

House Bill 187
Autism Insurance Reform
“An Act requiring insurance coverage for autism spectrum disorders”

Sponsor: Representative Petersen
Co-Sponsors: Representatives Dahlstrom, Wilson
Gruenberg, Munoz, Kerttula, Gara, Kawasaki

Talking Points

- **Autism** is a disorder affecting at least 1 in 150 children with approximately 1 in 500 requiring significant clinical treatment. Alaska currently has 1,512 children and youth under the age of 21 who have autism; approximately 454 need significant clinical treatment
- **Autism is treatable.** 30 years of research shows that with treatment, many children overcome the severe symptoms of their disorder.
 - ✓ About half the children who receive intensive early intervention achieve normal functioning after 2-3 years of treatment
 - ✓ There is an average gain of 22 IQ points
 - ✓ 1/3 gained 45 IQ points
 - ✓ Nearly 50% of those receiving intensive early intervention do not require lifelong services and supports
- **The earlier the diagnosis, the more effective treatment is.** The diagnostic process involves a comprehensive assessment (neurodevelopmental pediatrics, psychology, speech, occupational and physical therapy, ophthalmology, audiology) by a multidisciplinary team. Only those children who meet specific medical criteria are diagnosed with autism. (See the back page for a diagram of the diagnostic process).
- **Treatment equals savings.** With treatment, Alaska will see savings of \$208,500 per capita in avoided special education costs and lifetime savings of \$1.08 million per capita. Treatment may include the following medically necessary services
 - ✓ Pharmacy, psychiatric, psychological, rehabilitative and therapeutic care
 - ✓ Rehabilitative care includes applied behavior analysis (the design, implementation and evaluation of environmental modifications to produce socially significant improvement in human behavior or to prevent the loss of an attained skill or function)
- **Without treatment** it is estimated that it will cost the state \$3.2 million per capita (Michael Ganz, Harvard economist)
- **Coverage of medically necessary autism treatment** in Alaska will enable many children to access the services they need and live more productive lives.
- **Most private insurance policies specifically exclude coverage for treating autism**, even when the services are otherwise covered by the health plan
- **HB 187** requires private insurance policies (approximately 23% of all insurance plans) to provide a maximum coverage of \$36,000 a year for the diagnosis and treatment of autism spectrum disorders, including but not limited to applied behavior analysis
 - ✓ Must be prescribed by a licensed physician, psychologist or advanced nurse practitioner
 - ✓ Must be provided by an autism service provider as identified in a treatment plan developed following a comprehensive evaluation
 - ✓ Must identify the medically necessary pharmacy care, psychiatric care, psychological care, rehabilitative care and therapeutic care
- **The maximum likely cost** of such coverage to the private insurance ratepayer is approximately **0.92%** or **\$3.60** per policyholder per month

HB 187
Autism Insurance Reform
Frequently Asked Questions

Question: Why should private insurance cover autism? Isn't that the job of schools?

Answer: Autism is a complex neurobiological medical condition that is present from birth or the early stages of development. It affects thinking, social interaction, communication, cognitive development, imagination, learning and relationships with others.

It is often assumed that children from 3-21 are receiving medical services through Alaska's special education programs because of the Individuals with Disabilities Education Act (IDEA). However, services provided in accordance with the IDEA are required to be educationally relevant to allow a child to participate in his or her educational program. They are NOT intended to ameliorate medical conditions.

Private insurance IS intended to cover medical expenses, which includes medically necessary treatments for neurological disorder such as autism.

Question: What are the barriers to having autism covered? Don't we already have mandates in Alaska that cover autism?

Answer: The existing mandates that ought to cover autism don't do so adequately. For years, there have major obstacles to covering treatment for individuals with autism:

- Insurance companies consider the treatment as habilitative and not restorative; therefore, therapies that are covered for individuals who have lost function due to accident or illness have not been covered for those who have autism.
- The treatment is considered experimental. With the increasing number of meta-analysis studies as well as the multi-site random controlled trials and other credible research demonstrating the efficacy of treatment for autism, this argument is not holding up well.
- Insurance companies consider some services such as Applied Behavior Analysis and speech therapy to be educational and not medical.
- There are unreasonably low caps on the number and duration of visits.

