

# Alaska State Legislature

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Representative Pete Petersen  
District 19

## MEMORANDUM

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

FROM: Representative Pete Petersen

DATE: January 18, 2010

RE: Hearing Request for HB 187

Dear Representatives Keller and Herron,

I respectfully request the House Health and Social Services Committee to continue the process of considering HB 187: Insurance Coverage for Autism Spectrum Disorders.

Since HB 187 was heard and held in committee on March 24, 2009, 11 states have passed similar bills mandating insurance companies to cover the cost of treatment for autism spectrum disorders (ASD). Before this bill was heard, a total of 6 states had passed similar bills. Currently there are 19 states with pending legislation, in addition to legislation pending in Puerto Rico and Washington, DC, according to the National Conference of State Legislatures. In April of 2009, the Autism Treatment Acceleration Act (S. 819) was introduced in the United States Senate, which is waiting for committee hearings. A companion bill was introduced in the US House of Representatives the following month (H.R. 2413). It is clear the nation is becoming more aware of the rapidly growing number of autistic children, and the unfair discrimination of insurance companies to deny them coverage.

In the effort to keep families of autistic Alaskans in the state, to encourage healthcare professionals to move to Alaska to treat ASD youth, and to dissuade discrimination of ASD by health insurance companies, I respectfully request a second hearing for HB 187. Included with this request is the information requested.

Please feel free to contact me or my aide, Mercedes Theuer, at 465-4939 with any questions or concerns. Thank you for your further consideration of HB 187.

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## Representative Pete Petersen District 19

### Sponsor Statement

### HB 187 INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS

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

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

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

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

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

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

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

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

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District 19

## MEMORANDUM

TO: Members of the House Health & Social Services Committee

FROM: Representative Pete Petersen

DATE: January 18, 2010

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

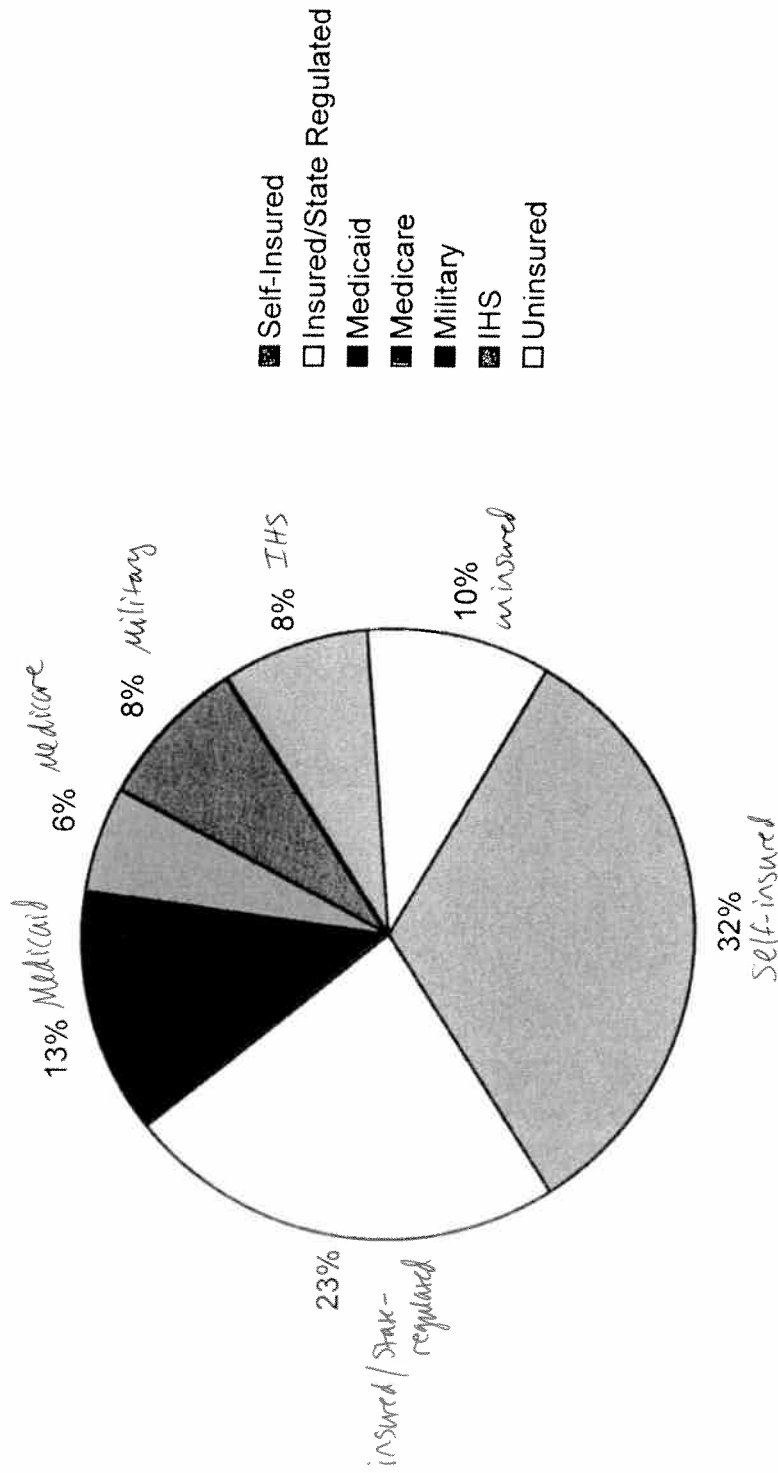
The following information pertains to questions received during the (H) HSS meeting held on March 24, 2009:

