controlled studies of this program.

The Denver model

The Denver model (Rogers & Lewis, 1989) is also based on a developmental model of intervention. This program is delivered within a classroom setting that is on a 12-month calendar and meets 4 to 5 hours a day, 5 days a week. The focus is on positive affect, pragmatic communication, and interpersonal interactions within a structured and predictable environment. Almost all activities and therapies are conducted within a play situation. Goals of the program include using positive affect to increase a child's motivation and interest in an activity or person, using reactive language strategies to facilitate communication, and teaching mental representation.

There is outcome data available on the program, based on 31 children between 2 and 6 years of age with ASDs. Children demonstrated significant developmental improvements in cognition, language, social/emotional development, perceptual/fine motor development, and gross motor development after 6 to 8 months in the program, after accounting for expected developmental progress. While only 53% of the children had functional speech when they entered the program, 73% had functional speech at follow-up.

CONCLUSION

The available evidence from a variety of programs and studies suggests that early intervention leads to better outcomes. As we have seen, a number of studies have demonstrated that children make greater gains when they enter a program at a younger age. It is important to keep in mind that most of the empirical support for the difference in gains is comparing children younger than 4 or 5 years to children older than 4–5 years of age. The preschool years are still considered "early" when it comes to early intervention.

There are many strategies for working with children with autism and not all of them are equally known or available. Most of the empirical studies have been conducted on ABA interventions. While there is evidence that certain strategies can be effective for teaching specific skills to children with autism, there is not currently evidence that one program is better than any other. Furthermore, most of the programs are developed for children aged 3 and older, and many interventionists are currently attempting to adapt their programs to better meet the needs of the 0 to 3 age group. This leads to complications when recommending intervention programs to parents of young children with autism. At this time, there is a great deal of interest in the common elements in the programs when making recommendations, including parent involvement, intensity, a predictable environment, incorporating the child's interests, actively engaging the child, and focusing on individualized developmental goals. It is important that professionals and parents are informed about the progress they can expect for their child, as well as remain aware that most research does not support a "cure" or "recovery" from autism. At this point, most of the programs focus on children of preschool age, and there is still much to learn about intervention for the birth to 3 age group.

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Autism Issues and Needs

The Governor's Council on Disabilities & Special Education

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

Governor's Council on Disabilities and Special Education

2006

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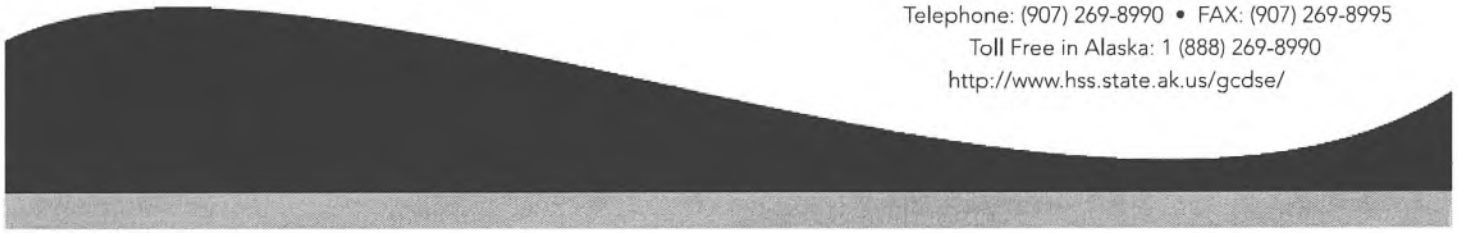

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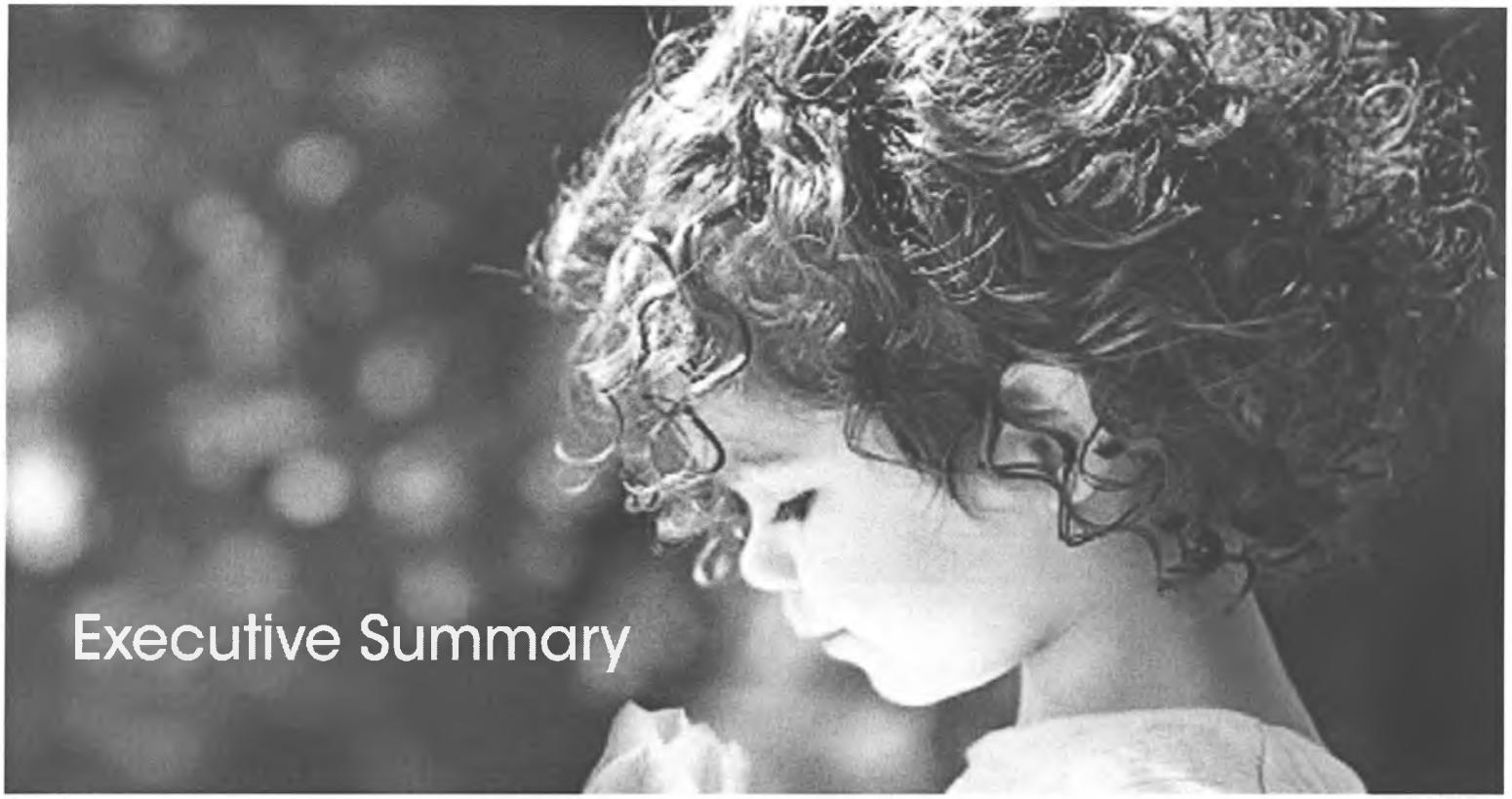
Table of Contents



Executive Summary

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

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

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

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

When children do not receive early intervention, the cost of caring for them over their lifetime exerts a substantial economic burden on society. Behavioral

therapies represent only 6.5% of the total cost of caring for an individual with ASD. By contrast, adult care represents 21% and lost productivity is nearly 31% of the total annual expense involved in caring for an individual with ASD.

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

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

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

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

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

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

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

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

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

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

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

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

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

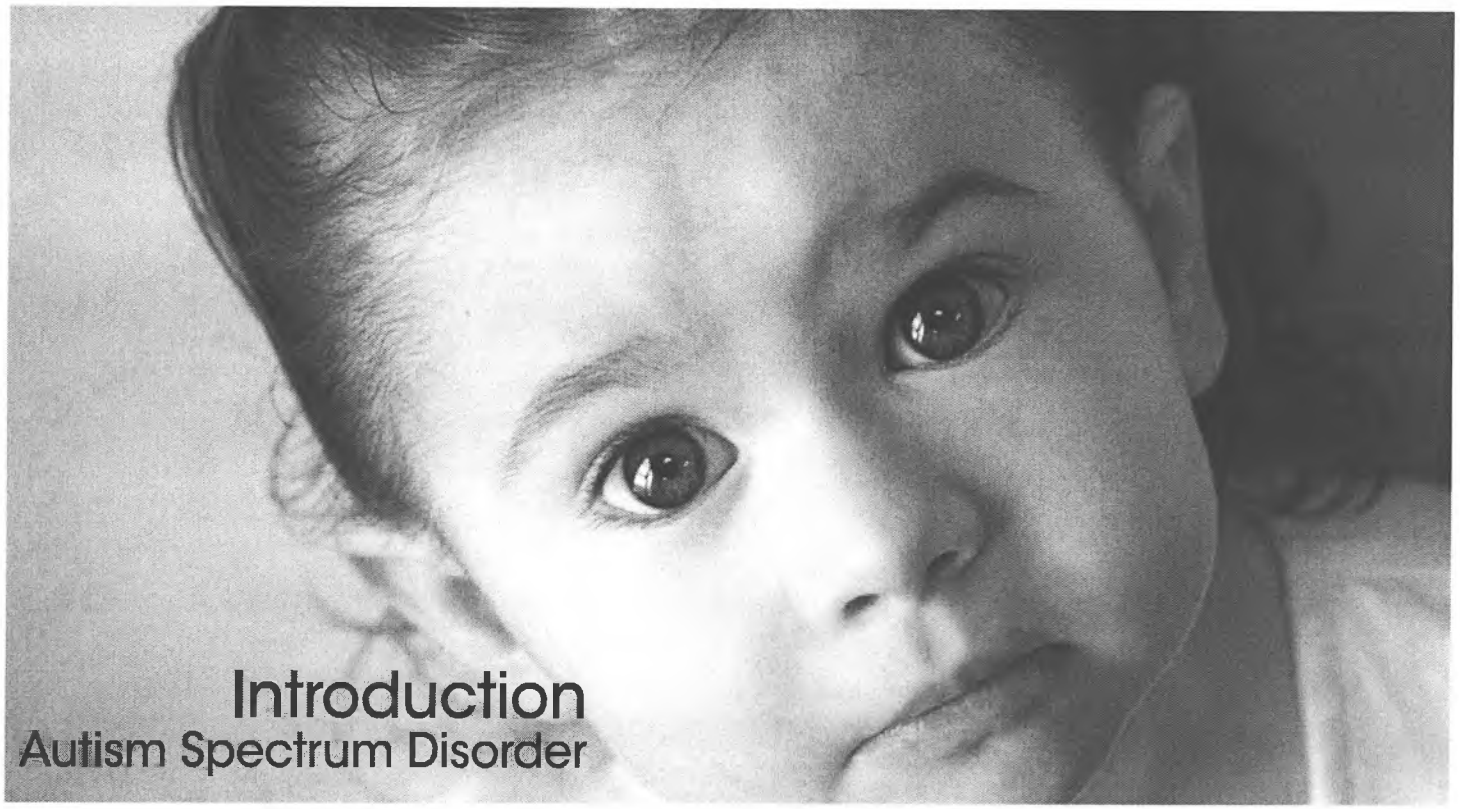
Assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family.

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

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

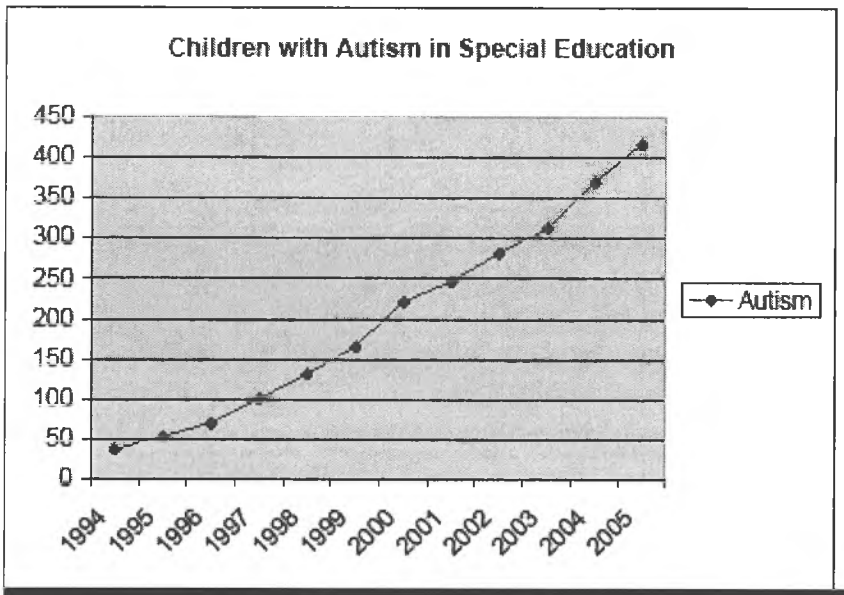
4. **Change Medicaid to ensure that children with ASD are able to receive time-limited, intensive intervention services.**

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



Introduction
Autism Spectrum Disorder

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



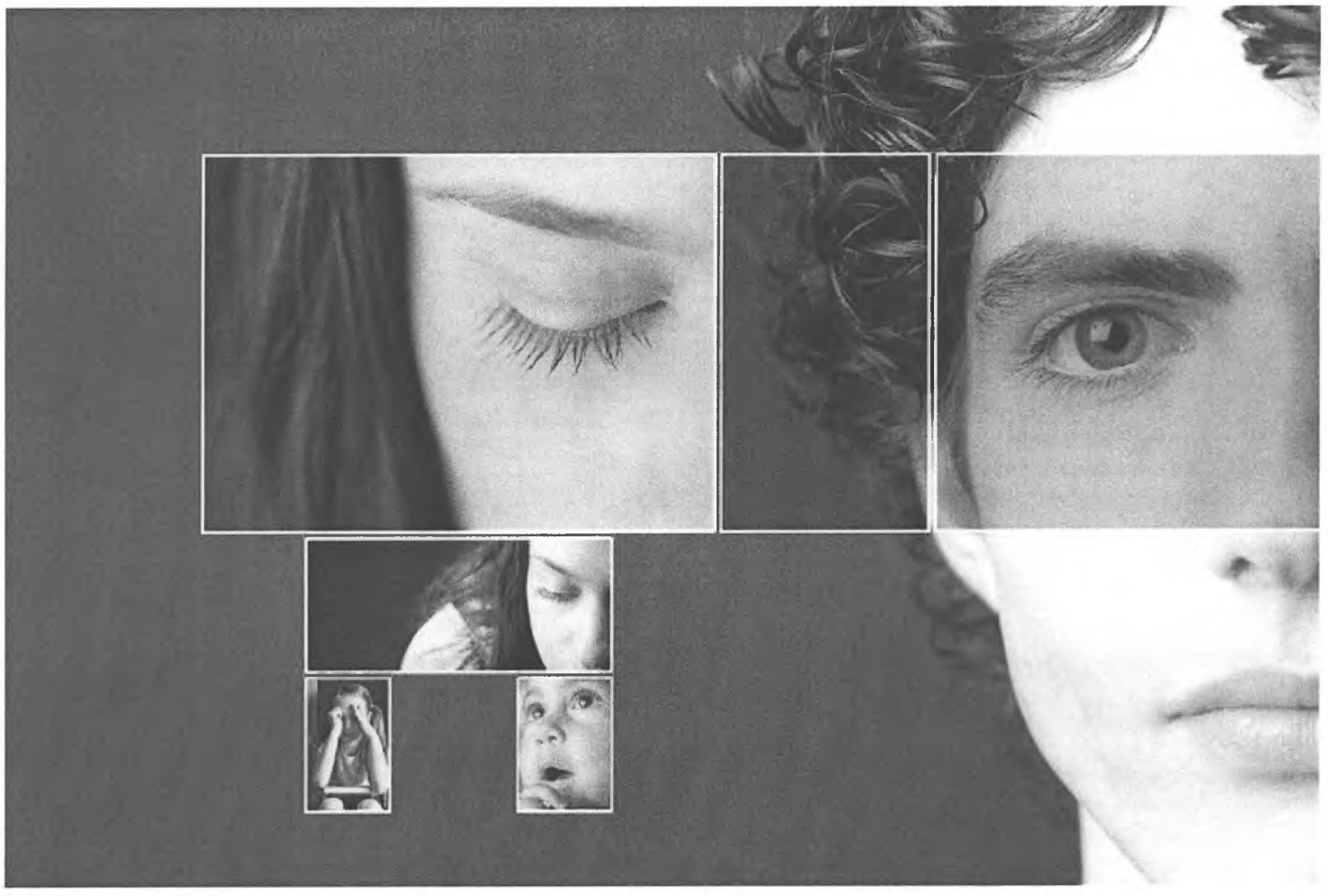
Growth of the Number of Cases of Autism in Alaskan Schools

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

Introduction Cont...

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

unusual attachments to objects. People with ASD might not seem interested in other people and prefer to be alone. Some children with ASD do not like to be held or cuddled, and many do not make eye contact with others. Individuals with ASD also show varied degrees of impairment in their verbal and nonverbal communication. Some individuals with ASD may be nonverbal, while others may not have any difficulty speaking. Some repeat something previously heard or use stock phrases or learned scripts to communicate. Cognitively, individuals with ASD develop differently from others. Many people with ASD have difficulty processing sensory stimuli and verbal input, and this affects their understanding of the world around them.



Ad hoc Committee on Autism

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

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

Values and Principles

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

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

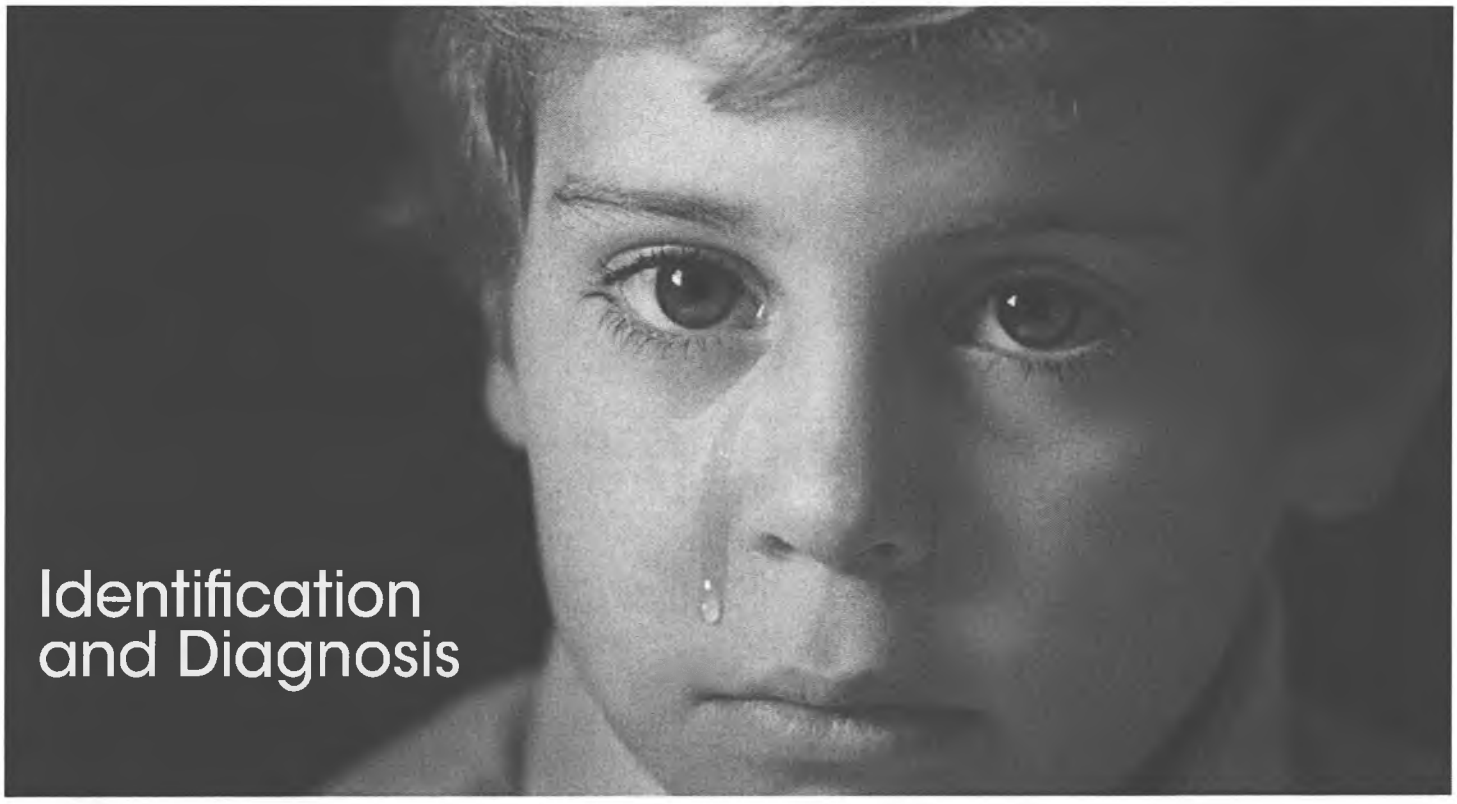
People with Autistic Spectrum Disorders:

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

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

Services for people with ASD need to be:

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



Identification and Diagnosis

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

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

Where we are now

For the past 14 years, the Children's Hospital at Providence has supported the Center for Children with Special Needs, staffed with a neurodevelopmental pediatrician skilled in the diagnosis of children with ASD and other developmental disabilities. In addition, the State of Alaska sponsors neurodevelopmental screening clinics in locations around the state. However, despite Child Find efforts on the part of early intervention and school districts, not all children with significant developmental delays

are referred for a neurodevelopmental evaluation prior to entering school. Children residing in more remote, rural locations may be identified later than children in communities in more urban settings. Accurate identification of the child's pattern of development/learning style and behavior (i.e. autism diagnosis) leads to an appropriate school certification and program as well as an approach to solving behavior problems. Families living outside of Anchorage with children who are suspected of having autism frequently must wait for an appointment and then travel to Anchorage for a medical work-up and diagnosis.

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

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

Identification and Diagnosis Recommendations

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

   Screening is a quick, simple and inexpensive process to identify children who have symptoms that could indicate a disorder. Like hearing or vision problems, early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children. Universal screening of children at well-child exams is

recommended to ensure that children with ASD are identified as early as possible in life. The M-CHAT is a 23-question, parent-completed survey that can be used at well-child check-ups and is valid for children between the ages of 16 and 36 months.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Where we are now

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

medical provider knowledgeable about the current status of autism treatment, would guide families in making informed decisions.

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

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

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

Providing effective autism treatments is found to be deficient in Alaska. Since individuals with ASD have different needs and abilities, providing a range of evidence-based treatments is extremely important. Many parents are forced to go out of state and spend a lot of

money to get the services their children need. There are currently pockets of well-trained professionals providing autism related services in Alaska, but they are mostly clustered in the major urban centers. In Alaska, Medicaid does not reimburse for intensive behavioral treatment as a medical service. Intensive behavioral treatment is an important component of autism treatment.

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

More in-state training is needed.

Service Recommendations

Medical Services

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

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

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

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

Service Recommendations Cont...

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

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

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

Educational Services

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

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

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

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

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

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

Service Recommendations Cont...

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

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

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

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

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

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

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

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

and behavioral needs of students with ASD.

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

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

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

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

Home and Community-Based Services

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

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

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

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

Service Recommendations Cont...

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

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

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

Bring training on diagnosis and interventions to Alaska.

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

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

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

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

Parent Training

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

Service Recommendations Cont...

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

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

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

Service Provider Development

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

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

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APPENDIX A

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

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

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

   a. exhibit a developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age three, that adversely affects educational performance; and

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

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

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

Characteristics of ASD include:

- Irregularities and impairments in communication
- Engagement in repetitive activities and stereotyped movements
- Resistance to environmental change or change in daily routines
- Unusual responses to sensory experiences

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

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

Autism Speaks

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

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Contents

Executive Summary

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

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

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

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

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

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

What is Autism Speaks?

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

What is Autism?

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

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

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

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

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

Variable	Children With Autism (n = 324 000)*	Children Without Autism (n = 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	5.0 (2.9-9.1)
Fair	7.4	2.9	7.7 (4.3-13.8)
Poor	3.5	0.4	21.1 (10.3-47.0)
Does the child use more medical care, mental health or educational services than is usual for most children of the same age?	59.6	11.9	12.9 (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 (24.0-52.6)
Does the child get special therapy, such as physical, occupational, or speech therapy?	76.0	6.2	44.4 (31.0-61.9)
Does the child have any emotional, developmental, or behavioral problem for which she needs treatment or counseling?	75.4	7.0	36.0 (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.

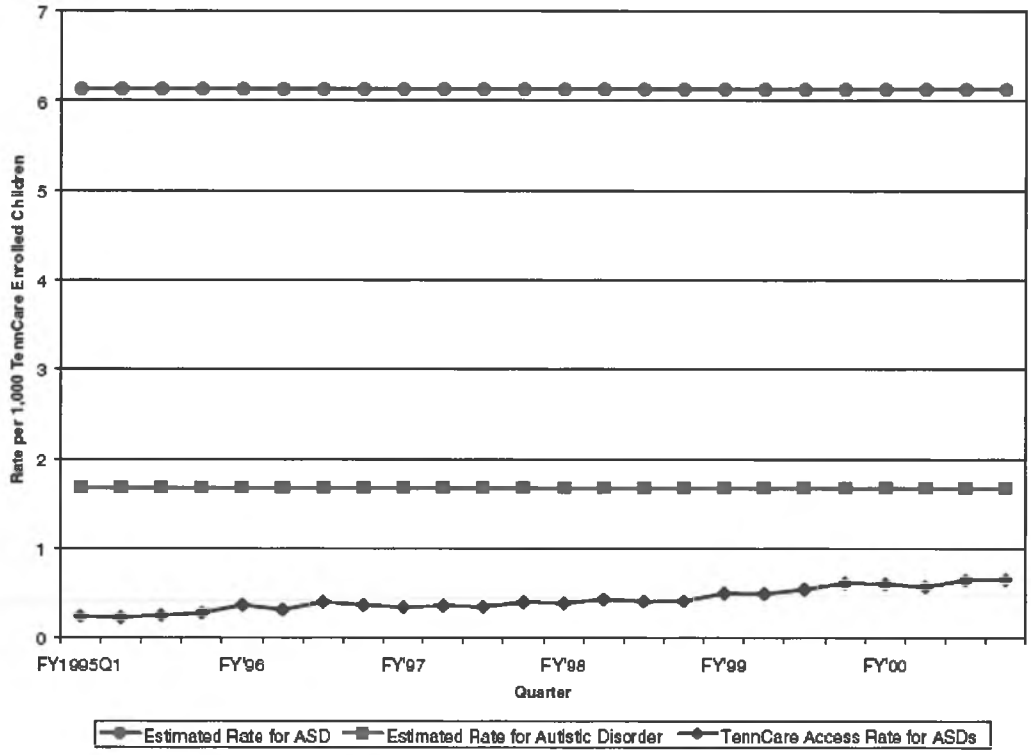

Fig. 1. Estimated incidence rates vs. service rates of autism spectrum disorders (ASDs) in TennCare for children ages 0–17 years, by quarter.

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.

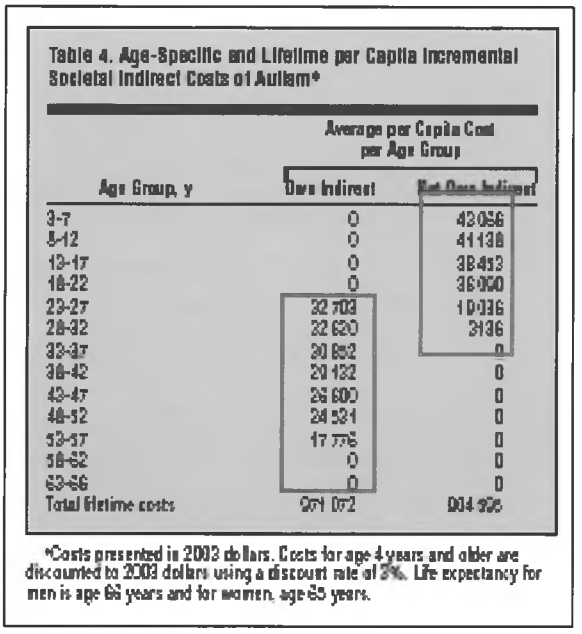

Table 4. Age-Specific and Lifetime per Capita Incremental Societal Indirect Costs of Autism*

Age Group, y	Average per Capita Cost per Age Group	
	Own Indirect	Net Own Indirect
3-7	0	42 056
8-12	0	41 138
13-17	0	38 453
18-22	0	36 050
23-27	32 703	10 036
28-32	32 620	3136
33-37	20 852	0
38-42	20 132	0
43-47	26 600	0
48-52	24 521	0
53-57	17 776	0
58-62	0	0
63-66	0	0
Total lifetime costs	971 072	994 926

*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 68 years and for women, age 85 years.

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

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

Conclusion

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

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

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

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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.

Insurance Coverage for Autism in Alaska

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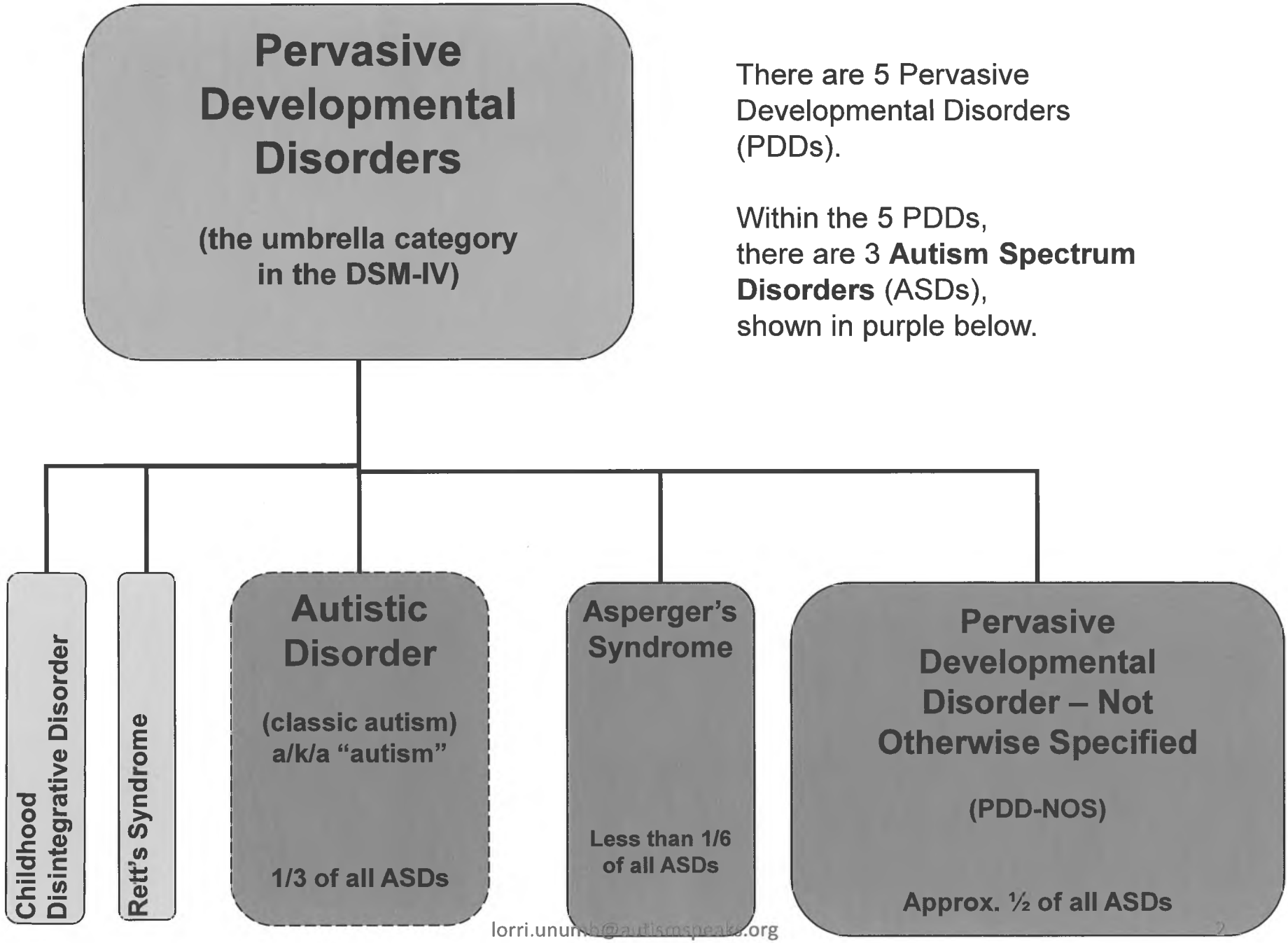

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Autism Spectrum Disorder

- 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**

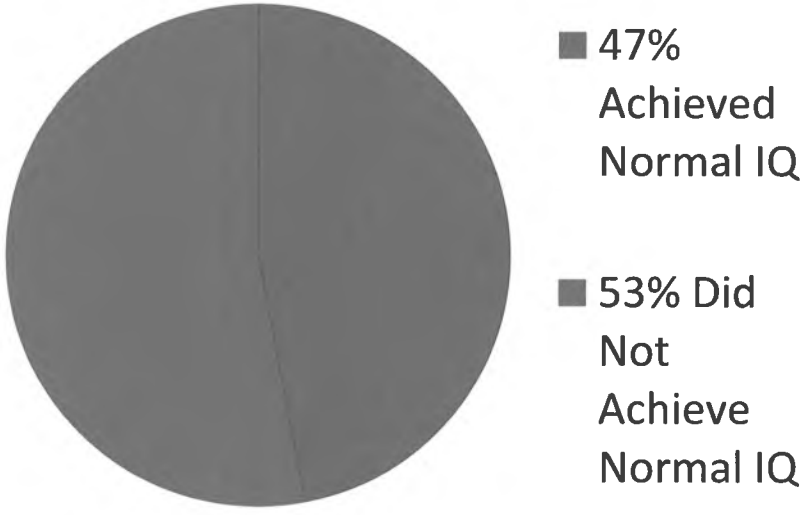
- Line therapists
  - 40 hours per week
  - $10 - $30/hour
  - 40 hours x $20 = $800/week
  - $800/week x 52 weeks = **$41,600**

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

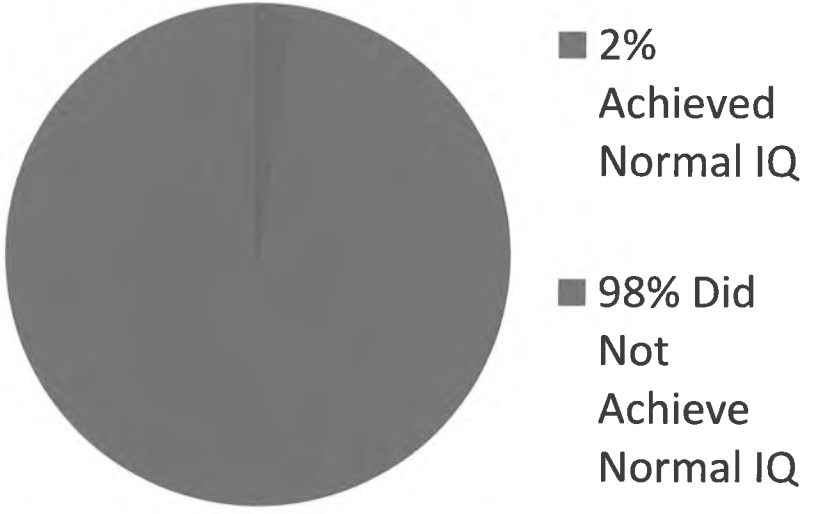
Savings to the State: Special Education

Outcome of 1987 UCLA Study on Efficacy of ABA

ABA Group



Other Intervention (Control) Group



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

*Autism Prevalence On The Rise**

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

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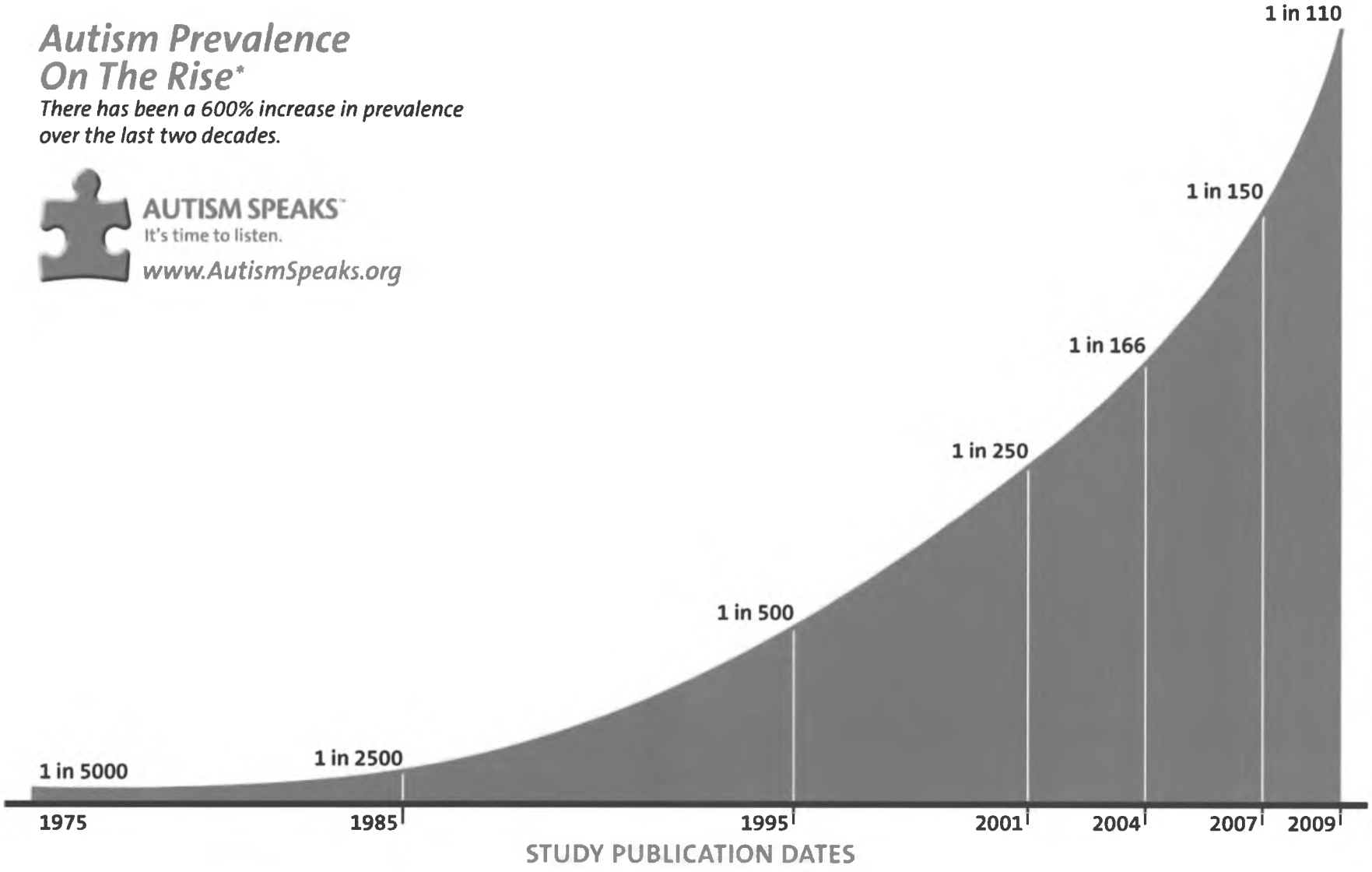
It's time to listen.
www.AutismSpeaks.org