1. RE: Age of covered participants. The bill allows those under the age of 21 to access services for Autism Spectrum Disorders (ASD). This age is consistent with both Medicaid coverage in Alaska, and is a reasonable age in regards to private insurance coverage. Many plans cover dependent children up to a certain age, generally through the college years. Therefore 21 is a reasonable age at which to discontinue these services.
2. RE: out-of-state coverage. If services rendered out-of-state were not available in Alaska, yes, insurance companies would have to cover those out-of-state services—just like they cover those services not available here in Alaska for any number of other health related issues. However, the claims cap would still remain at \$36,000 per year per child. As noted by many of the parents who testified, even the \$36,000 doesn't always cover the needs of the child. Seeking services outside of Alaska would raise the cost for services, and that \$36,000 would not go very far. In addition, except for children who require hospitalization care, ABA is best delivered in the child's own environment which could include home or school. Behavioral treatment sought outside of Alaska would likely be for the most severe cases, including aggression and self-injury, that could not be managed in facilities in the state. Moreover, it is unlikely these more costly forms of treatment would be sought out-of-state due to the nature of such treatment. While ABA

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

3. RE: Sustainable market for ASD service providers. There was a question posed as to whether the percentage of Alaskans covered by this legislation would be enough to sustain the industry of autism service providers. For this question I think it is important to refer to the pie chart provided by Linda Hall at the Division of Insurance (attached). This chart identifies the types of insurance held by Alaskans. The original report containing this breakdown of Alaska's population was done in 2003. However, the division has adjusted the numbers for the 2008 population. I will discuss each section beginning with the Self-Insured at the top of the key:
  - a. Self-Insured plans are not currently subject to state mandates. They are protected, as was stated in the committee, by Federal ERISA preemption. There is a Federal ERISA mandate that was filed on April 2, 2009, that made this 32% of Alaskans subject as well, and allow those families to access services.
  - b. Insured/State Regulated are the plans that are directly affected by HB 187. This 23% is very close to the 25.3% projected by the cost analysis done by Jim Boudier. His figure of 45.5% was in reference to group-insured Alaskans, which fall under HB 187, and contains about 25.3% of the total population of Alaska—not far off from the 23% cited by the Division of Insurance.
  - c. Medicaid in Alaska currently provides some treatment for ASD. It is the primary method by which Alaskan families access these services, however limited the coverage might be. Many families, as we heard, are fully insured, but don't have coverage for the treatments their children need. These families persistently apply for Medicaid waivers to access these funds, but the waiting list can be years, which is not time that autistic children have to spare. In addition, insured families are adding stress to what is already an overburdened system.
  - d. Medicare would likely not be a significant contributor to or drawer from any of these services.
  - e. Military families already have access to some ASD treatments, including ABA as provided in the federal TRICARE ECHO program for families with children with disabilities.
  - f. IHS, or Indian Health Services, is a benefits program for American Indians and Alaskan Natives. IHS draws funds to cover treatment, for those who qualify, from several different sources including Medicaid and private health insurance. The issue of coverage for the treatment of ASD has not come up with IHS due to the fact that they currently draw from places like Medicaid and private insurance to cover other services and it is likely they would do the same for services requested to treat ASD.
  - g. HB 187 would not affect the uninsured group of Alaskans.

# Health Coverage of Alaska Population



\*Navigant 2003 Report, 2008 Population

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Archive for Monday, October 05, 2009

## CDC survey finds higher incidence of autism

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

By Trine Tsouderos  
October 05, 2009

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

[ttsouderos@tribune.com](mailto:ttsouderos@tribune.com)

## Doing the math

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

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

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

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

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

American Academy of Pediatrics: [www.aap.org](http://www.aap.org)

CDC: [www.cdc.gov/ncbddd/autism/](http://www.cdc.gov/ncbddd/autism/)

Health Resources and Services Administration [www.hrsa.gov/](http://www.hrsa.gov/)

— Associated Press



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

Legislation would require insurers to cover autism diagnosis and treatment

April 2, 2009

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

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

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

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

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04/01/09 Casey Bill Would Improve the Lives of Older Citizens and Direct Care Workers »

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potential."

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

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

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

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

- Requiring that insurers provide coverage for the diagnosis and treatment of autism including Applied Behavioral Analysis therapy and assistive communication devices;
- Creating a demonstration project to develop Autism Care Centers. These centers would provide a full array of medical, behavioral, mental health, educational and family care services to individuals and families in a single location. These comprehensive treatment facilities would increase access to quality health care services and communication among health care providers, educator and other providers of services;
- Creating a demonstration project to provide a full array of services to adults with autism to improve their quality of life and enable them to live as independently as possible;
- Establishing a voluntary population-based autism case registry to help understand the root causes, rates, and trends of autism;
- Developing a national multimedia campaign to increase public education and

awareness about healthy developmental milestones and autism throughout the lifespan;