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

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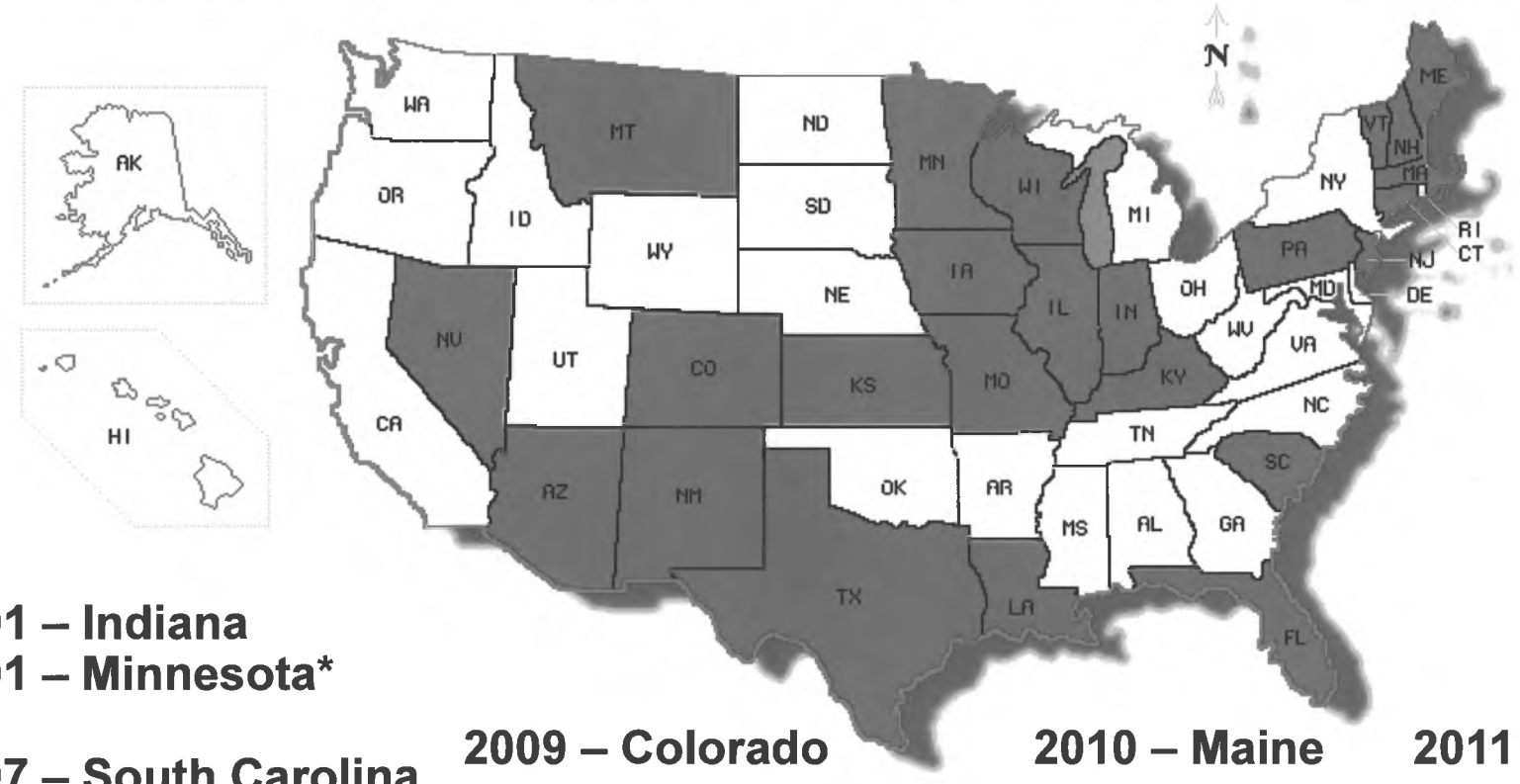
States with Autism Insurance Reform



2001 – Indiana
2001 – Minnesota*

2007 – South Carolina
2007 – Texas

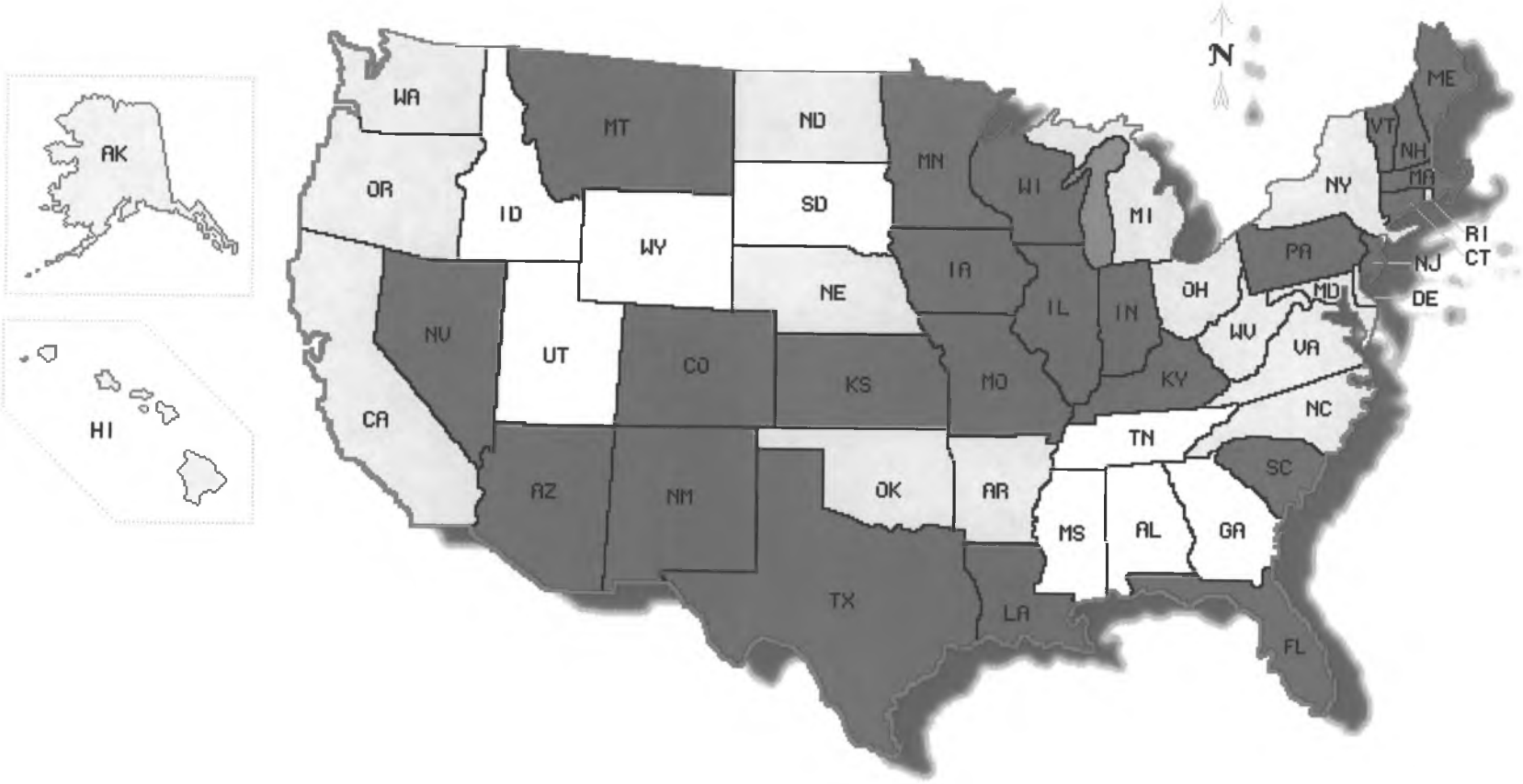
2008 – Arizona
2008 – Florida
2008 – Louisiana
2008 – Pennsylvania
2008 -- Illinois

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

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

South Carolina

APS HEALTHCARE
Healthy Together

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

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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

APS HEALTHCARE
Healthy Together

- 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 on ABA
  - 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

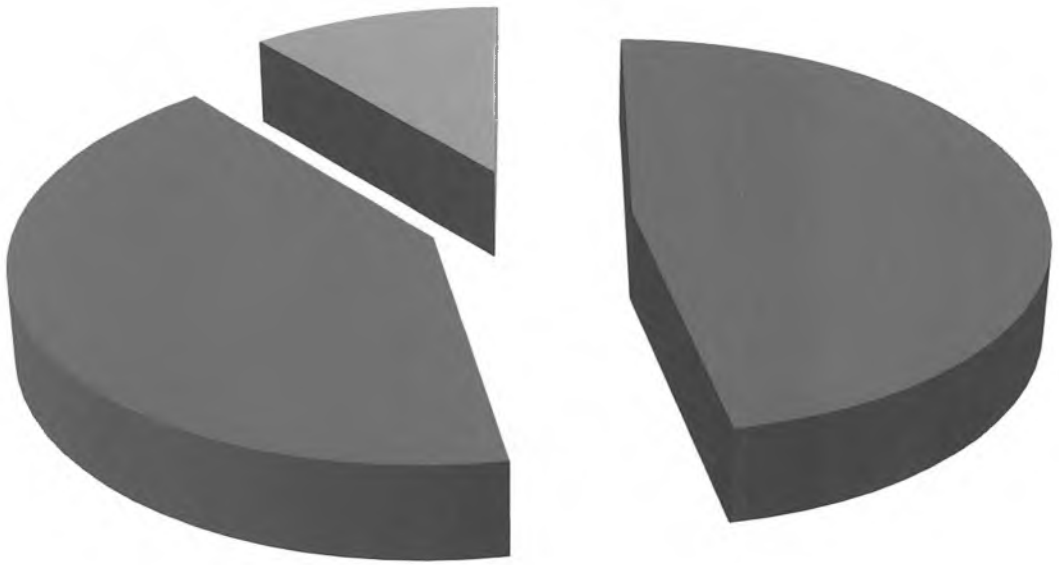
  (using 2010 South Carolina actual claims data; SC has age 16 & $50,000 cap on ABA)
- =

  _____
- 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)

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

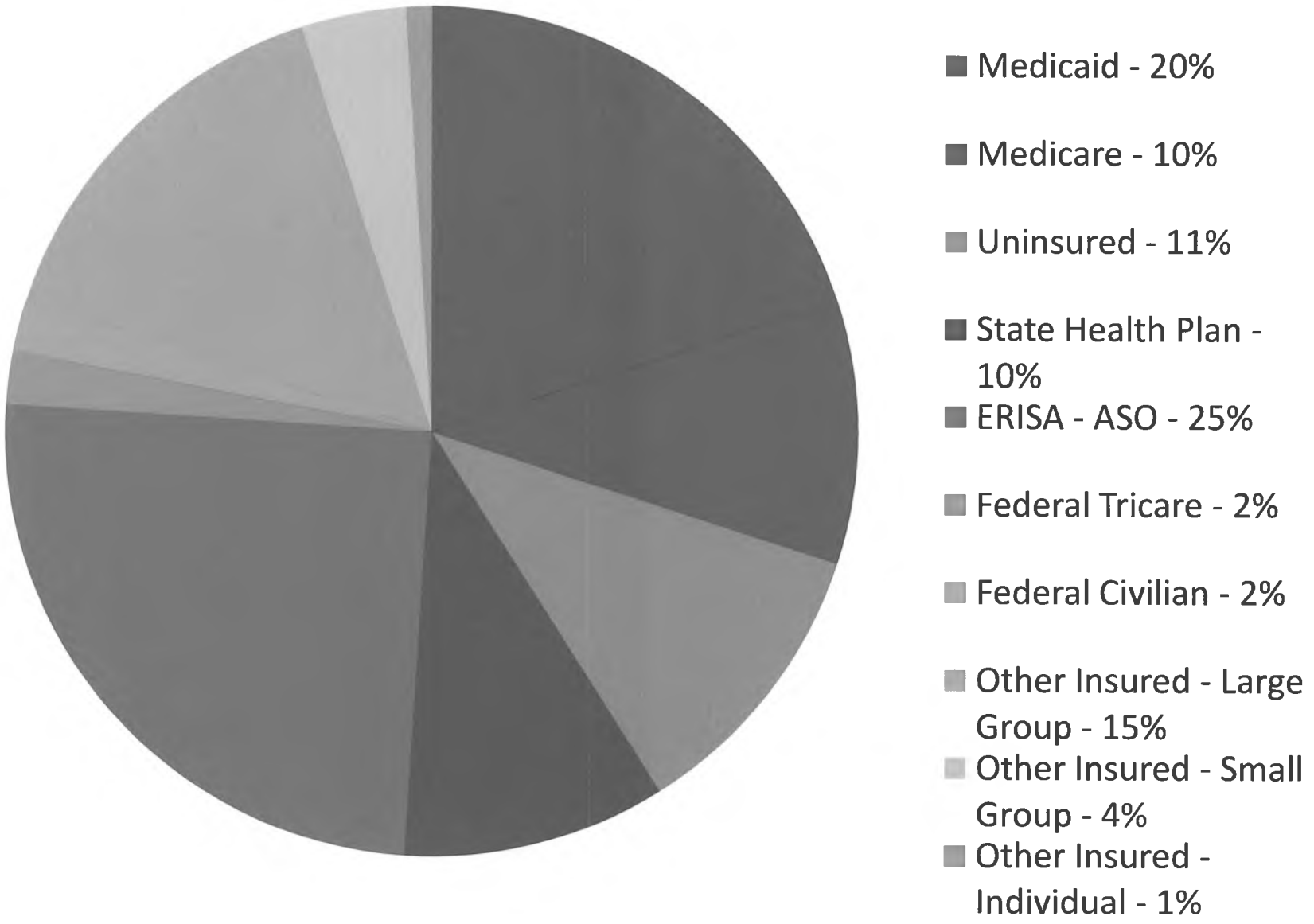
Impact of 2008 Federal Mental Health Parity Law

- 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

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 . . .

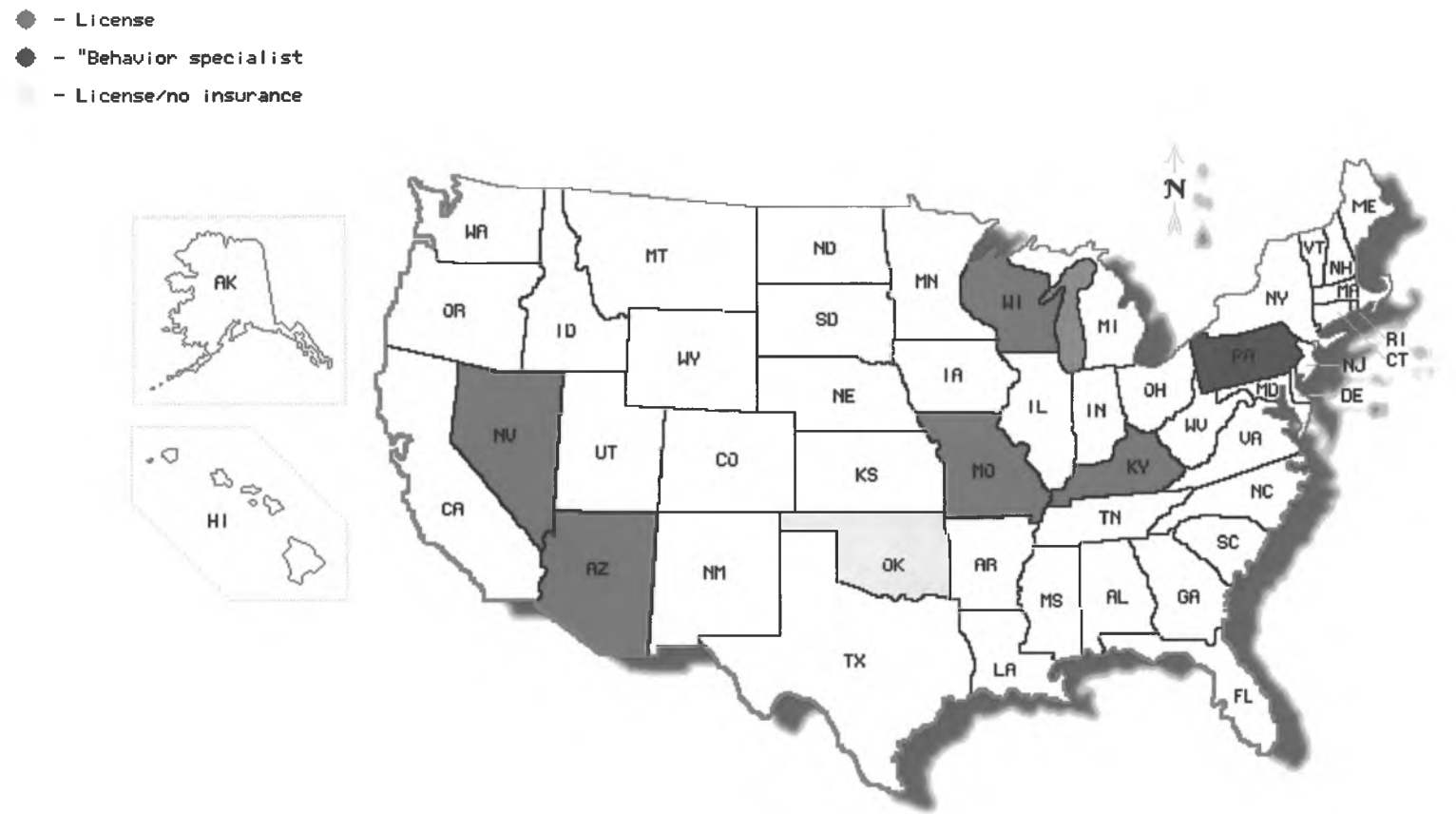
Provider Credentials

www.BACB.com

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

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

Insurance States that License Behavior Analysts



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Neurology

January 2007 Issue

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

Disorder	Class of evidence	Range of ages included (y)	Median estimates: Annual incidence Rate/ 100,000	Annual incidence No.*	Prevalence Rate/ 1,000	Prevalence 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

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.

Arch Pediatr Adolesc Med. 2007;161:343-349

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.

Author Affiliations: Abt Associates Inc, Lexington, and Harvard School of Public Health, Boston, Mass.

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

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.

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

Age Group, y	Average Per Capita Cost per Age Group			Total Per Capita Cost
	Direct Medical	Direct Nonmedical	Indirect	
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	26 660	216 439
48-52	1447	13 152	24 531	195 650
53-57	1290	11 292	17 276	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.

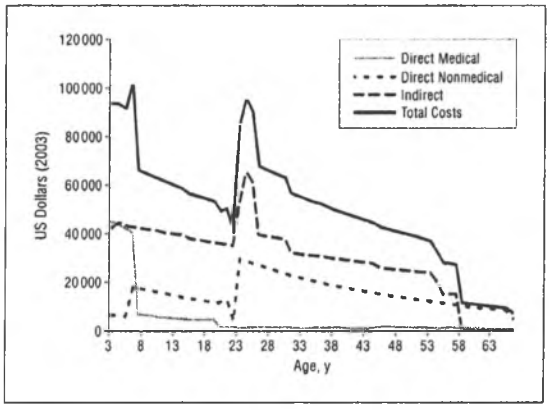

Figure 1. Age distribution of incremental societal costs of autism (present value).

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

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

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.

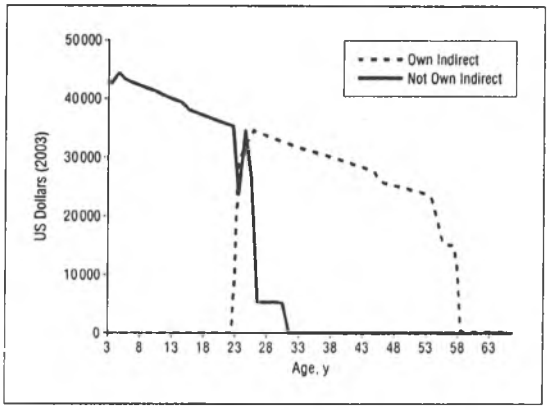

Figure 2. Age distribution of own and not own indirect incremental costs (present value).

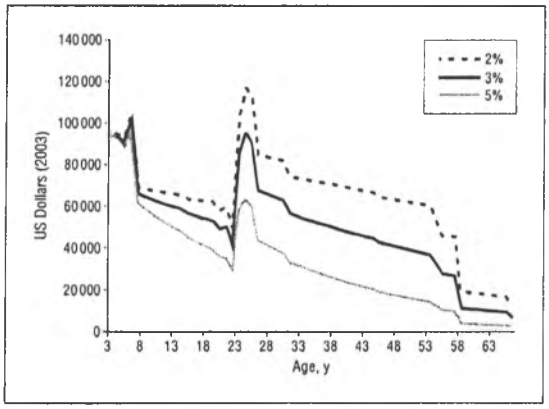

Figure 3. Age distribution of total incremental societal costs of autism computed at different discount rates.

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.

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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NCSL
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Insurance Coverage for Autism

January 2012

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.

A total of 34 states and the District of Columbia have laws related to autism and insurance coverage. At least 29 states—Arizona, Arkansas, California, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, Pennsylvania, Rhode Island, South Carolina, Texas, Vermont, Virginia, West Virginia 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 four 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 2011, Arkansas, California, New York, Rhode Island, Virginia, and West Virginia enacted legislation requiring insurance coverage for autism spectrum disorders.

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

If you are a consumer with questions about health insurance coverage for autism, discuss them with your employer's benefits manager or contact your state's department of insurance.