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

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

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

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

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

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

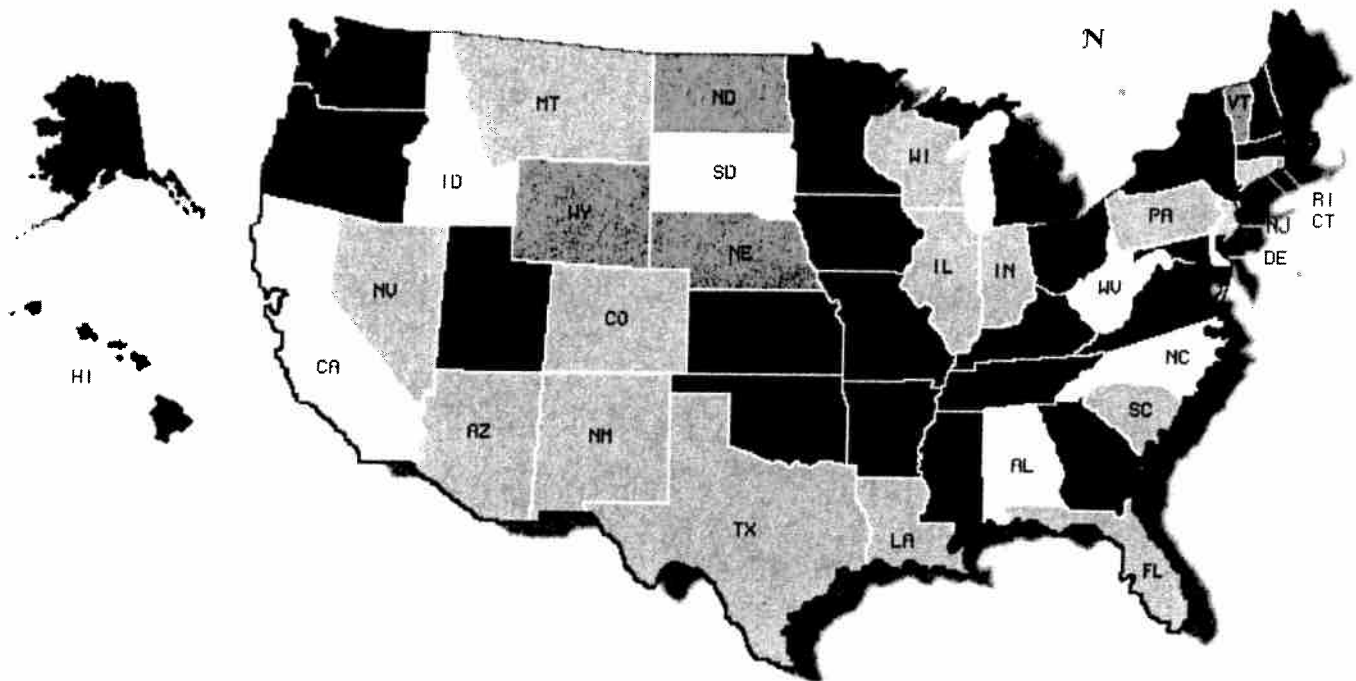
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#### Press Contact

Larry Smar - (202) 228-6367



## Autism Speaks 2009 State Autism Insurance Reform Initiatives



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

## HB 187 Questions

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

## **ABA-BASED INTERVENTIONS FOR YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDERS**

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

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

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

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

### ***Service delivery and workforce development needs***

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

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

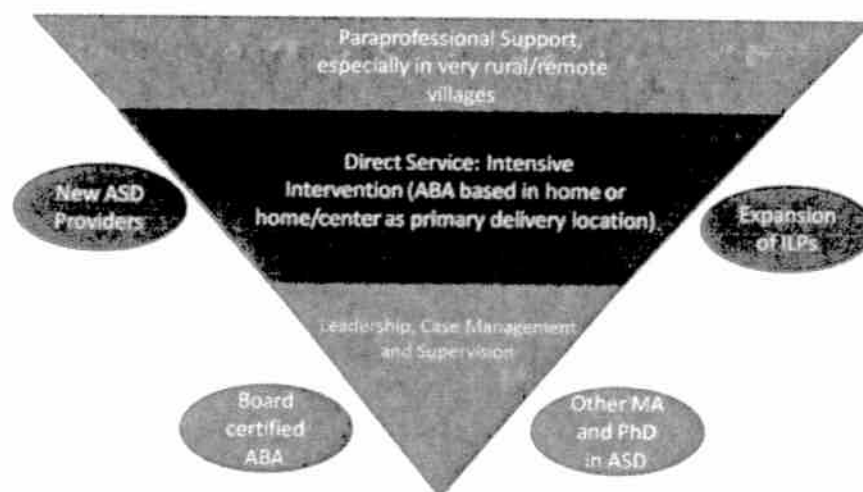
Professionals must guide and oversee the quality and continuity of services for these young children. Typically, Board Certified Behavior Analysts (BCBA) are employed to provide that leadership role. However, those children who require the most intense early intervention may also need services from several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