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.
Arkansas	2011 Ark. Acts, Act 196 (HB 1315 of 2011) Requires health benefit plans to provide coverage for the diagnosis and treatment of autism spectrum disorders. Treatment is defined to include applied behavior analysis, pharmacy care, psychiatric care, psychological care, therapeutic care, necessary equipment to provide evidence-based treatment, and any care that is determined by a licensed physician to be medically necessary and evidence-based. Applied behavioral analysis is limited to $50,000 annually and to children under 18 years of age. Coverage is not subject to any limits on the number of visits an individual may make to an autism services provider. The law specifies that on or after January 1, 2014, to the extent that these provisions require benefits that exceed the essential health benefits specified under the federal Patient Protection and Affordable Care Act, the benefits that exceed the essential health benefits shall not be required of a health benefit plan when the plan is offered by a health care insurer in the state through the state medical exchange.
California	Cal. Insurance Code § 10144.5 Requires every policy of disability insurance that covers hospital, medical, or surgical expenses in the state to provide coverage for the diagnosis and medically necessary treatment of severe mental illnesses, including pervasive developmental disorder or autism, for a person of any age under the same terms and conditions applied to other medical conditions. Cal. Insurance Code § 10144.51 and § 10144.52 (2011 Cal. Stats., Chap. 650; SB 946) Require every health insurance policy to provide coverage for behavioral health treatment for pervasive developmental disorder. The law also specifies that this provision does not require any benefits to be provided that exceed the essential health benefits required by the federal Patient Protection and Affordable Care Act. Cal. Health and Safety Code § 1374.72 Requires every health care service plan to provide coverage for the diagnosis and medically necessary treatment of severe mental illness, including pervasive developmental disorder or autism, of a person of any age under the same terms and conditions applied to other medical conditions. Cal. Health and Safety Code § 1374.73 (2011 Cal. Stats., Chap. 650; SB 946) Requires every health care service plan contract that provides hospital, medical or surgical coverage to provide coverage for behavioral health treatment for pervasive developmental disorder or autism. The law specifies that this provision does not require any benefits that exceed the essential health benefits required by the federal Patient Protection and Affordable Care Act.
Colorado	Colo. Rev. Stat. § 10-16-104 (1.3)(q), § 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; 2011 Conn. Acts, P.A. 11-4, HB 6278 of 2011) Requires specified group health insurance policies to provide coverage for the diagnosis and treatment of autism spectrum disorder. Treatments must 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,

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	prescription drugs, psychiatric services, psychological services, physical therapy, speech and language pathology services and occupational therapy. Coverage for behavioral therapy may be limited to $50,000 per year for a child who is less than nine years of age, $35,000 for a child who is at least nine years of age and less than 13 years of age, and $25,000 for a child who is at least 13 years of age and less than 15 years of age. The policy may not impose limits on the number of visits to an autism services provider. This law repealed the previous version of § 38a-514b (2008 Conn. Acts. P.A. 132; HB 5696, Fiscal Note), which specified that group health insurance policies must 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. Conn. Gen Stat. § 38a-488b (2008 Conn. Act. P.A. 132: HB 5696, Fiscal Note; 2011 Conn. Acts. P.A. 11-4, HB 6278 of 2011) Requires individual health insurance policies to provide coverage for physical, speech, and occupational therapy services for the treatment of autism spectrum disorder, as defined by the American Psychiatric Association's "Diagnostic and Statistical Manual of Mental Disorders (DSM)," to the extent such services are a covered benefit for other diseases and conditions.
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 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 et seq. (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, October 2009.
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	Kan. Stat. Ann. § 75-6524 (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. Kan. State. Ann. § 40-2.105a (HB 2214 of 2009; HB 2033 of 2001) The law was amended in 2009 by Kan. Sess. Laws, Chap. 136 to require any group health insurance policy, medical service

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	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.
Kentucky	Ky. Rev. Stat. § 319C (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	Me. Rev. Stat. Ann. Tit. 24-A § 2766 (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.
Massachusetts	Mass. Gen. Laws Ann. ch. IV § 32A-25 (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

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	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	Mo. Rev. Stat. § 337.300 et seq. and § 376.1224 (HB 1311 of 2010; 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.
New Hampshire	N.H. Rev. Stat. Ann. § 417-E:2 (2010 N.H. Laws, Chap. 363; HB 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.

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	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.
New York	N.Y. Insurance Law § 3216, § 3221 and § 4303 Require specified policies and contracts that provide coverage for hospital or surgical coverage to not exclude coverage for the screening, diagnosis and treatment of medical conditions otherwise covered by the policy solely because the treatment is provided to diagnose or treat autism spectrum disorder. The law was amended by 2011 N.Y. Laws, Chap. 595 (AB 6305) to also require every policy which provides physician services, medical, major medical or similar comprehensive-type coverage to provide coverage for the screening, diagnosis and treatment of autism spectrum disorder. The law prohibits any limitations on visits that are solely applied to the treatment of autism spectrum disorder. Treatment of autism spectrum disorder is defined to include behavioral health treatments, psychiatric care, psychological care, medical care, therapeutic care and specified pharmacy care. 2011 N.Y. Laws, Chap. 596 (SB 5845) amended these provisions to specify that coverage for applied behavior analysis is subject to a maximum benefit of $45,000 per year.
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.
Rhode Island	R.I. Gen. Laws § 27-20.11-1 et seq. (2011 R.I. Pub. Laws, Chap. 159, HB 5275 and 2011 R.I. Pub. Laws, Chap. 175, SB 107) Require specified contracts and policies to provide coverage for autism spectrum disorder. Benefits include coverage for applied behavior analysis, physical therapy, speech therapy and occupational therapy services for the treatment of autism spectrum disorder and apply until the covered individual reaches age 15. Coverage for applied behavior analysis is limited to $32,000 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 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	Vt. Stat. Ann. Tit. 8 § 4088i (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.
Virginia	2011 Va. Act, Chap. 876 and 2011 Va. Act, Chap. 878 (HB 2467 of 2011, SB 1062 of 2011) Requires health insurers, health care subscription plans and health maintenance organizations to provide coverage for the diagnosis and treatment of autism spectrum disorders in individuals from age two to six. The requirement applies to the state employees' health insurance plan and to the local choice health program; and does not apply to an insurer, corporation, or health maintenance organization, or to government employee programs, if the costs associated with

Statutes specifically requiring insurance coverage of autism

State	Statute Summary
	coverage exceed one percent of premiums charged over the experience period. Treatment is defined to include behavioral health treatment, pharmacy care, psychiatric care, psychological care, therapeutic care and applied behavior analysis. Coverage is limited to an annual maximum benefit of $35,000 for applied behavior analysis unless the insurer elects to provide coverage in a greater amount. Coverage is not subject to any visit limits. As of January 1, 2014, to the extent that these required benefits exceed the essential health benefits specified under the federal Patient Protection and Affordable Care Act, the specific benefits that exceed the essential health benefits are not required of qualified health plans that are offered in the state by a health carrier through a health benefit exchange. 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; 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.
West Virginia	2011 W. Va. Act, Chap. 13 (HB 2693 of 2011; Children's Health Insurance Program fiscal note; Department of Health and Human Resources fiscal note; Insurance Commission fiscal note; Public Health Insurance Agency (PEIA) fiscal note) Requires specified health insurers, including the state's Children's Health Insurance Program (CHIP), to provide coverage for the diagnosis and treatment of autism spectrum disorders in individuals from the age of 18 months through 18 years. To be eligible for coverage, the individual must be diagnosed with autism spectrum disorder at age 8 or younger. Coverage includes treatments that are medically necessary and ordered or prescribed by a licensed physician or licensed psychologist, including but not limited to, applied behavioral analysis. The annual maximum benefit for applied behavioral analysis is $30,000 per year for the first three years after treatment commences, and $2,000 per month after three years.
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
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.
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.
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.

Statutes that may require limited insurance coverage of autism	
State	**Statute Summary**
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.

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, 2012.

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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.

Through

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 ▶

By Kristin Sainani

Photographs by Timothy Archibald

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.

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—

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

COURTESY J.C. FLORES

Autism is a CATCHALL DIAGNOSIS that likely includes a host of DISTINCT DISORDERS.

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 twenty-fold 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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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

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.

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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

UAA Center for Human Development
UNIVERSITY of ALASKA ANCHORAGE

Workforce Development for Serving Young Children with Autism

Background

For the last 2 years, the UAA Center for Human Development has operated a program to prepare professionals wishing to serve as *Autism Specialists*. This role is one that plans and provides direct service, trains staff and parents, and oversees services on several levels. Those services may include evidence-based ABA interventions covered under the proposed Autism Insurance legislation. Nationally, the "credential of choice" for this post-Master's role is called BCBA, or Board Certified Behavior Analyst. An American Psychological Association (APA) division, named *Applied Behavior Analysis, International*, created a structure to provide guidance, oversight and national certification of graduate-level professionals. Their certification body, the *Behavioral Analysis Certification Board* (http://www.bacb.com/) sets training standards, accredits graduate and undergraduate programs (for associate level behavior analysis at the bachelors or paraprofessional level), administers national testing, and maintains state registries of programs and professionals. Currently, we partner with two state universities (Northern Arizona University and University of Kansas) to provide training for professionals. We also work with the UAA Department of Psychology to meet paraprofessional workforce needs.

Typically an individual who has earned BCBA national credentialing also has a Masters or Ph.D. in Psychology, Special Education, Social Work or Speech/Language Pathology. For most, it is a 2-3 year process with 1 year of the program of study associated with didactic coursework and 2 years needed for clinical field work. It is not the only way to be proficient in serving children with autism, or with use of Applied Behavior Analysis (e.g., the graduate program in Special Education at UAA has 2-3 related courses in their program), but has become the standard, especially for states that have Autism Waiver programs. BAC Board then also sets standards for and provides certificates for undergraduate level "associate" behavior analysts (BCABA).

Current workforce status in Alaska

Two years ago, there was but one Alaskan BCBA professional. She did not provide direct service but worked only as a Special Education administrator for Fairbanks-North Star Borough Schools. We now have **5 certified Alaskan BCBAs**. This number is down 1 from a high of 6, with one BCBA-MSW from South Central Foundation recently leaving the state with her husband's military re-assignment. **Two BCBA businesses now exist in Alaska** to provide this service for young children. Recently the Fairbanks BCBA resigned her position with the district and began a business providing Autism treatment services in her community. A second, new BCBA professional in the Anchorage area currently works with military families, serving 19 children with autism, billing through Tri-Care. Besides having a Masters in Special Education, she is the parent of a young teen with Autism. While there are NO standards for the size of the caseload for each BCBA when working with young children with autism, several state Autism Waiver programs suggest a caseload of 1 BCBA specialist for every 10 children served.

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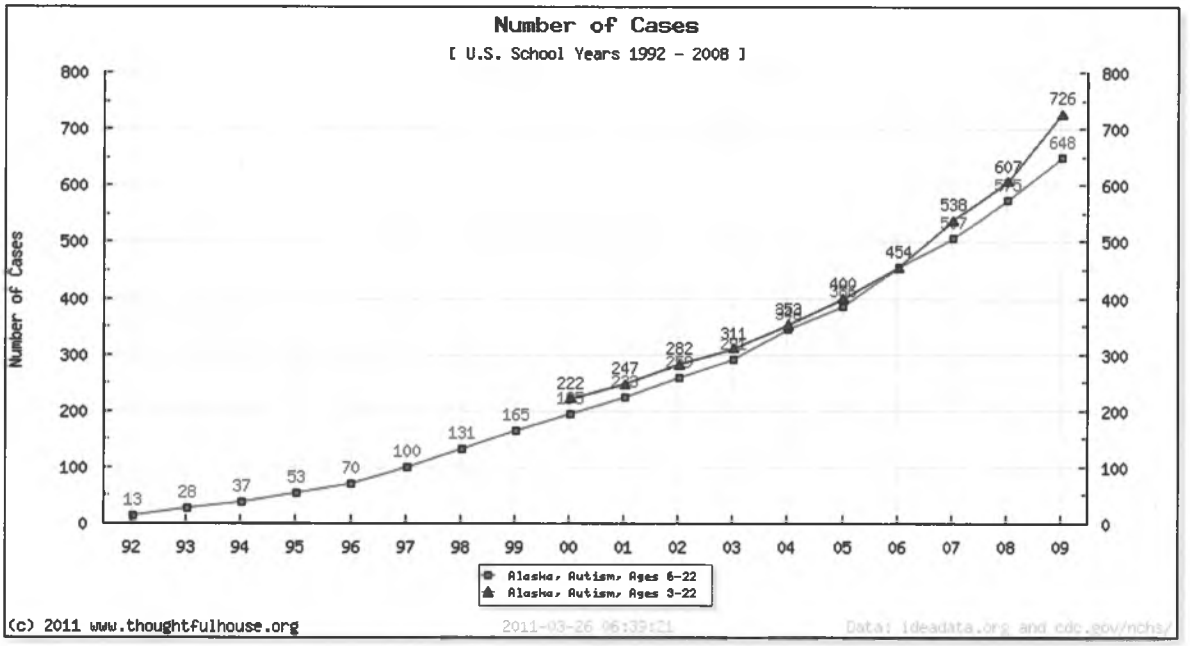
They plan and provide direct services with the child, train staff, and provide oversight of their services. Typically most of the direct services are provided by the entry level BCABA

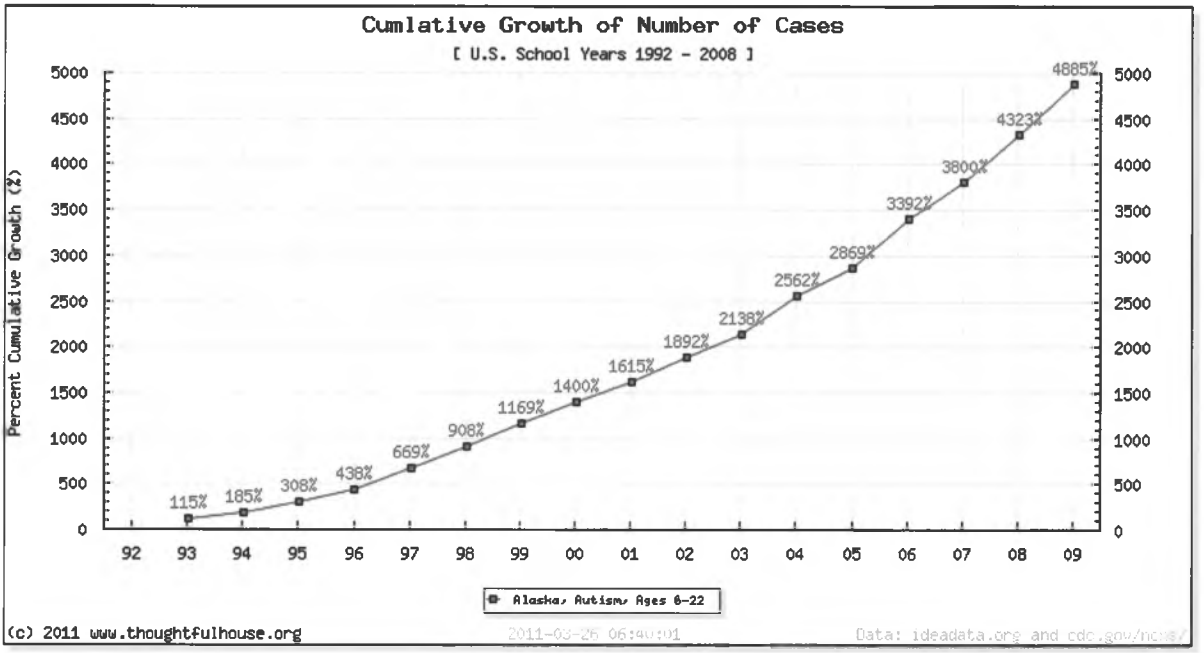
Then, there are a total of **17 Alaska professionals engaged in graduate BCBA training**. Three are doing so independent of the service CHD provides. They will be sitting for their exam within 9 months. Fourteen BCBA students across Cohort 1 and 2 are supported by our state/Trust funding. Seven students in Cohort 1 will be sitting for the national exam within 1 year. The other seven began their program this last January. While a BCBA student is engaged in the required 1500 hr clinical experience and is working under the supervision of a credentialed BCBA, they can **engage in direct service and be paid**. Several of the staff working with the Tri-Care funded program are in fact also members of our Cohort 1 or 2.

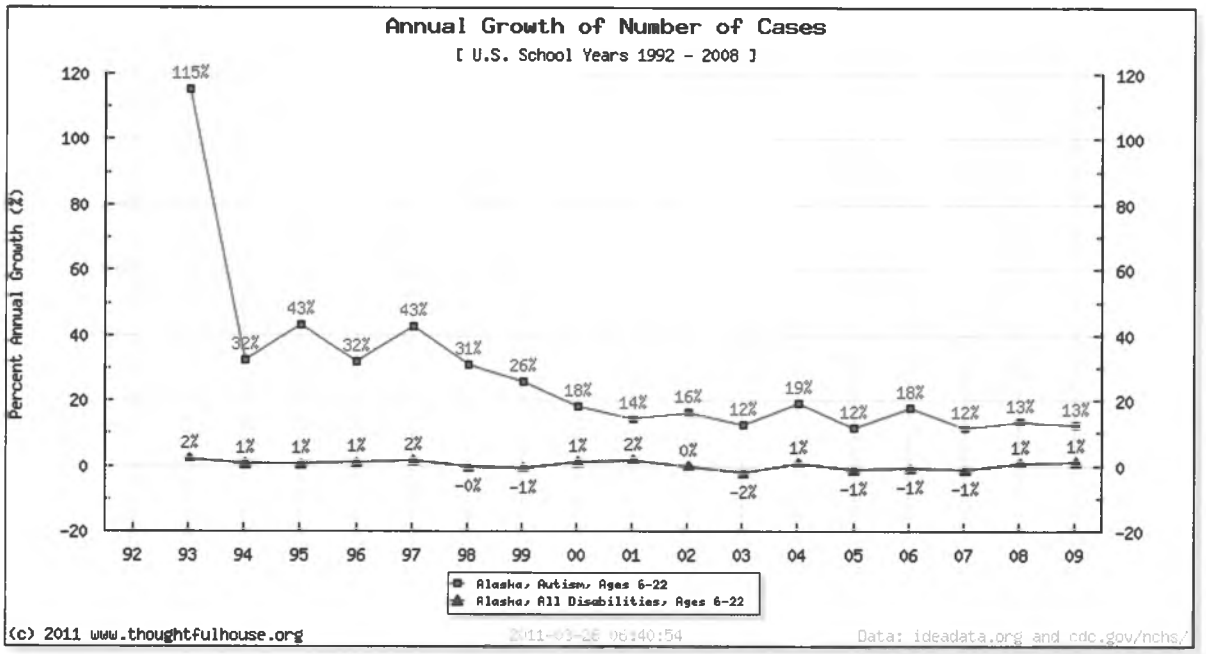
There are **3 BCABAs** known to be working in the state and **3 more paraprofessionals in training** via distance delivered programs. All six currently work serving children and adults with autism in a direct service capacity. Many more are needed. We are very actively working with the UAA Department of Psychology, to obtain UA approval of a new Autism Occupational Endorsement (OE) that is also part of the junior-senior year course offering for typical majors. This OE will then also fulfill these same BCABA standards with the Department and CHD also looking at meeting national BCABA accreditation. We are hoping for this program to pass UA OE review Fall 2011, with initial implementation Spring 2012. Once this 4 semester program becomes operational, it will result in 15 individuals earning the Autism OE annually, with 1/3rd being non-degreed (five OE only) and 2/3rd doing so as part of their Psychology major (15 bachelor's level).

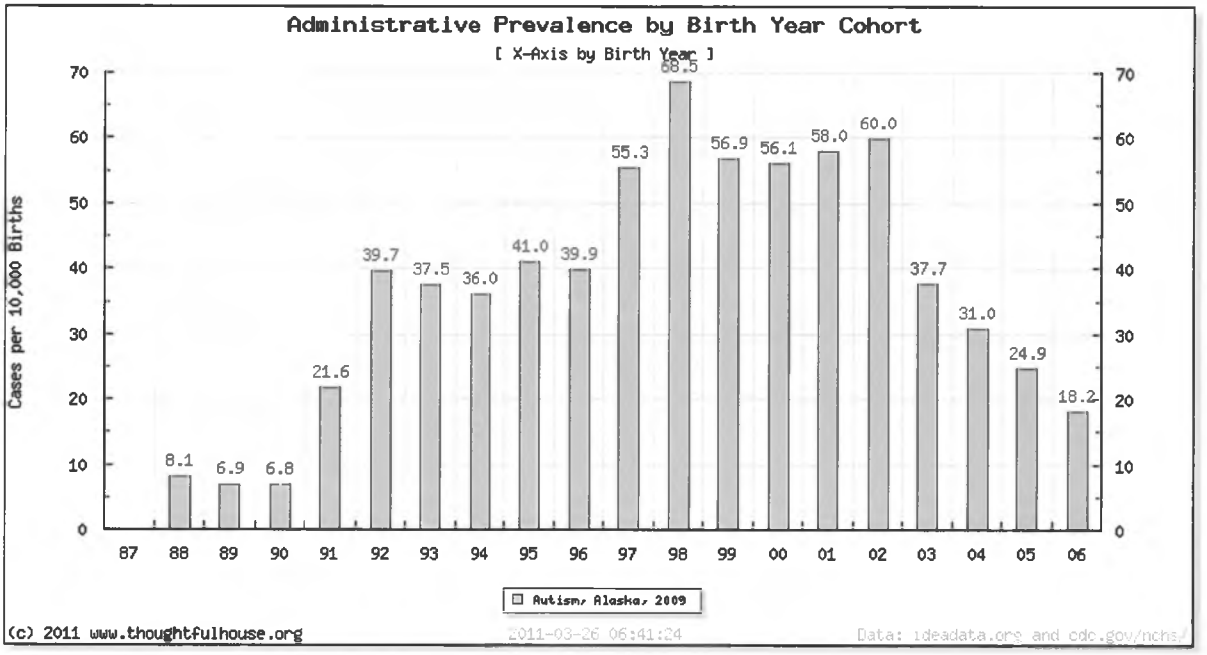
Finally, we have taken steps to link the BCBAs (credentialed or students) to services and together as part of a statewide organization. Earlier this year, a group of 35 individuals met to discuss and frame the mission of such a group. Most in attendance were practicing BCBAs/BCABAs or graduate students in Cohort 1 or 2. We anticipate using this network for several key functions, including serving as a vehicle to link service requests to practitioners.

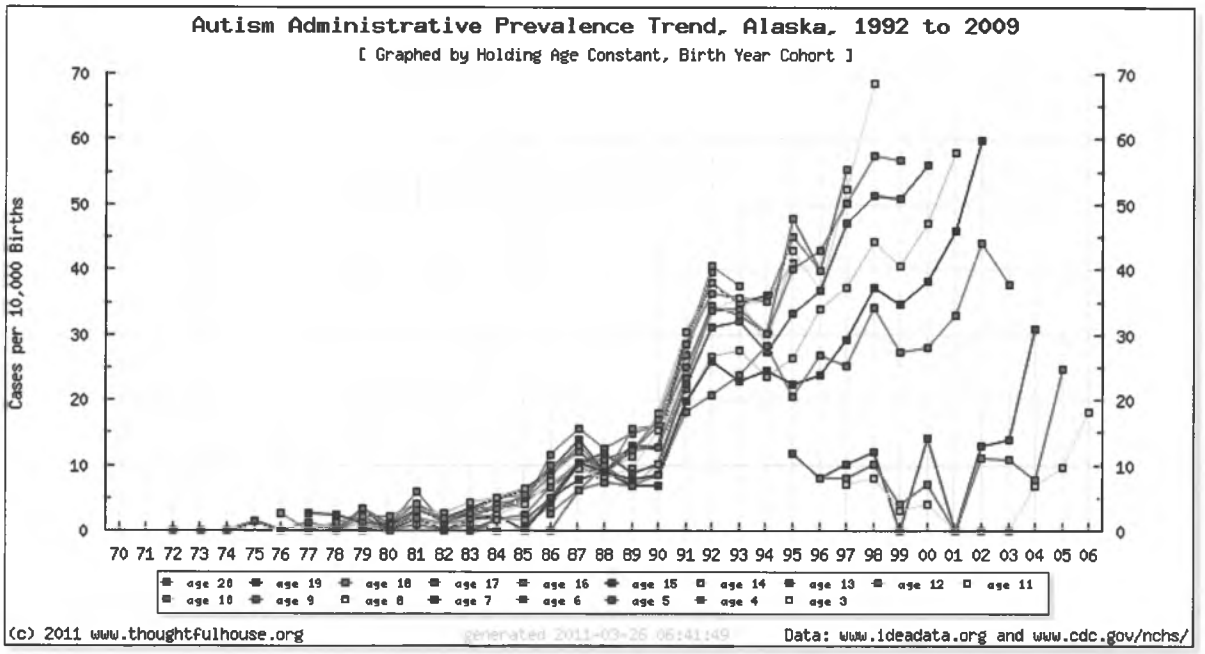
Autism Spectrum Disorders – Alaska Statistics, Incidence, Prevalence, Rates

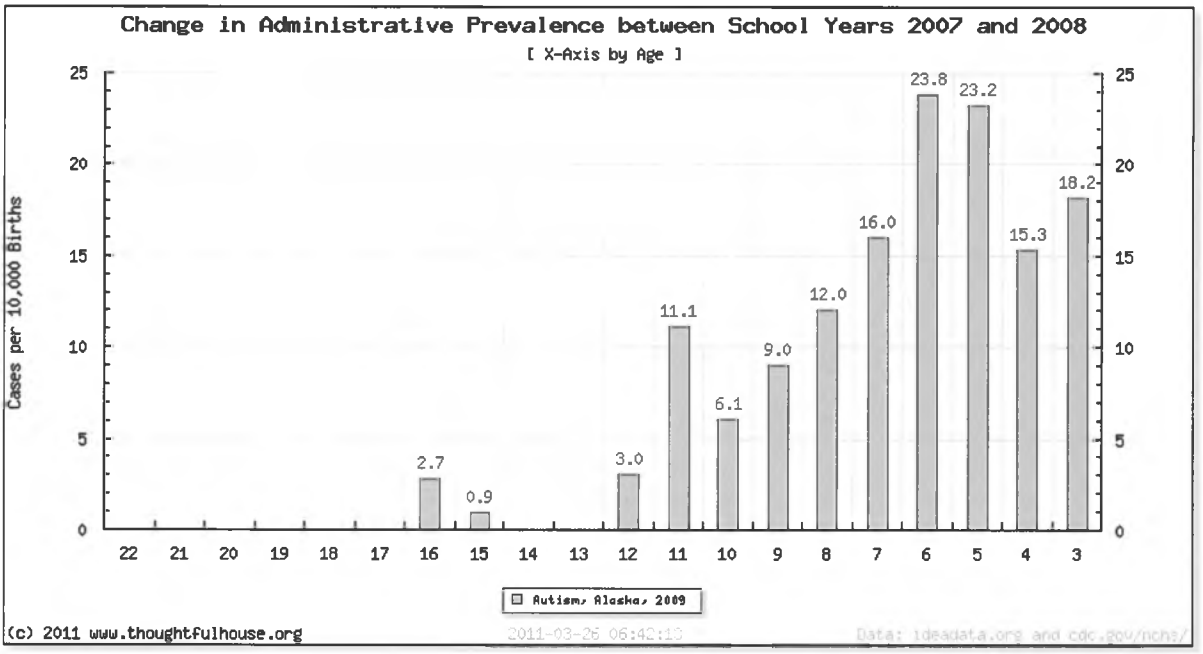





Annual Growth of Number of Cases
[U.S. School Years 1992 - 2008]
Percent Annual Growth (%)
115%
32%
43%
32%
43%
31%
26%
18%
14%
16%
12%
19%
12%
18%
12%
13%
13%
2%
1%
1%
1%
2%
-0%
-1%
1%
2%
0%
-2%
1%
-1%
-1%
-1%
1%
1%
92 93 94 95 96 97 98 99 00 01 02 03 04 05 06 07 08 09
Alaska, Autism, Ages 6-22
Alaska, All Disabilities, Ages 6-22
(c) 2011 www.thoughtfulhouse.org
2011-03-26 06:40:54
Data: ideadata.org and cdc.gov/nchs/


Administrative Prevalence by Birth Year Cohort
[X-Axis by Birth Year]
Cases per 10,000 Births
8.1
6.9
6.8
21.6
39.7
37.5
36.0
41.0
39.9
55.3
68.5
56.9
56.1
58.0
60.0
37.7
31.0
24.9
18.2
87 88 89 90 91 92 93 94 95 96 97 98 99 00 01 02 03 04 05 06
Autism, Alaska, 2009
(c) 2011 www.thoughtfulhouse.org
2011-03-26 06:41:24
Data: ideadata.org and cdc.gov/nchs/


Autism Administrative Prevalence Trend, Alaska, 1992 to 2009
[Graphed by Holding Age Constant, Birth Year Cohort]
Cases per 10,000 Births
0 10 20 30 40 50 60 70
70 71 72 73 74 75 76 77 78 79 80 81 82 83 84 85 86 87 88 89 90 91 92 93 94 95 96 97 98 99 00 01 02 03 04 05 06
age 20 age 19 age 18 age 17 age 16 age 15 age 14 age 13 age 12 age 11
age 10 age 9 age 8 age 7 age 6 age 5 age 4 age 3
(c) 2011 www.thoughtfulhouse.org
generated 2011-03-26 06:41:49
Data: www.ideadata.org and www.cdc.gov/nchs/


Change in Administrative Prevalence between School Years 2007 and 2008
[X-Axis by Age]
Cases per 10,000 Births
0 5 10 15 20 25
2.7
0.9
3.0
11.1
6.1
9.0
12.0
16.0
23.8
23.2
15.3
18.2
22 21 20 19 18 17 16 15 14 13 12 11 10 9 8 7 6 5 4 3
Autism, Alaska, 2009
(c) 2011 www.thoughtfulhouse.org
2011-03-26 06:42:10
Data: ideadata.org and cdc.gov/nchs/

AUTISM SPEAKS
It's time to listen.

The Fiscal Impact of Autism Insurance Reform

Recognizing the importance of early intervention for Autism Spectrum Disorders (ASD), 29 states have enacted autism insurance reform laws. Each of these states require that health insurance cover medically necessary treatment for ASD including behavioral health treatments such as Applied Behavior Analysis (ABA).

In order to determine the fiscal impact of autism insurance reform, Autism Speaks is collecting claims data from states where such laws apply to members of the state employee health plan and have been in effect for at least one year.

Interpretive Summary

1. Autism insurance reform laws have been in effect for at least one year in 15 states. Twelve of these states require coverage for members of their state employee health plan. The terms of coverage vary and are detailed in Appendix 1.

2. Claims data has been requested from all 12 states. Data has been received from 6 states and is presented in Appendix 2.

3. Claims data is available from the first year of implementation in 5 states (i.e., SC, IL, FL, AZ and KY). The first year costs of coverage range from $0.09 per member per month (PMPM) to $0.30 PMPM. The average first year cost of coverage is $0.15 PMPM. (Table 1)

4. Claims data is available from the second year of implementation in 5 states (i.e., SC, IL, LA, FL and AZ). The second year costs of coverage range from $0.10 PMPM to $0.43 PMPM. The average second year cost of coverage is $0.31 PMPM. (Table 2)

5. Minnesota has not enacted autism insurance reform. However as a result of a settlement of litigation against Blue Cross and Blue Shield of Minnesota, they have been required to cover unlimited treatment for ASD since 2001. After 6 years, the premium impact on the commercial market resulting from unlimited coverage for ASD was $0.83 PMPM. (BCBS Minnesota)

6. Fiscal notes were prepared for the legislatures in 5 of the states where we have been able to obtain claims data. These cost projections were prepared for fiscal or calendar years that correspond to available claims data in 3 states. Fiscal projections overestimated the actual cost of autism insurance reform by 293% to 1,261%. (Table 3)

Table 1. Year One Costs

	Year of coverage	Number of Covered Lives	Total Claims	PMPM cost
South Carolina	1	371,384	$856,369	$0.19
Illinois	1	171,979	$187,684	$0.09
Florida	1	382,083	$390,724	$0.09
Arizona	1	130,000	$473,818	$0.30
Kentucky	1	240,000	$278,922	$0.10
	Average first year cost			**$0.15**

Table 2. Year Two Costs

	Year of coverage	Number of Covered Lives	Total Claims	PMPM cost
South Carolina	2	397,757	$2,042,394	$0.43
Illinois	2	170,790	$197,290	$0.10
Louisiana	2	149,477	$722,828	$0.40
Florida	2	386,203	$1,748,849	$0.38
Arizona	2	130,000	$388,662	$0.25
	Average second year cost			**$0.31**

Table 3. Projected versus Actual Costs

	Year of coverage	Total Claims	Fiscal Note from State Legislature	Difference in projected versus actual cost
South Carolina	1	$856,369	$10,590,000	1,237%
	2	$2,042,394	$10,590,000	519%
Louisiana	2	$722,828	$2,118,307	**293%**
	2	$722,828	$2,686,796	372%
Arizona	1	$473,818	$2,500,000	528%
	1	$473,818	$4,900,000	1,034%
	2	$388,662	$2,500,000	643%
	2	$388,662	$4,900,000	**1,261%**

Appendix 1. Terms of Coverage

	Bill Number	Statute	Date Enacted	Date Implemented	Terms of Coverage	Applicable to SEHP?
Indiana	HB 1122	Indiana Code 27-8-14.2	5/3/01	5/3/01	unlimited	YES
Texas	HB 1919		6/15/07	1/1/08	unlimited age 0-6	NO
	HB 451		6/19/09	1/1/10	unlimited age 0-10	
South Carolina	S 20		6/7/07	7/1/08	$50,000* age 0-16	YES
Illinois	SB 934	Public Law 095-1005	12/13/08	12/12/08	$36,000/yr age 0-21	YES
Louisiana	HB 958	Act 648	7/2/08	1/1/09	$36,000/yr age 0-17	YES
Florida	SB 2654	Florida Statute s. 627.6686	5/2/08	4/1/09	$36,000/yr age 0-19	YES
New Mexico	SB 39		4/2/09	6/19/09	$36,000/yr age 0-21	NO
Arizona	SB 1263	A.R.S. § 20-181 A.R.S. § 20- 182	3/21/08	7/1/09	$50,000/yr* age 0-8 $25,000/yr* age 9-16	YES
Pennsylvania	HB 1150		7/9/08	7/1/09	$36,000/yr age 0-21	YES
Wisconsin	AB 75	sec. 3197 w. on page 596 of Act 28	10/19/09	11/1/09	$50,000 for 4 yrs; $25,000 thereafter	YES
Connecticut	SB 301	Public Act 09-115	6/9/09	1/1/10	$50,000/yr* age 0-9 $35,000/yr* age 9-12 $25,000/yr* age 13-14	YES
Montana	SB 234		5/5/09	1/1/10	$50,000/yr age 0-8 $20,000/yr age 9-18	YES
New Jersey	S 1651		8/13/09	2/9/10	$36,000/yr* age 0-21	YES
Kentucky	HB 159		4/14/10	5/14/10	$50,000/yr age 0-7 $1,000/mo age 7-21	YES
Colorado	SB 09-244	C.R.S. 10-16-104	6/2/09	7/1/10	$34,000/yr* age 0-8 $12,000/yr* age 9-19	NO

Appendix 2. Claims Data

	Date Implemented	Terms of Coverage	Date of Claims Data	Year	Number of Covered Lives	Total Claimants with ASD Diagnosis	Total Claims	PMPM cost	Source	Fiscal Note from State Legislature
South Carolina	7/1/08	$50,000* age 0-16	CY 2009	1	371,384	60	$856,369	$0.19	APS Healthcare	$10,590,000 per year South Carolina Budget and Control Board
			CY 2010	2	397,757	80	$2,042,394	$0.43		
Illinois	12/12/08	$36,000/yr age 0-21	CY 2009	1	171,979	2,420 (?)	$187,684	$0.09	Illinois Department of Healthcare and Family Services	NA
			CY 2010	2	170,790	3,314 (?)	$197,290	$0.10		
Louisiana	1/1/09	$36,000/yr age 0-17	CY 2009	1	NA	NA	NA	NA	Louisiana Office of Group Benefits	$2,118,307 - $2,686,796 (FY 10-11) Louisiana Legislative Fiscal Office
			CY 2010	2	149,477	386	$722,828	$0.40		
Florida	4/1/09	$36,000/yr age 0-19	07/01/2009 - 06/30/2010	1	382,083	372	$390,724	$0.09	Florida Department of Management Services	*"difficult to assess"* *The Professional Staff of the Florida Banking and Insurance Committee*
			07/01/2010 - 06/30/2011	2	386,203	511	$1,748,849	$0.38		
Arizona	7/1/09	$50,000/yr* age 0-8 $25,000/yr* age 9-16	07/01/2009 - 06/30/2010	1	130,000	257	$473,818	$0.30	Arizona Department of Administration	$2.5 - $4.9 million (FY 2010) Jorgensen/Zylla for Arizona Legislature
			07/01/2010 - 06/30/2011	2	130,000	187	$388,662	$0.25		
Kentucky	5/14/10	$50,000/yr age 0-7 $1,000/mo age 7-21	May 2010 - April 2011	1	240,000	NA	$278,922	$0.10	Kentucky Department of Employee Insurance	$4,000,000 (FY 2012) Kentucky Legislative Research Commisssion

* monetary cap applies only to Applied Behavior Analysis

Insurance Coverage for Autism

January 2012

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.

A total of 34 states and the District of Columbia have laws related to autism and insurance coverage. At least 29 states—Arizona, Arkansas, California, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, Pennsylvania, Rhode Island, South Carolina, Texas, Vermont, Virginia, West Virginia 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 four 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 2011, Arkansas, California, New York, Rhode Island, Virginia, and West Virginia enacted legislation requiring insurance coverage for autism spectrum disorders.

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

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

If you are a consumer with questions about health insurance coverage for autism, discuss them with your employer's benefits manager or contact your state's department of insurance.

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.
Arkansas	2011 Ark. Acts, Act 196 (HB 1315 of 2011) Requires health benefit plans to provide coverage for the diagnosis and treatment of autism spectrum disorders. Treatment is defined to include applied behavior analysis, pharmacy care, psychiatric care, psychological care, therapeutic care, necessary equipment to provide evidence-based treatment, and any care that is determined by a licensed physician to be medically necessary and evidence-based. Applied behavioral analysis is limited to $50,000 annually and to children under 18 years of age. Coverage is not subject to any limits on the number of visits an individual may make to an autism services provider. The law specifies that on or after January 1, 2014, to the extent that these provisions require benefits that exceed the essential health benefits specified under the federal Patient Protection and Affordable Care Act, the benefits that exceed the essential health benefits shall not be required of a health benefit plan when the plan is offered by a health care insurer in the state through the state medical exchange.
California	Cal. Insurance Code § 10144.5 Requires every policy of disability insurance that covers hospital, medical, or surgical expenses in the state to provide coverage for the diagnosis and medically necessary treatment of severe mental illnesses, including pervasive developmental disorder or autism, for a person of any age under the same terms and conditions applied to other medical conditions. Cal. Insurance Code § 10144.51 and § 10144.52 (2011 Cal. Stats., Chap. 650; SB 946) Require every health insurance policy to provide coverage for behavioral health treatment for pervasive developmental disorder. The law also specifies that this provision does not require any benefits to be provided that exceed the essential health benefits required by the federal Patient Protection and Affordable Care Act. Cal. Health and Safety Code § 1374.72 Requires every health care service plan to provide coverage for the diagnosis and medically necessary treatment of severe mental illness, including pervasive developmental disorder or autism, of a person of any age under the same terms and conditions applied to other medical conditions. Cal. Health and Safety Code § 1374.73 (2011 Cal. Stats., Chap. 650; SB 946) Requires every health care service plan contract that provides hospital, medical or surgical coverage to provide coverage for behavioral health treatment for pervasive developmental disorder or autism. The law specifies that this provision does not require any benefits that exceed the essential health benefits required by the federal Patient Protection and Affordable Care Act.
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; 2011 Conn. Acts, P.A. 11-4, HB 6278 of 2011) Requires specified group health insurance policies to provide coverage for the diagnosis and treatment of autism spectrum disorder. Treatments must 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,

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	prescription drugs, psychiatric services, psychological services, physical therapy, speech and language pathology services and occupational therapy. Coverage for behavioral therapy may be limited to $50,000 per year for a child who is less than nine years of age, $35,000 for a child who is at least nine years of age and less than 13 years of age, and $25,000 for a child who is at least 13 years of age and less than 15 years of age. The policy may not impose limits on the number of visits to an autism services provider. This law repealed the previous version of § 38a-514b (2008 Conn. Acts. P.A. 132; HB 5696, Fiscal Note), which specified that group health insurance policies must 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. Conn. Gen Stat. § 38a-488b (2008 Conn. Act. P.A. 132: HB 5696, Fiscal Note; 2011 Conn. Acts. P.A. 11-4. HB 6278 of 2011) Requires individual health insurance policies to provide coverage for physical, speech, and occupational therapy services for the treatment of autism spectrum disorder, as defined by the American Psychiatric Association's "Diagnostic and Statistical Manual of Mental Disorders (DSM)," to the extent such services are a covered benefit for other diseases and conditions.
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 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 et seq. (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, October 2009.
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	Kan. Stat. Ann. § 75-6524 (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. Kan. State. Ann. § 40-2,105a (HB 2214 of 2009; HB 2033 of 2001) The law was amended in 2009 by Kan. Sess. Laws. Chap. 136 to require any group health insurance policy, medical service

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	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.
Kentucky	Ky. Rev. Stat. § 319C (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	Me. Rev. Stat. Ann. Tit. 24-A § 2766 (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.
Massachusetts	Mass. Gen. Laws Ann. ch. IV § 32A-25 (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

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	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	Mo. Rev. Stat. § 337.300 et seq. and § 376.1224 (HB 1311 of 2010; 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.
New Hampshire	N.H. Rev. Stat. Ann. § 417-E:2 (2010 N.H. Laws, Chap. 363; HB 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.