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

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

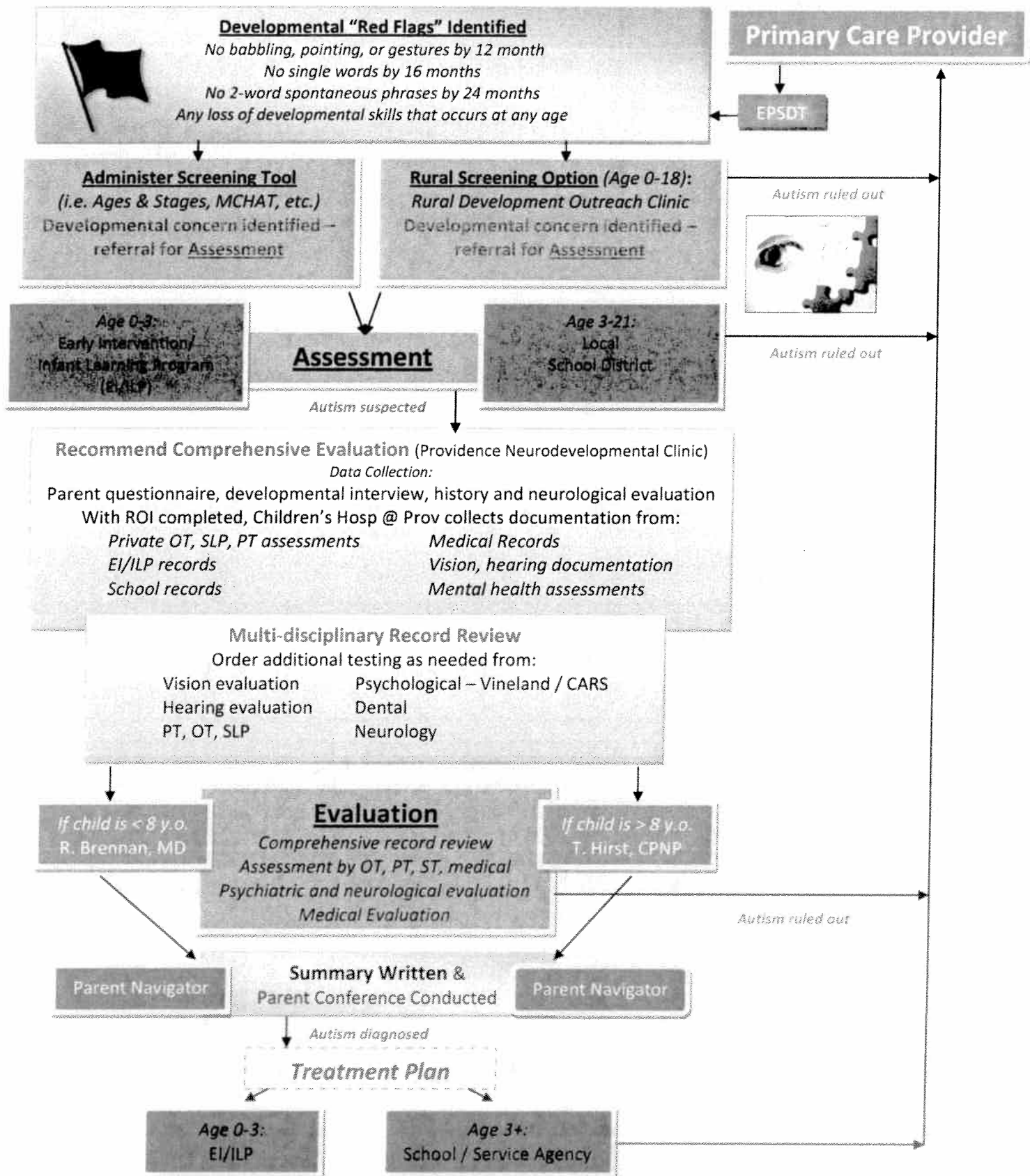
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### Intensive Early Intervention Workforce Development Needs



# Alaska's Goals in Response to Autism

2009



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

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

**Keywords** Health services · Insurance · Autistic disorder · Economics

### Introduction

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

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

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

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

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

## Methods

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

spent on medical services covered by the plan. This number was then divided by the total revenue to private insurance companies in Pennsylvania. More specifically, we used the formula:

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

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

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

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

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

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

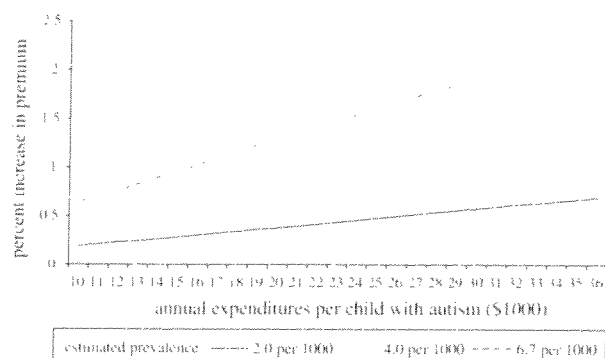
MLR is medical loss ratio. The MLR refers to the proportion of revenues from health insurance premiums spent on medical services covered by the plan. The MLR was calculated by dividing the total medical losses incurred by total premium revenue collected by insurers. The MLR is used to convert increased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

**Table 1** Summary of cost and expenditure studies for individuals with autism; all monetary amounts converted to 2006 \$<sup>a</sup>

	Data source	Treated prevalence	Sample	Grand total	Medical				
					Total	Inpatient	Meds	Other	School
(Mandell et al. 2008)	Allegheny County, PA Medicaid data 1994–1999	2.0/1,000	334 Children with autism diagnosis	\$12,000	\$12,000	\$8,300	–	\$3,700	–
(Croen et al. 2006)	Kaiser Permanente, Northern CA 2003–2004	–	3,053 Children with autism diagnosis	\$2,900	\$2,900	\$1,500	\$770	\$600	–
(Liptak et al. 2006)	National sample from MEPS 1997–2000	2.1/1,000	31 Children with autism diagnoses	\$7,400	\$7,400	\$880	\$1,170	\$5,300	–
(Leslie and Marlin 2007)	Large US self-insured employers 2000–2004	Per 1,000: 0.9 (2000) 1.3 (2001) 1.8 (2002) 2.1 (2003) 1.9 (2004)	256,646 Children diagnosed with a mental disorder 2000–2005	\$4,965 (2000) \$5,979 (2004)	–	–	–	–	–
(Ganz, 2006)	Synthetic estimate	–	–	Lifetime: \$3,439,800	Lifetime: \$333,000	Lifetime: \$39,400	Lifetime: \$6700	Lifetime: \$286,800	Lifetime: \$163,800
(Jarbrink and Knapp 2001)	Center of Economics data & survey of 250 parents	–	228 Children with autism or high functioning autism (HFA)	Autism: \$1,834,600 HFA: \$687,200	Autism: \$237,500 HFA: \$164,000	Autism: \$62,200 HFA: \$71,800	Autism: \$8,000 HFA: \$19,400	Autism: \$167,300 HFA: \$72,900	Autism: \$418,600 HFA: \$254,100

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





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

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

## Results

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

## Discussion

The results of this analysis suggest that even dramatic increases in the treated prevalence of autism and associated annual healthcare expenditures would result in relatively small increases to healthcare insurance premiums. The average family healthcare insurance plan in the United States costs \$1,009 per month, of which families pay an average of 28% (Kaiser/HRET Survey of Employer-Sponsored Health Benefits, 1994–2005, 2007). Our

analysis suggests that, using current treated prevalence estimates and an annual expenditure for children with autism of \$10,000, the average family would pay an additional \$0.54 a month, or \$6.44 a year. If current treated prevalence were to double as a result of the new benefit and annual expenditures rose to \$20,000, families' annual increased contribution would be \$26.10. Even in the unlikely event that treated prevalence were to rise to the accepted community prevalence of 1 in 150 children, and per capita expenditures rose to \$36,000 per year, the increase in the family contribution would reach \$6.53 a month, or \$78.31 per year.

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

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

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

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