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	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.
New York	N.Y. Insurance Law § 3216, § 3221 and § 4303 Require specified policies and contracts that provide coverage for hospital or surgical coverage to not exclude coverage for the screening, diagnosis and treatment of medical conditions otherwise covered by the policy solely because the treatment is provided to diagnose or treat autism spectrum disorder. The law was amended by 2011 N.Y. Laws, Chap. 595 (AB 6305) to also require every policy which provides physician services, medical, major medical or similar comprehensive-type coverage to provide coverage for the screening, diagnosis and treatment of autism spectrum disorder. The law prohibits any limitations on visits that are solely applied to the treatment of autism spectrum disorder. Treatment of autism spectrum disorder is defined to include behavioral health treatments, psychiatric care, psychological care, medical care, therapeutic care and specified pharmacy care. 2011 N.Y. Laws, Chap. 596 (SB 5845) amended these provisions to specify that coverage for applied behavior analysis is subject to a maximum benefit of $45,000 per year.
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.
Rhode Island	R.I. Gen. Laws § 27-20.11-1 et seq. (2011 R.I. Pub. Laws, Chap. 159, HB 5275 and 2011 R.I. Pub. Laws, Chap. 175, SB 107) Require specified contracts and policies to provide coverage for autism spectrum disorder. Benefits include coverage for applied behavior analysis, physical therapy, speech therapy and occupational therapy services for the treatment of autism spectrum disorder and apply until the covered individual reaches age 15. Coverage for applied behavior analysis is limited to $32,000 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 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	Vt. Stat. Ann. Tit. 8 § 4088i (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.
Virginia	2011 Va. Act. Chap. 876 and 2011 Va. Act. Chap. 878 (HB 2467 of 2011, SB 1062 of 2011) Requires health insurers, health care subscription plans and health maintenance organizations to provide coverage for the diagnosis and treatment of autism spectrum disorders in individuals from age two to six. The requirement applies to the state employees' health insurance plan and to the local choice health program; and does not apply to an insurer, corporation, or health maintenance organization, or to government employee programs, if the costs associated with

Statutes specifically requiring insurance coverage of autism	
State	**Statute Summary**
	coverage exceed one percent of premiums charged over the experience period. Treatment is defined to include behavioral health treatment, pharmacy care, psychiatric care, psychological care, therapeutic care and applied behavior analysis. Coverage is limited to an annual maximum benefit of $35,000 for applied behavior analysis unless the insurer elects to provide coverage in a greater amount. Coverage is not subject to any visit limits. As of January 1, 2014, to the extent that these required benefits exceed the essential health benefits specified under the federal Patient Protection and Affordable Care Act, the specific benefits that exceed the essential health benefits are not required of qualified health plans that are offered in the state by a health carrier through a health benefit exchange. 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; 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.
West Virginia	2011 W. Va. Act, Chap. 13 (HB 2693 of 2011; Children's Health Insurance Program fiscal note; Department of Health and Human Resources fiscal note; Insurance Commission fiscal note; Public Health Insurance Agency (PEIA) fiscal note) Requires specified health insurers, including the state's Children's Health Insurance Program (CHIP), to provide coverage for the diagnosis and treatment of autism spectrum disorders in individuals from the age of 18 months through 18 years. To be eligible for coverage, the individual must be diagnosed with autism spectrum disorder at age 8 or younger. Coverage includes treatments that are medically necessary and ordered or prescribed by a licensed physician or licensed psychologist, including but not limited to, applied behavioral analysis. The annual maximum benefit for applied behavioral analysis is $30,000 per year for the first three years after treatment commences, and $2,000 per month after three years.
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**
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.
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.
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.

Statutes that may require limited insurance coverage of autism	
State	**Statute Summary**
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.

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, 2012.

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Jeremiah W. (Jay) Nixon
Governor
State of Missouri

Department of Insurance
Financial Institutions
and Professional Registration
John M. Huff, Director

Feb. 1, 2012

The Honorable Jeremiah W. (Jay) Nixon, Governor
State Capital Building
Room 216
Jefferson City, Missouri 65101

Re. Report to General Assembly pursuant to 376.1224 RSMo, regarding the impact of Autism / ABA coverage mandates on the insurance marketplace

Dear Governor Nixon:

The Department of Insurance, Financial Institutions & Professional Registration (DIFP) has completed a report assessing the impact on the insurance marketplace of recent requirements that health insurers provide coverage for the treatment of autism, including applied behavior analysis (ABA). Pursuant to 376.1224, the DIFP issued a data call from all insurers providing comprehensive health insurance subject to the mandate for claims experience during 2011. Among the findings:

- Insurers incurred claims equal to $4.3 million for the treatment of autism, of which $1.1 million was directed to ABA therapies. These amounts represent 0.1 percent and 0.02 percent of total claim costs incurred by health insurers during 2011, and are consistent with initial DIFP projections.

- Nearly 4,000 individuals diagnosed with autism received treatment covered by their insurer, a figure that amounts to 1 in every 350 insureds.

- For each individual diagnosed with an ASD that received treatment during 2011, the average monthly cost was $143, of which $35 consisted of ABA therapies.

- By year-end, all individuals insured through the small and large group markets had the mandated coverage. Only one-third of persons insured in the individual market had such coverage. In total, nearly 1.6 million individuals either have the coverage or have the option of purchasing it as an endorsement for an additional premium.

- The mandate was effective for all policies issued or renewed after January 1, 2011. By year-end, the infrastructure necessary to deliver services for autism was still growing. One example is the licensure of behavior analysts. The first licenses were issued in Missouri in December, 2010. By the end of June, 85 licenses had been issued, increasing to 120 by mid-January, 2012. An additional 24 persons obtained assistant behavior analyst licenses mid-January.

Now that medical delivery systems are more fully developed, it is expected that the benefits of the mandate will be more fully realized over the course of the new year. While costs are expected to increase somewhat as a result, no credible evidence suggests that they will exceed 0.2 – 0.5 percent of claim costs, and a smaller percentage of premiums. Given the low costs of autism treatment as a percent of all claims costs, the autism mandate is expected to have minimal impact of health insurance premiums. However, because the DIFP has no authority over health insurance rates and does not receive rate filings, a more exact assessment of the rate impact cannot be provided.

The DIFP continues to monitor insurance carriers to ensure full compliance with relevant statutes, and will continue to monitor market trends in response to the autism mandate. Additional detail can be found in the full report.

Sincerely,

John M. Huff

Annual Report
to the
Missouri Legislature

Insurance Coverage for Autism Treatment & Applied Behavior Analysis

Statistics Section
Jan. 31, 2012

DIFP

Jeremiah W. (Jay) Nixon
Governor

Department of Insurance,
Financial Institutions &
Professional Registration

John M. Huff
Director

The efficacy of behavioral interventions for the treatment of Autism Spectrum Disorders (ASDs) has been well established in the scientific literature. Over the past several decades, intensive early behavioral therapy has been shown to increase IQ, language skills, academic performance and sociality. In turn, improved cognitive and social functioning resulting from such treatment has been shown to reduce long-term medical and other costs. However, while Missouri's mental health parity statute (§376.1550 RSMo.) has been in effect since 2005, many behavioral therapies proven to effectively treat ASDs have in the past been routinely excluded from health insurance coverage.

House Bill 1311, signed into law by Governor Jay Nixon on June 10, 2010, mandated health insurance coverage for medically efficacious treatments for ASDs. All group policies issued or renewed after January 1, 2011 were required to cover medically necessary treatments for autism. All policies issued in the individual market were required to offer such coverage as an optional benefit. In addition, the law requires coverage for applied behavior analysis (ABA) for individuals up to 18 years of age. Required coverage for ABA was initially capped at $40,000 per year, to be adjusted for inflation each year thereafter. The cap currently stands at $41,263.

To assess the impact of the mandate on the health insurance market, the Department of Insurance, Financial Institutions & Professional Registration (DIFP) obtained data from all insurers that had comprehensive health insurance in force subject to the autism mandate. These data indicate that the mandate has succeeded in broadly extending coverage to autistic individuals during its first year, and is expected to expand access to medically efficacious treatments to Missouri's autistic population in the future.

Summary of Key Findings

The data reflect the fact that 2011 was a transitional year during which much of the infrastructure necessary to deliver the mandated benefits was developed. By the second half of the year clinics had acquired the staff and other capacities to begin treatments pursuant to the mandate, insurance coverage became effective, and patients began to receive treatment.

1. **Coverage** By year-end, all insureds in the small and large group market were covered for the mandated benefits, including ABA therapy. A much lower proportion, about one-third, received similar coverage in the individual market, including individually-underwritten association coverage. A few large providers of individual insurance extended autism coverage to all of their insureds. However, Missouri statute only requires autism benefits as an optional coverage in the individual market, and most insurers do not provide it as a standard benefit.

2. **Number impacted** Nearly 4,000 individuals received treatment covered by insurance for an ASD at some point during 2011. This amounts to 1 in every 350 insureds, a figure in line with estimates in the scientific literature of treatment rates.[1]

3. **Licensure** The first licenses for applied behavior analysis were issued in Missouri in December, 2010. As of January 20, 2012, 120 individuals held an applied behavior analyst license, and an additional 24 persons obtained assistant behavior analyst licenses.

4. **Claim payments** Claims costs incurred for autism services during 2011 amounted to $4.3 million, of which nearly $1.1 million was directed to ABA services. These amounts represent 0.1 percent and 0.02 percent of total claims incurred during this period, consistent with initial projections produced by the DIFP.[2] For each member month of autism coverage, total autism-related claims amounted to $0.25, while the cost of ABA treatment amounted $0.06.

5. **Average Monthly Cost of Treatment –** For each individual diagnosed with an ASD that received treatment at some point during 2011, the average *monthly* cost of treatment across all market segments was $143, of which $35 consisted of ABA therapies. The average, of course, includes individuals with minimal treatment as well as individuals whose treatments very likely cost much more.

6. **Medical infrastructure** Anecdotal evidence indicates that fully operational ABA programs were not widely available during the first half of 2011. Among the many requisites for such a program are the negotiation of contracts and reimbursement rates, the development of billing systems, and the hiring of trained and licensed staff. Correspondence with several clinics indicates that ABA operations began in full between July and September.

7. **Impact on premiums** While claims costs are expected to grow somewhat in the future, it seems very unlikely that costs for autism treatment will have an appreciable impact on insurance premiums. However, because the DIFP has no authority over health insurance rates and does not receive rate filings, a more exact assessment of the impact of the mandate on rates cannot be provided.

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[1] While the CDC estimates that the prevalence of autism is between 1/100 and 1/150, autism presents with a high degree of variability. Not all such individuals will benefit from, or seek, treatment specifically targeted at the ASD.

[2] The DIFP estimated that the mandate would produce additional treatment costs of between 0.2 percent and 0.8 percent. The analytical assumptions associated with the lower-end of the estimate range appear to be validated by the claims data presented in this report.

Background

The term Autism Spectrum Disorder (ASD) encompasses a variety of related neurobiological developmental disorders that can present with varying degrees of impairment. Beyond classic autism, the term ASD includes Asperger's Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder. Generally, autism and related conditions are associated with deficits in communicative skills and capacity for social interaction and reciprocity, restricted repetitive behavioral patterns and sometimes severe cognitive and perceptual dysfunction.

The etiology of ASDs is not currently well understood, although studies have associated the disorder with anomalies in the structures of the brain related to facial recognition and emotional response (Mosconi, et. al., 2009) and with abnormalities associated with neurotransmitters and synapses (Wittenmayer, et. al., 2009). Left untreated, severe cases may require life-long care.

While there is no cure, the success of behavioral therapies in improving cognitive, linguistic and social functioning has been convincingly demonstrated in controlled studies. Behavioral interventions have led to robust improvements in IQ, behavioral adaptation, and a reduction in other symptoms associated with ASDs. Remington et. al. (2007) found that early intensive behavioral intervention led to dramatic increases in intelligence, language, daily living skills and positive social behavior compared to a control group that received "treatment as usual." Similar results were obtained by Cohen, Amerine-Dickens and Smith (2006), who found that a community-based behavioral treatment program resulted in significantly higher IQ scores and adaptive behavior scores. Nearly one-third of the children receiving behavioral treatment were able to transition into a regular educational setting without additional assistance, and 11 others did so with assistance, compared to only 1 in the control group.

There appears to be a strong consensus within the literature regarding the efficacy of behavioral treatments for autism in a variety of settings (see also Eikeseth, Smith, Jahr and Eldevik, 2002 and 2006; Howard, et. al. 2005; Sallows and Graupner, 2005). A good overview of clinical practice related to behavioral interventions can be found in Scott and Johnson (2007). Summarizing the large body of research, the Surgeon General reported as early as 1999 that "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 increasing communication, learning, and appropriate social behavior" (US Department of Health and Human Services, 1999).

History of HB 1311 and the ABA mandate

Prior to the passage of HB 1311 in 2010, Missouri enacted a mental health parity statute that became effective in 2005 (§376.1550). The purpose of this statute was to ensure that health insurers offered mental health benefits in a manner consistent with the provision of services for physical health: "A health benefit plan shall provide coverage for treatment of a mental health condition and shall not establish any rate, term, or condition that places a greater financial burden on an insured for access to treatment for a mental health condition than for access to treatment for a physical health condition" (§376.1550.1(2)). Under the terms of the statute, the term *mental health condition* is defined broadly to include all of the disorders recognized in the Diagnostic and Statistical Manual.

By this definition, insurers were required to cover treatment of ASDs even prior to the passage of HB 1311. However, the prior statute granted a broad exemption for treatments that were considered primarily for familial, educational or training purposes, that were custodial in nature, that were not clinically appropriate or that were experimental (§376.1550.5). Many, and perhaps most health insurance contracts issued in Missouri prior to HB 1311 included broad exclusionary language. For example, a typical exclusion was "...no Benefits will be provided for any of the following services, supplies, equipment or care; or for any complications, related to, or received in connection with, such services, supplies, equipment or care that are:

Not Medically Necessary.

Not specifically covered under this Agreement.

Any Health Care Service that is determined by the Company, in its discretion and subject to the right to submit a Grievance as set forth in Section 12 of this Agreement, to be Experimental or Investigational for the treatment of a specific patient's disease and clinical circumstance..." was excluded from coverage.

Autism treatments such as ABA were commonly excluded via the rationale that they are experimental in nature. Prior analysis by the DIFP indicated that even under the most generous set of assumptions, insurance carriers did not offer benefits of a level or kind that could have been expected to have any significant impact on individuals diagnosed an ASD. This analysis was consistent with the academic literature, which has documented that treatment for ASDs are either generally paid out-of-pocket by parents and relatives, are provided via public services such as special education programs, or, as was more likely, left largely untreated (Peele, Lave and Kelleher, 2002). Further, insurer-compensated treatment was not targeted to young individuals for whom treatments are known to be most effective and most likely to achieve an enduring and dramatic improvement in symptoms.

The paucity of insurance benefits for effective treatments of ASDs very likely contributed to lasting functional impairment of individuals with autistic and related disorders. To the extent that

such care cannot be funded by parents, nor provided publicly, individuals are likely to endure life-long cognitive and social deficits with enormous direct and indirect social costs (see Ganz, 2007).

To address the inadequate coverage for the treatment of ASDs in the private insurance market, and to ensure broader access to treatments that were known to be efficacious, HB 1311 established broad coverage requirements for ASD treatments. Applied behavior analysis (ABA) was specifically mandated for individuals 18 and under, for an amount up to $40,000 per year (adjusted for inflation in each subsequent year). All group plans were required to offer blanket coverage for all insureds. Individual plans, and individually-underwritten association plans, were required to extend an offer to cover the mandated benefits, though the offer can be refused by the policy-holder. In addition, HB1311 established a system of licensure for behavioral analysts to ensure the delivery of high-quality care.

HB1311 became effective for all health insurance plans issued or renewed in Missouri after January 1, 2011. Earlier this year, the DIFP issued a data call to assess the impact of the new law through June 30th, and to serve as a trial run to assess the kinds and quality of information that could be provided by insurers. A follow-up data call was issued at year-end. The experience during the first half of 2011 revealed that significant lags were associated with the implementation of the new law: mandated coverage was not extended until the renewal date of a health insurance policy; individuals required training and credentialing to practice ABA; medical providers faced the task of developing the infrastructure to secure compensation for services that were previously excluded by most health insurance plans; and insureds faced a learning curve with respect to the scope of the newly available benefits. Data below indicate that as the medical delivery infrastructure was put into place, significant benefits delivered through health plans were steadily increasing by the second half of 2011.

Coverage

All group plans issued or renewed after January 1, 2011, are required to extend the mandated benefits for the treatment of ASDs, including ABA, to all insureds. An offer of such coverage must accompany any insurance purchased in the individual market, including individually-underwritten association plans.[3] As such, many insureds will not have received ASD coverage until well after the January 1 effective date, since renewal dates will not coincide with the calendar year.

[3] Association health coverage, such as insurance sold through the AARP and a broad variety of other groups, is considered group coverage for some purposes. However, because it is individually-underwritten in a fashion similar to the true individual market, it is often treated as individual coverage. Under HB1311, such association coverage is considered individual coverage and therefore must only offer the mandated benefits.

By year-end, all insureds in the group market, and about one-third of insureds in the individual market were covered for the mandated ASD and ABA benefits. Over 90 percent of "member-months" over the course of the entire year in the group market were covered for the benefit, indicating the relative rapidity with which coverage went into effect after the effective date of the mandate.[4] The percentage of annual member months with such coverage in the individual market is considerably lower at 32.2 percent, which is virtually unchanged since the first half of the year.

Percent of Member Months With Coverage for Mandated ASD Benefits By Market Segment 2011

Market Segment	Total Member Months	Member Months of Policies with Autism Coverage	% With Coverage
Individual	3,272,121	1,053,043	32.2%
Small Group	5,524,721	5,034,574	91.1%
Large Group	11,871,686	11,245,146	94.7%
Total	**20,668,528**	**17,332,763**	**83.9%**

It is less likely that coverage will be broadly extended in the individual market due to the distribution of costs in this market. For group coverage, costs associated with the mandate are borne by the entire group in the same manner as any other illness. Since only the offer of coverage is required in the individual market, there will be a strong tendency of "adverse selection" with respect to autism benefits. Namely, the vast majority of individuals accepting ASD coverage will already have a dependent with an autism-related diagnosis. Since the coverage is usually provided as a rider at an additional premium, the entire costs of the mandated benefits will therefore be concentrated among such policyholders. The resulting premiums will likely make such coverage unaffordable for many. The DIFP is aware that the cost for an autism endorsement in the individual market can range from $500 to several thousand dollars per month.

[4] That is, most member months without ABA coverage occurred during the beginning of the year. Implementation of coverage occurred as plans were renewed over the course of the year.

For those individual plans for which coverage is optional, the take-up rate for ASD benefits is nearly zero. As noted earlier, a few large insurers have extended ABA coverage to all of their policy-holders in the individual market, though they are only required to extend it as an optional coverage that can be purchased for additional premium. The remaining insurers offering individual coverage comprise 69 percent of the market. For these carriers, less than $1/10^{th}$ of 1 percent of member months had such coverage in effect for 2011.

Coverage in the Individual Market – *Excluding* Insurers That Offer ABA Coverage to All Policyholders			
Member Months	**% of Individual Market**	**Member Months With Autism Coverage**	**% Member Months With Autism Coverage**
2,251,456	68.8%	1,353	0.1%

Treatment Rates

The DIFP attempted to assess the prevalence of individuals diagnosed with an ASD with coverage under a licensed health insurer. Unfortunately, insurers are only able to identify such individuals via information available from submitted claims, such that an individual with an ASD diagnosis must have sought a treatment for conditions specific to the ASD during the period under examination to appear in our data.[5] Thus, the estimates that follow should not be considered as even a proxy for all ASD-diagnosed individuals with health insurance coverage, but rather a subset of that group that received some form of ASD-related treatment during 2011. The overall prevalence of ASD-diagnosed insureds is quite likely to be significantly larger.

Lastly, the DIFP sought to estimate the number of individuals diagnosed with an ASD that *lacked* coverage under the autism mandate. However, because such individuals would be far less

[5] That is, individuals that did not seek treatment directly associated with the ASD would not normally be identified on a typical claims form. The DIFP requested that insurers count anyone who sought an ASD-related treatment during the preceding 12 months as part of their autistic population.

likely to seek treatment than their covered counterparts, and would be less likely to submit the claim when treatment was sought, these estimates are considered unreliable and not presented here.

During the last year, over 1.3 million Missourians obtained comprehensive coverage through a licensed insurer[6] in the individual, small group or large group markets. Of this number, nearly 4,000 individuals sought treatment during the reporting period for which the primary diagnosis was an ASD. The majority of these individuals, or 3,123, were 18 and under and therefore eligible for coverage under the ABA mandate. Across all market segments, 1 insured in 350 sought treatment for an ASD-related condition. Treatment rates are considerably lower than the prevalence rate of ASDs in the general population, which the Centers for Disease Control has estimated to be between 1/100 and 1/150. Autism can present with a high degree of variability. Many autistic individuals will neither seek, nor benefit from, extensive treatment.

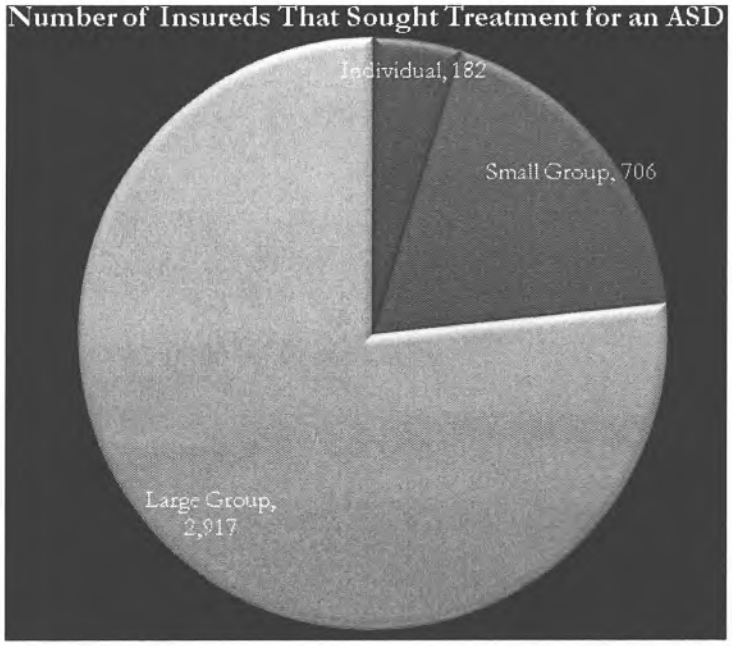
Prevalence of ASD Covered Treatment[7]

Market Segment	Insureds	Insureds With an ASD, Covered Under Mandate	1 Covered ASD Diagnosed Individual Per X Insureds	Insureds Under 18 With an ASD
Individual	249,188	182	1,369	153
Small Group	379,767	706	538	585
Large Group	702,218	2,917	241	2,385
Total	**1,331,173**	**3,805**	**350**	**3,123**

As expected, the percent of insureds with a covered ASD was nearly twice as high in the group market compared to the individual market. Only 182 individuals sought treatment for an ASD covered in the individual market, representing only 4.8 percent of all such individuals across all market segments.

[6] These figures exclude the non-licensed market and employers that self-insure under federal ERISA statutes. Self-insurers comprise a significant portion of the group market. Prior estimates by the DIFP suggest that self-insureds represent as much as 2/3 of the group market. Also excluded from these figures are all forms of public coverage.

[7] Figures are based solely on initial survey responses of licensed insurers for fully-insured plans related to the data period 2011. Some entities that are known to offer autism-related benefits, such as the Missouri Consolidated Health Care Plan (MCHCP) and some self-insured employer plans, are not included in the data.



Licensure

House Bill 1311 requires that each behavior analyst and assistant behavior analyst pass an examination and obtain board certification to be eligible for a license to practice in Missouri. The first licenses were issued in December, 2010. By mid-January of 2012, licenses were issued to 120 behavior analysts. In addition, 24 assistant behavior analysis licenses were issued. Assistants must practice under the supervision of a behavior analyst. In addition to licensed behavior therapists, licensed psychologists may also provide ABA therapy.

These figures indicate that Missouri is well on the way to developing the necessary medical infrastructure and expertise to deliver ABA services to a broad population. Correspondence with medical providers specializing in ASD treatment reinforce this impression, but also illustrate the considerable time and effort necessary to make ABA treatment more widely available as coverage for such treatment is extended. Coding methodology and claim transmittal protocols must be developed. Rates for the provision of previously excluded services must be negotiated. Appropriately trained and licensed personnel must be added to existing staff. One clinic indicated that they were not fully operational to deliver ABA services until July 1. A second began providing ABA treatments as of September 1.

Applied Behavior Analyst Licensure in Missouri				
	Behavior Analysts		Assistant Behavior Analysts	
Month License Issued	No. Lic. Issued During Month	Cumulative Licensed Analysts	No. Lic. During Month	Cumulative Licensed Analysts
December, 2010	19	19	0	0
January	28	47	5	5
February	11	58	4	9
March	14	72	2	11
April	9	81	2	13
May	3	84	0	13
June	1	85	1	14
July	11	96	3	17
August	0	96	4	21
September	2	98	0	21
October	3	101	1	22
November	6	107	1	23
December	6	113	1	24
January, 2012 (partial)	7	120	0	24
Total	**120**		**24**	

Claim Payments

During 2011, comprehensive health plans incurred a total of $4.3 billion in total claim costs. Only a small fraction of this amount resulted from autism-related treatments, which amounted to $4.6 million or 0.1 percent of total claims. Costs incurred for ABA therapies were only 0.02 percent of total claims, or $1,050,764.

The DIFP has previously estimated that the ABA mandate would produce claim costs of between 0.2 percent and 0.8 percent of total premium. Amounts incurred thus far are well below this estimate, but for reasons already discussed are expected to grow as the benefits of the mandate are more fully realized.

Autism-Related Claim Costs			
Line of Business	Total Incurred Losses	All Autism-Related Incurred Losses	Losses Incurred, ABA
Individual	$484,064,498	$543,916	$36,252
Small Group	$975,765,332	$1,027,953	$205,499
Large Group	$2,889,525,540	$2,737,959	$809,013
Total	**$4,349,355,370**	**$4,309,828**	**$1,050,764**

Autism Treatment as Percent of Incurred Losses		
Line of Business	All Autism-Related Incurred Losses	ABA-Related Incurred Losses
Individual	0.11%	0.01%
Small Group	0.11%	0.02%
Large Group	0.09%	0.03%
Total	**0.10%**	**0.02%**

Another method of expressing the costs of the mandate is the ratio of autism-related treatment costs to the total member months during which autism coverage was in effect. Across all market segments, the average autism-related claim costs for each month of autism coverage was $0.25, and $0.06 for the costs of ABA treatments.

Claim Costs for Autism Per Member Per Month for Policies with Autism Coverage					
Market Segment	Member Months of Policies With Autism Coverage	All Autism Related Claims	ABA Claims	All Autism-Related Claims, PMPM	ABA-Related Claims, PMPM
Individual	1,053,043	$543,916	$36,252	$0.52	$0.03
Small Group	5,034,574	$1,027,953	$205,499	$0.20	$0.04
Large Group	11,245,146	$2,737,959	$809,013	$0.24	$0.07
Total	**17,332,763**	**$4,309,828**	**$1,050,764**	**$0.25**	**$0.06**

For each individual receiving any form of treatment directly associated with an ASD, the average monthly claims cost during 2011 was $143, ranging from $293 in the individual market to $142 in the large group market. With respect to the population 18 years of age and younger, the costs of ABA treatments ranged from $15 in the individual market to $58 in the large group market.

Average Monthly Claim Cost Per Individual Treated for Autism				
	All Ages		Age 18 and Under	
Market Segment	All Autism-Related Treatment	ABA	All Autism-Related Treatment	ABA
Individual	$293	$19	$314	$15
Small Group	$115	$23	$122	$29
Large Group	$142	$42	$161	$58
Total	**$143**	**$35**	**$160**	**$47**

Other DIFP Activities Related to Autism

The DIFP worked on numerous fronts to successfully implement the autism mandate during 2011. Following the passage of the law, staff engaged stakeholders representing a wide variety of perspectives and needs – from insurance companies to providers to parents and advocates. This outreach was designed to anticipate and address any potential problems. Additionally, the Department was able to provide education and resources to parents and providers as they began navigating through the process of obtaining insurance coverage for autism benefits for the first time.

Complaints

The DIFP monitors the number of complaints and inquiries received that are related to the autism mandate. Over the course of 2011, DIFP staff responded to 109 consumer contacts by insureds with questions about autism coverage. Only six of these contacts resulted in formal complaints against an insurer. Subject matter ranged from the lack of medical providers, the lack of coverage in self-funded plans under federal jurisdiction, to concerns about costs and requests for clarification of various aspects of the new law.

Impact on Small Business

Initial concerns about the potential costs of the mandate resulted in an opt-out provision for small employers. Any small employer may petition the director for a waiver of the mandate if providing the coverage causes premiums to increase by 2.5 percent or more over any 12 month period. The earliest such a waiver request could have been made is therefore January 1, 2012. To date, the DIPF has received no requests for a waiver.

National recognition for online education

Before the law took effect on Jan. 1, 2011, the Department launched new educational content online for parents, health care providers and insurers on its website. The online resources include explanations of the new law's various provisions, frequently asked questions, instructions for filing consumer complaints, a Parent Resource Center and content specifically designed for health care providers. The Department's efforts in creating this comprehensive online guide were heralded by Autism Speaks, the nation's largest advocacy group for autism. At its Autism Law Summit in October 2011, the group recognized the DIFP for outstanding efforts on behalf of individuals with autism.

Outreach

The Department assembled an autism working group meeting in Jefferson City during November, 2010, which was attended by parents, advocates, medical providers and representatives of major insurance companies in the Missouri market. At the meeting, stakeholders discussed concerns and how the Department could best facilitate consumer and provider education about the new law as well as facilitate an open exchange of information between the insurance industry and the provider community.

In response to many of the issues identified through the working group, the DIFP issued a bulletin to all health insurance companies on January 3, 2011, outlining Department plans for enforcing the new law. This bulletin:

- Encourages the insurance industry to accept HCPCS codes
- Asks any companies that are not able to utilize these codes make information readily available to providers both in- and out-of-network.
- Reminds that the department will closely monitor the delivery of autism related services and ensure no unnecessary barriers to treatment are imposed
- Encourages companies to exercise flexibility in accommodating children already enrolled in ABA treatment, so as not to interrupt their ongoing therapy.

- Extends a one year "safe harbor" from any enforcement or disciplinary action related to temporary modifications or deviations to practices or procedures in order to accommodate those currently enrolled in ABA treatment.

Following the passage of HB 1311, Director Huff and other members of the DIFP team appeared throughout the state at more than 10 public events for consumers, industry and stakeholders.

Most recently, the Department hosted the Autism Provider Summit in December of 2011. The summit served as a one-day training program to educate autism treatment providers about insurance billing, navigating the insurance world, and ensuring that their staffs are properly credentialed and licensed. Close to 80 providers and interested parties attended the summit.

Conclusion

Applied behavior therapies have been shown to dramatically reduce long-term costs for a significant proportion of individuals diagnosed with an ASD, and to significantly improve their quality of life. The costs associated with the autism and ABA coverage mandate has thus far been minimal, even as the mandate has led to dramatically expanded coverage and the delivery of medically beneficial services. The law has achieved its purposes in an unqualified way for every measureable metric.

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Insurance Consumer Hotline

Contact DIFP's Insurance Consumer Hotline
if you have questions about your insurance policy
or to file a complaint against an
insurance company or agent:

difp.mo.gov

800-726-7390

DIFP

Department of Insurance,
Financial Institutions &
Professional Registration

Harry S Truman Building, Room 530
301 W. High St.
PO Box 690
Jefferson City, MO 65102

JANUARY 2012

The TRUST

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

From: **AUTISM SPEAKS**

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Rubenstein Communications, Inc.
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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.

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

September 2, 2008

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

Dear Dr. Casscells:

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

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

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

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

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

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

ABA is medically necessary treatment for ASD

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

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

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

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

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

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

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

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

ABA is not special education

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

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

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

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

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

Very respectfully,

Gina Green, PhD, BCBA

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

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.

NASW ALASKA CHAPTER
National Association of Social Workers

401 E. Northern Lights Blvd., Suite 205
Anchorage, Alaska 99503
907-332-NASW (6279) Fax: 907-332-6270
1-800-478-NASW (6279)
Director@naswak.org
http://www.naswak.org

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 Chapter of NASW 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. NASW of Alaska supports SB 74, which mandates that private insurance companies include coverage for treatment of autism spectrum disorders.

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.

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 2-3years 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.

Sincerely,

M. L.

Meg Loomis
Executive Director

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

ALASKA
PRIMARY CARE ASSOCIATION

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,

Marilyn Kasmar
Executive Director

903 W. Northern Lights Blvd., Suite 200, Anchorage, AK 99503-2400
main: 907.929.2722 *fax:* 907.929.2734 www.alaskapca.org
supporting Alaskans' health care homes

February 15, 2012

Senator Johnny Ellis
State Capitol, Room 119
Juneau, Alaska 99801-1182

Dear Senator Ellis,

We are writing to commend you for your commitment to protecting vulnerable children, particularly those with special needs. We applaud your recent work on sponsoring Senate Bill 74, providing treatment assurances for families with autistic children. As you know, Boys & Girls Clubs welcomes all children through its doors, including some with autism spectrum disorders. We understand many of their families struggle to afford progressive treatments, care that leads to greater independence and contributions of these young Alaskans.

Boys & Girls Clubs of Southcentral Alaska serves 10,000 young members in 36 communities in youth-friendly facilities. Club professionals provide essential academic, career and character development programs during afterschool hours, school breaks and summer vacation. With nearly 2,000 youth coming through Clubhouse doors each day, these facilities are bustling and on the front lines of inspiring and empowering youth. Children with special needs are valued within the membership and accommodated to ensure inclusion in our dynamic programs.

Again, Senate Bill 74 takes an important step in mobilizing families with autistic children toward solid treatment, and ultimately strengthens our communities. On behalf of the families we serve, we look forward to its passage.

Warm regards,

Alana Humphrey, Chief Executive Officer
Boys & Girls Clubs of Southcentral Alaska
(907)770-7349

Scott Miller, Incoming Chair
Boys & Girls Clubs of Southcentral Alaska

ALASKA WOMEN'S LOBBY

AWL Mission: To defend and advance the rights and needs of Women, Children and Families in Alaska

P.O. Box 20891
Juneau, Alaska 99802-0891
www.akwomenslobby.org

Letter of Support - SB74
Insurance Coverage for Autism Spectrum Disorders

The Alaska Women's Lobby, a statewide group with steering committees in Fairbanks, Anchorage and Juneau organized to protect and advance the rights of women, children and families supports SB74. A Centers for Disease Control and Prevention study in 2006 estimates an average of one in 110 children have an autism spectrum disorder (ASD).

Alaska should join the 35 states and the District of Columbia that have laws related to autism and insurance coverage. A November 2010 Insurance Coverage for Autism paper by the National Conference of State Legislatures (NCSL) documents at least 23 of those 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. The increasing number of states adopting comprehensive autism mandates, Medicaid coverage of ASD-related services, and coverage of these services by the U.S. military health plan provide further evidence that health insurance coverage of ASD-related services is appropriate.

While some ASD-related services are provided in the public schools, medical experts, advocacy groups, and parents indicate that there is a need for additional services outside of the school setting. Although the insurance industry often claims that treatment for ASDs, such as Applied Behavior Analysis (ABA)-based therapy are educational and their coverage not appropriate for health insurance, if the premise that the role of health insurance is to promote public health, encourage the use of preventative care, and provide financial protection for excessive financial expenses for unexpected illnesses, the proposed mandate appears consistent with the role of health insurance.

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 treatments out-of pocket or forego them. These treatments may be costly. Some families may spend more than $50,000 per year on autism-related therapies, such as ABA (NCSL 2010 report). 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.

Please help Alaskan families struggling with providing the best care possible for their children with ASD and pass SB74

HOPE
Community Resources Inc.

Regional Centers

South Central Region
540 W. International Airport Rd.
Anchorage, AK 99518-1110
(907) 561-5335
1-800-478-0078
Fax: (907) 564-7429

Mat-Su Valley Region
851 E. Westpoint Drive, Suite 306
Wasilla, AK 99654
(907) 357-3750
Fax: (907) 357-3751

Dillingham/Bristol Bay Region
P.O. Box 715
Dillingham, AK 99576-0715
1-800-478-2117
Fax: (907) 842-5007

Kodiak/Aleutian Region
1623 Mill Bay Road
Kodiak, AK 99615-6235
(907) 486-5011
Fax: (907) 486-5019

Seward/Resurrection Bay Region
P.O. Box 1933
Seward, AK 99664
(907) 224-2063
Fax: (907) 224-2063

Juneau/Southeast Region
9109 Mendenhall Mall Rd., Ste. 5D
Juneau, AK 99801
(907) 463-3602
Fax: (907) 463-3605

Barrow/North Slope Region
P.O. Box 2123
Barrow, AK 99723
(907) 852-3151
Fax: (907) 852-2855

www.hopealaska.org

Stephen P. Lesko
Executive Director

Roy T. Scheller
Deputy Executive Director

April 5, 2011

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

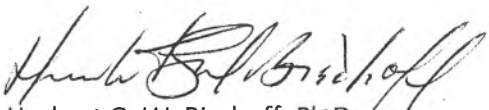
Re: SB 74 Insurance Coverage for Autism Spectrum Disorders

Dear Senator Ellis:

Thank you for sponsoring SB 74, requiring that private insurance coverage is to be provided to those under 21 experiencing Autism Spectrum Disorders. Hope Community Resources is a statewide non-profit agency supporting individuals and their families. With over 1,200 individuals choosing our supports we are familiar with the struggles experienced by families trying to meet the costs of related treatment services. We currently serve close to 200 individuals, including children, adolescents, adults and elders, identified on the Autism spectrum. Among those receiving supports a disproportionate number of individuals experience related developmental delays, challenging behaviors and mental health concerns. This bill can go a long way toward allowing families to afford medically necessary treatment by providing needed pharmacy, psychiatric, psychological, habilitative or rehabilitative, and therapeutic care in a timely manner.

Please add my name to the list of those in support of this legislation. As this bill moves forward I respectfully ask those reviewing this bill for their careful consideration and support of Senate Bill 74.

Thank you for your continued support of this important legislation.



Herbert G. W. Bischoff, Ph.D.
Licensed Psychologist

AaNA
Alaska Nurses Association
3701 E Tudor Road Suite 208
Anchorage, Alaska 99507

April 13, 2011

The Honorable Johnny Ellis
Alaska State Senate
Alaska State Capitol

Re: SB74, Insurance Coverage for Autism Spectrum Disorders

Dear Senator Ellis:

Thank you for introducing SB74. The Alaska Nurses Association (AaNA) supports this bill.

Autism is a medical /neurological condition which impacts the way the brain functions. It requires early and intensive medical and educational interventions in order to have the best possible outcomes for our children. Unfortunately, many insurance policies contain specific exclusions for autism. Individuals with Autism Spectrum Disorders (ASDs) often display unusual behaviors and interests, unusual ways of learning and paying attention, and impaired verbal and non-verbal communication skills. In addition to these behavioral symptoms, individuals with autism will often have physical ailments such as asthma, digestive disorders, persistent viral infections and epilepsy.

The Centers for Disease Control (CDC) estimates that up to 730,000 people between the ages of 0 and 21 have an ASD and more children than ever before are being classified as having autism spectrum disorders. (Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, United States, 2006) Alaska currently has 1,512 children and youth under the age of 21 who have autism, with 454 of these individuals needing significant clinical treatment.

Health insurance should assist families in helping to ensure that children with an ASD receive recommended levels of therapeutic services as early as possible. There is a window of opportunity for helping these children while they are young, and missing this window due to lack of finances or protracted appeals processes with insurance companies, can prevent children from reaching their maximum potential in terms of learning and functioning in society.

The AaNA wishes to express our thanks for your sponsorship of this important measure.

Sincerely,

Nancy C. Davis, RN, MS
AaNA President
907-274-0827 Office

Debbie Thompson, BSN, RN, CNOR
AaNA Executive/Labor Program Director
907-274-0827 Office

aahc
ALASKA ASSOCIATION OF
Homes for Children

Alaska Baptist Family Services
Anchorage, AK

Alaska Children's Services
Anchorage, AK

Alaska Family Services
Palmer, AK

Covenant House of Alaska
Anchorage, AK

Family Centered Services of Alaska
Fairbanks, AK

Juneau Youth Services
Juneau, AK

Kenai Peninsula Community Care Center
Kenai, AK

Maniilaq Association
Kotzebue, AK

Nome Children's Home
Nome, AK

North Slope Borough Children's Services
Barrow, AK

North Star Behavioral Health
Anchorage & Palmer, AK

Presbyterian Hospitality House
Fairbanks, AK

Providence Behavioral Health Systems
Anchorage, AK

Residential Youth Care
Ketchikan, AK

Searhc
Sitka, AK

The Boys and Girls Home of Alaska
Fairbanks, AK

The Salvation Army Booth Memorial Home
Anchorage, AK

Youth Advocates of Sitka
Sitka, AK

April 12, 2011

Senator Johnny Ellis
Alaska Senate
State Capitol
Juneau, Alaska 99801

RE: Support for SB74 – Insurance coverage for Autism Spectrum Disorder

Dear Senator Ellis,

On behalf of the Alaska Association of Homes for Children (AAHC) we would like to thank you for introducing SB74. We wholeheartedly support your efforts to require health insurers to offer coverage for the types of services necessary to improve the children's health who are affected by autism spectrum disorders (ASD).

Over the lifespan, the average societal cost of caring for one person with autism is $3.2 million (Harvard School of Public Health, 2006). These staggering costs could certainly be reduced by affording parents options through medical coverage that could include behavioral therapies, psychological, psychiatric, physical therapy, occupational therapy and other developmentally–based interventions. With insured care, many families would find it possible to maintain their child in their home with needed support, rather than failing due to limited resources, and potentially causing costly institutionalization.

Alaska currently has 1,512 children and youth under the age of 21 who have autism; approximately 454 need significant clinical treatment. Coverage of medically necessary autism treatment in Alaska is a key to enable many children to access the services they need and live more productive lives. AAHC strongly endorses Senate Bill 74.

Thank you,

Brad Ohs
AAHC President

NFIB

The Voice of Small Business®

ALASKA

January 31, 2011

The Honorable Johnny Ellis
Alaska State Senate
State Capitol Building
Juneau, Alaska 99801-1182

RE: Senate Bill 74

Dear Senator Ellis,

On behalf of the National Federation of Independent Business/Alaska, I wish to express our opposition to Senate Bill 74. The National Federation of Independent Business is the largest small-business advocacy group in Alaska.

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

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

Unfortunately SB 74 mandates coverage for autism spectrum disorders that may not fit employee's needs but for which small employers providing health insurance bear the cost. Increased mandates force employers to consider whether they can afford to continue coverage or are forced by increased prices to eliminate health insurance for their employees. Mandates prevent small employers from providing affordable insurance programs tailored to its specific work force.

SB 74 is discriminatory against small employers as the mandate applies only to those who provide coverage regulated by state insurance statutes, but not programs offered by the state and other governmental entities, unions, or large employers who typically offer ERISA programs. Thus it creates a less fair business environment for Alaska's small employers and favors outside business interests.

Sincerely yours,

Dennis L. DeWitt
Alaska State Director

cc: Health and Social Services Committee

LIST OF POSSIBLE TESTIFIERS

Millie Ryan (HSS)

Judith Ursitti, Autism Speaks

Mark Lambright, Oliver Wyman Actuarial Consulting

Dennis Bailey, bill drafter

Stephen Williams, Mental Health Trust Authority

Kelly Donnelly, Stone Soup Group

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.
Fairbanks, AK 99709
907-452-7294
cheneyamber@yahoo.com

PREMERA | BLUE CROSS BLUE SHIELD OF ALASKA

April 6, 2012

Jack C. McRae
Senior Vice President

Representative Wes Keller
State Capitol Room 432
Juneau, Alaska 99801

Re: SB 74, Mandated Autism Benefit

Dear Representative Keller,

On behalf of Premera Blue Cross Blue Shield of Alaska, I would like express our policy concerns with SB 74, which mandates coverage for autism spectrum disorders (ASD) for children under age 21.

Premera fully understands the challenges faced by children with autism and their families. Therefore, we want to approach this issue in a manner that is in their best interest, balanced by the interests of all the members we serve. Accordingly, we would like to highlight the following information for your consideration:

- The mandate included in this legislation does not extend to the State of Alaska's employees, Native health plans, federal employees, Medicare, Medicaid, or to self-insured groups.
- Therefore, SB 74 imposes an expensive mandate exclusively on Alaska's employers and individuals.
  - The employer and individual markets comprise only 15% of Alaskan citizens.
  - These two markets are fragile and disproportionally affected by "one size fits all" mandates.
  - This is a burdensome mandate for the state to impose on just the 15% of Alaskans who have private insurance, without imposing the same mandate on itself for its employees and other populations with publicly-funded insurance.
- We would like to reiterate that under federal health care reform, the subsidized cost of any new mandate passed by a state after December 31, 2011 must be picked up by the State if the mandate is not included as part of "essential health benefits."
  - This means that federal subsidies offered in the Exchange will not cover the cost of any new mandates: states would be required to pay this cost for subsidized individuals in the Exchange.
  - Using data presented to the Alaska Health Care Commission in October 2011 and March 2012, the state would be financially responsible for covering the cost of autism treatment for subsidized individuals in the Exchange, estimated to be 47,000 Alaskans in 2019.
- We also operate affiliates in two other states that have considered autism mandates during the past few legislative sessions.

P.O. Box 327
Seattle, WA 98111

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jack.mcrae@premera.com

www.premera.com

- **Washington State <u>has not passed</u>** a similar, less extensive autism mandate bill, primarily due to the estimated cost impact of the bill to the state, more specifically the impact to the state employee plan. The state estimated a fiscal impact to the state employee health plan of over $140 million impact for the first biennium, growing to over $200 million per biennium in future years.

- This equates to state costs of between $68 and $192 per month for a family of four.

- Similarly, **Oregon <u>did not pass</u>** an autism mandate due to cost.

We offer this information in light of increasing autism prevalence rates: another factor to consider related to this legislation. In late March 2012, the Centers for Disease Control and Prevention increased its estimate for autism prevalence rates to 1 in 88 children who will be identified with an autism spectrum disorder (ASD).

Before voting on SB 74, we believe it is important—from a policy perspective—to determine what the short- and long-term costs of SB 74 would be on the State Treasury, and on those individual Alaskans and small businesses who will bear the financial burden of the mandate.

We appreciate your consideration of this input with respect to Senate Bill 74. Please feel free to give me a call if you have any questions pertaining to this letter.

Sincerely,

Jack C. McRae

Jack C. McRae
Senior Vice President

NFIB

The Voice of Small Business®

ALASKA

April 2 2012

The Honorable Wes Keller, Chair
House Health & Social Services Committee
Alaska State Legislature
120 4th Street
State Capitol, Room 3
Juneau, Alaska 99801-1182

RE: SB 74 Mandated Insurance Coverage for Autism Spectrum Disorder

Dear Representative Keller:

Senate Bill 74 proposes to lay an expensive new burden on small businesses already struggling to provide health care. SB 74 mandates new and unprecedented coverage for autism and requires small businesses to cover the costs. The bill does not include the state nor most local governmental agencies. Federal law already exempts most large firms and union health plans from the mandate.

The Legislature has virtuous intent in addressing the serious epidemic of autism, but SB 74 goes beyond coverage parity with other diseases and could cost millions of extra dollars for privately insured Alaskans and the dwindling number of small employers who provide health benefits.

It is understandable that legislators consider the autism mandate too expensive for the state, but it is puzzling that, at a time when the ranks of the uninsured swell, they expect Alaska small businesses to shoulder a burden that government itself is unwilling to take on. In addition to the economic implications, lawmakers are also sending a highly contradictory message to their constituents. If this legislation is important, why shouldn't state workers and the thousands of low-income children covered by Denali Kid Care and Medicaid have the same access to this new coverage?

The unfairness of SB 74 is compounded by federal law, which prohibits states, including Alaska, from placing such mandates on large employers who self-insure. So if you are a larger business, you can operate under one lower-cost, lower-mandate set of federal rules; however, if you are an Alaska small business, you must comply with 28 mandates (29 if SB 74 becomes law) that drive up the costs.

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

health care for their employees also pay 18 percent more in premiums than the largest firms do -- for the same benefits -- according to a Commonwealth Fund-supported study.

No one should get trapped into an argument over whether or not it is important to include autism in health coverage. What small businesses have been asking for is the ability to work with health insurers to individually tailor health plans that fit the needs of their particular businesses and their employees -- which might or might not include autism coverage -- rather than be forced to operate under the one-size-fits-all, legal straightjacket of mandates. So far, states, including Alaska, have said no. "Pay up or drop health care if you can't afford it," has been the effective response.

SB 74 is discriminatory against small employers as the mandate applies only to those who provide coverage regulated by state insurance statutes, estimated to be only 15% of Alaska's population. It does not cover programs offered by the state and other governmental entities, unions, or large employers who typically offer ERISA programs – about 70% of our population. Thus, it creates a less fair business environment for Alaska's small employers and favors outside business interests.

Even with this legislative mandate and its heavy negative impact on small businesses, only 15% of Alaska's population will be affected and 85% will not. It will offer no help to the 121,000 uninsured Alaskans. If Senate Bill 74 becomes law, its first and most lasting effect will be to increase the cost of health insurance and contribute to driving more Alaska workers into the ranks of the uninsured.

Sincerely yours,

Dennis L. DeWitt
Alaska State Director

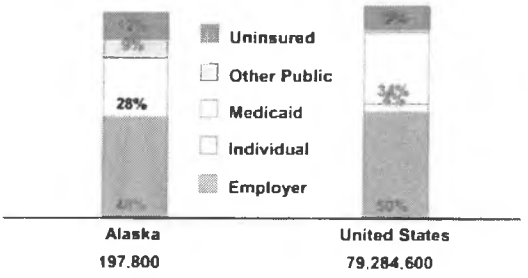
Cc: NFIB/AK Leadership Council
Senator Johnny Ellis

Health Coverage & Uninsured

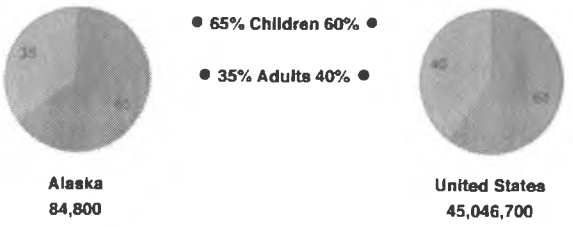
Compare: High/Low/US Two locations: AK and US

Facts At-A-Glance	AK #	AK %	US #	US %	Notes
Health Insurance Status of Total Population	-	-	-	-	% total population
Employer	357,200	53	149,890,200	49	
Individual	19,500	3	14,926,300	5	
Medicaid	92,500	14	48,400,200	16	
Medicare	49,100	7	38,128,000	12	
Other Public	36,600	5	3,942,500	1	
Uninsured	121,800	18	49,903,900	16	
Nonelderly Uninsured Rate by FPL	-	-	-	-	% nonelderly uninsured
Under 100%	47,000	36	19,933,800	34	
Under 139%	59,400	34	26,330,200	34	
139-250%	30,600	24	11,869,700	24	
251-399%	19,500	14	6,235,200	12	
400%+	10,200	6	4,676,900	5	
Firms Offering Insurance by Size	-	-	-	-	
Firms with Fewer than 50 Employees	-	29.6	-	39.2	% offer insurance
Firms with 50 Employees or More	-	93.4	-	96.4	% offer insurance
Percent of Firms Offering Insurance	-	44.4	-	53.8	

Health Insurance Coverage of Children, states (2009-2010), US (2010)



Distribution of the Nonelderly with Medicaid by Age, states (2009-2010), U.S. (2010)



Please see statehealthfacts.org for sources and notes.

	Market	Testing/Evaluation	Pharmacy	Psychiatric	Psychological	Rehab	Therapeutic	Age
Premera	**Individual** - excluded							
	Group Plans	x				x	x	<7 years
	Mental health rider			x	x			all
	Pharmacy rider		x					all
Mega (2)	Group	x	x			x	x	>2 - <6 years
Aetna	Group	x						
Aetna (3)	Group					x	x	<7 years
Time/John Alden	Individual/Group							
Celtic	Individual			x				
ODS	Individual/Group	x						
Connecticut General	Group							
Trustmark	Group					x	x	
United Healthcare	Group	x	x	x	x	x	x	

(1) alternative visit limit may be selected by policyholder
(2) Texas Mandate
(3) Short Term, optional benefit requested by policyholders, limits selected by policyholde

OPTIONAL Rider
Entirely Excluded

$$ limit
{$250 - unlimited}
$2500 limit on all psychiatric care
Neurocognitive therapy [$1,000 - $10,000] annual max, Home health care [$50,000 - $100,000]

ɛr, mirrors Washington mandate

visit limit
inpatient: 30 days/calendar year, outpatient: 45 visits/calendar year
inpatient: {6} days/calendar year, outpatient: {12} visits/calendar year(1)
{20 - unlimited}

10-100 days/calander year

Janet Ogan

From: Hall, Linda S (CED) <linda.hall@alaska.gov>
Sent: Friday, March 30, 2012 5:08 PM
To: Ernest Prax
Cc: Janet Ogan; Koeneman, Crystal A (CED); Thayer, Curtis W (CED)
Subject: RE: SB 74 and health care exchanges
Attachments: Autism Coverage in Alaska 2012.xlsx

First, attached is a chart with analysis of mental health coverage in the various policies currently written in Alaska. We do not have a coverage today that is labeled as Autism or Autism Spectrum Disorder. Coverage is determined by CPT codes for specific services but there is nothing specifically labeled as Autism coverage.

Under the federal health care bill, there will need to be a definition of "essential benefits" that are determined by each state. These are based on the three largest small group health insurance plans in effect today. This would be the coverage mandated in the health exchanges. Today since we do not have coverage specifically for Autism, it is fair to assume that this would not be one of the "essential benefits". it is my understanding that there is some risk to a state when adopting mandates now, in that if the mandate is not already in effect and is not included in the essential benefits, the state may be obligated to pay for the coverage required under the mandate.

We do not know if the mandated coverage would apply to Medicaid but it would apply to private insurance plans and in some instances to self-insured plans. This is a complex issue and there are still a number of unclear provisions with regulations continuing to be promulgated by the Department of Health and Human Services and CMS. I am sorry I cannot be more precise in answering the questions.

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

From: Ernest Prax [mailto:Ernest_Prax@legis.state.ak.us]
Sent: Friday, March 30, 2012 8:34 AM
To: Hall, Linda S (CED)
Cc: Ogan, Janet B (LAA)
Subject: SB 74 and health care exchanges
Importance: High

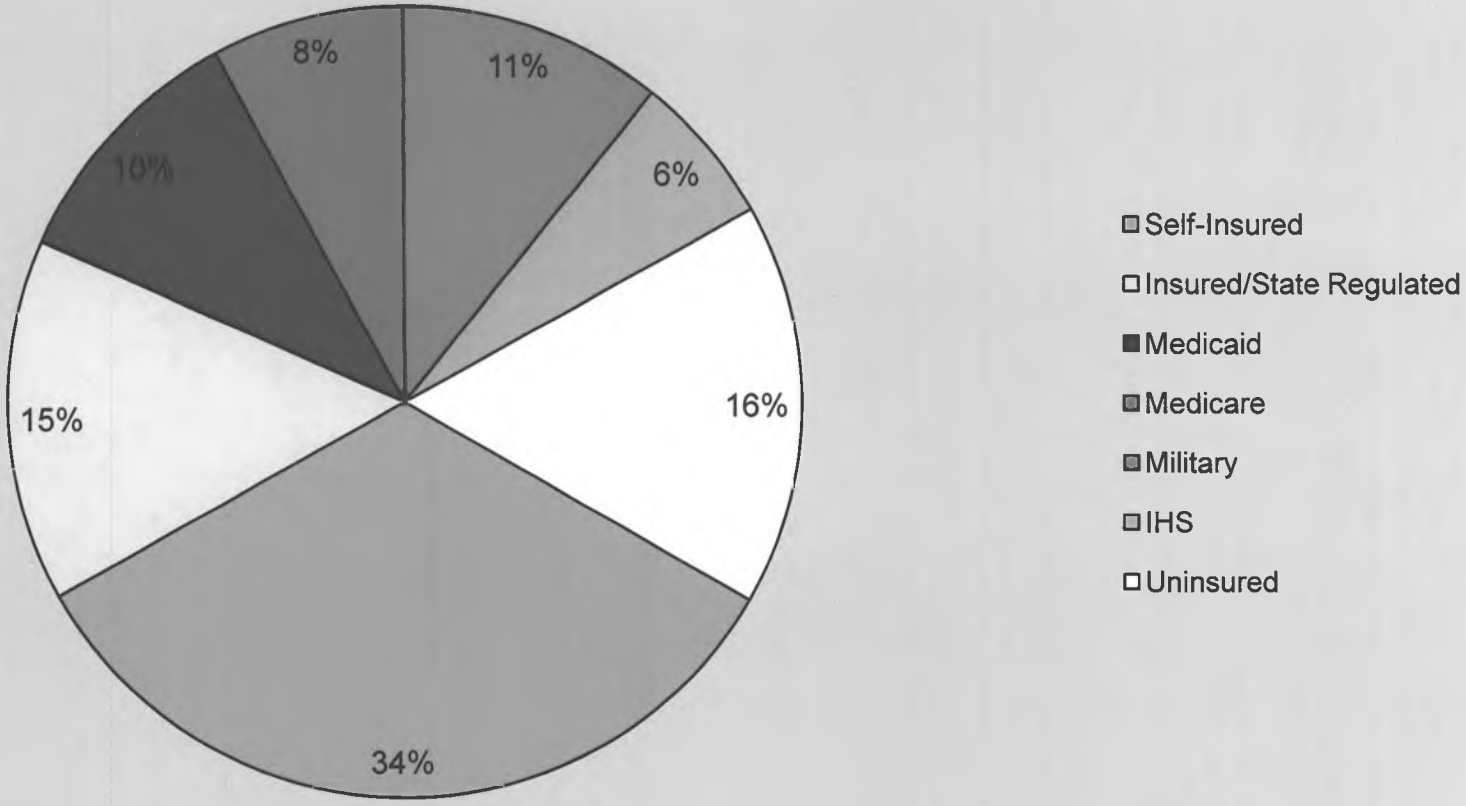
Hi Linda,

Rep. Keller would like to know what would happen if SB 74 (Autism Spectrum Disorder Insurance) is passed in the following context. If this insurance coverage is mandated by the state, under ObamaCare, is everyone in the established health exchanges required to offer autism spectrum disorder coverage---private, self-insured, Medicaid?

Thanks,

Ernest Prax
Office of Representative Wes Keller
State Capitol, Room 432
Juneau, AK 99801
Phone: 465-2186; Fax: 465-3818

Health Coverage of Alaska Population



Alaska Impact 2019 (MAFA Projections)

- Increase in health care spending: +$289 M
  - State of Alaska: +41 M
  - Alaska Households: $124 M
  - Federal Gov: $124 M

- Increase in insurance coverage: +53,000 Alaskans
  - Medicare: 0
  - Medicaid: +38,000
  - Employer sponsored: - 45,000
  - Exchanges: +78,000 (60% supported by fed subsidies)
  - Other Private: - 18,000
  - Other Public: 0

SCIENTIFIC AMERICAN™

Permanent Address: http://www.scientificamerican.com/article.cfm?id=autism-new-criteria

Redefining Autism: Will New *DSM-5* Criteria for ASD Exclude Some People?

Experts call for small and easy changes to the *Diagnostic and Statistical Manual,* the "bible" of psychiatry, so that everyone with autism spectrum disorder qualifies for a diagnosis

By Ferris Jabr | Monday, January 30, 2012 | 7

People have been arguing about autism for a long time—about what causes it, how to treat it and whether it qualifies as a mental disorder. The controversial idea that childhood vaccines trigger autism also persists, despite the fact that study after study has failed to find any evidence of such a link. Now, psychiatrists and members of the autistic community are embroiled in a more legitimate kerfuffle that centers on the definition of autism and how clinicians diagnose the disorder. The debate is not pointless semantics. In many cases, the type and number of symptoms clinicians look for when diagnosing autism determines how easy or difficult it is for autistic people to access medical, social and educational services.

The controversy remains front and center because the American Psychiatric Association (APA) has almost finished redefining autism, along with all other mental disorders, in an overhaul of a hefty tome dubbed the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*)—the essential reference guide that clinicians use when evaluating their patients. The newest edition of the manual, the *DSM-5,* is slated for publication in May 2013. Psychiatrists and parents have voiced concerns that the new definition of autism in the *DSM-5* will exclude many people from both a diagnosis and state services that depend on a diagnosis.

The devilish confusion is in the details. When the APA publishes the *DSM-5,* people who have already met the criteria for autism in the current *DSM-IV* will not suddenly lose their current diagnosis as some parents have feared, nor will they lose state services. But several studies recently published in child psychiatry journals suggest that it will be more difficult for new generations of high-functioning autistic people to receive a diagnosis because the *DSM-5* criteria are too strict. Together, the studies conclude that the major changes to the definition of autism in the *DSM-5* are well grounded in research and that the new criteria are more accurate than the current *DSM-IV* criteria. But in its efforts to make diagnosis more accurate, the APA may have raised the bar for autism a little too high, neglecting autistic people whose symptoms are not as severe as others. The studies also point out, however, that minor tweaks to the *DSM-5* criteria would make a big difference, bringing autistic people with milder symptoms or sets of symptoms that differ from classic autism back into the spectrum

A new chapter

Autism is a disorder in which a child's brain does not develop typically, and neurons form connections in unusual ways. The major features of autism are impaired social interaction and communication—such as delayed language development, avoiding eye-contact and difficulty making friends—as well as restricted and repetitive behavior, such as repeatedly making the same sound or intense fascination with a particular toy.

The *DSM-5* subsumes autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS)—which are all distinct disorders in *DSM-IV*—into one category called autism spectrum disorder (ASD). The idea is that these conditions have such similar symptoms that they do not belong in separate categories, but instead fall on the same continuum.

Essentially, to qualify for a diagnosis of autistic disorder in *DSM-IV,* a patient must show at least six of 12 symptoms, which are divided into three groups: deficits in social interaction; deficits in communication; and repetitive and restricted behaviors and interests. In contrast, the *DSM-5* divides seven symptoms of ASD into two main groups: deficits in social communication and social interaction; and restricted, repetitive behaviors and interests. (For a closer look at the changes, read the companion piece: "Autism Is Not a Math Problem". You can also compare *DSM-IV* and *DSM-5* criteria for autism on the APA's Web site.)