Question: How is autism treated?

Answer: There is no single treatment protocol for all children with autism. However, most children are treated with a combination of structured behavioral, speech and occupational therapies, and in some cases, medications for co-occurring conditions such as seizures, anxiety, attention deficit disorder or other disorders.

Question: What treatment modalities will be covered?

Answer: As long as treatments are prescribed by a licensed physician, psychologist or advanced nurse practitioner, meet Alaska's criteria for "medically necessary" and are identified in a treatment plan following a comprehensive evaluation, they are covered. If the treatments do not have a procedure code, they are typically not covered by insurance (i.e., over the counter dietary supplements or foods).

The bill as introduced would provide coverage for children birth to 21 years of age for the following treatments:

- Pharmacy, psychiatric, psychological, rehabilitative and therapeutic care
- Rehabilitative care includes applied behavior analysis therapy (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)

Question: Who currently pays for autism treatment in Alaska?

Answer: There is no required insurance for the diagnosis or treatment of autism in Alaska. The state of Alaska through the Department of Health & Social Services (DHSS) acts as the "payer of last resort for certain autism services such as speech, occupational and physical therapies for school-aged children and youth whose family's income falls below poverty level. This income restriction does not apply to DHSS's early intervention/infant learning program that serves children from birth-3; however, children with autism are rarely able to access these services since they are seldom diagnosed prior to age 3. There is coverage for children paid by DHSS the state for on-going medical conditions when they meet certain criteria. That coverage is based on the child's income not the family so it covers more kids which is good for the kids but expensive for the state. DHSS does not provide intensive early intervention services to any children with autism.

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.

Question: Is private insurance coverage for autism mandated in other states?

Answer: Nearly 30 states have introduced autism insurance reform legislation this year. To date, 13 states have enacted some form of insurance coverage for autism. In the state with autism insurance reform. . .

- Children who have never before been able to receive treatment are making remarkable progress

- Providers have joined adequate networks of participating providers and negotiated satisfactory reimbursement rates
- The impact on premiums has been negligible
- The insurance industry's own association – the Council for Affordable Health Insurance – estimates that mandated autism benefits have increased premium costs by LESS than 1%.

In addition, an autism insurance reform amendment has been added to H.R. 3200 “America’s Affordable Health Choice Act of 2009.” The amendment will prohibit discrimination in benefits against persons with autism by amending current sections of H.R. 3200 to include behavioral health treatments as part of the essential benefits package.

Question: Why should Alaska require private insurance companies to pay a share of the treatment costs related to autism?

Answer: Families would not have to bear the often-ruinous financial strain of exorbitant out-of-pocket costs and more children would enter school ready and able to learn in a mainstream classroom. Costs would be spread among families, insurance companies and the Department of Health & Social Services.

Question: Will the Alaska bill significantly increase insurance premiums for employers and/or businesses?

Answer: The Alaska bill would generate an estimated impact of **0.92%** or **\$3.60** per policyholder per month.

Question: Who will provide needed services? Won't people have to go out of state to get services?

Answer: Workforce development is a critical component of the Governor’s Council on Disabilities & Special Education’s *5-Part Autism Initiative*. To date, 6 graduate-level Alaskans are being supported to secure distance-delivered board certification in *Applied Behavior Analysis (ABA)* in exchange for participating in a state autism network. A Memorandum of Agreement has been negotiated for Northern Arizona University to offer Alaska-specific distance-delivered ABA for a new cohort of graduate-level students. An in-state bachelor-level early childhood/family-centered program that matches core requirements for associate behavior analyst certification is being developed at the University of Alaska Anchorage as well as an occupational endorsement to train and certify paraprofessional to deliver one-one-one behavioral interventions.

Question: is autism being over-diagnosed?

Answer: A diagnosis of autism is only given after a comprehensive, multi-disciplinary evaluation across development and physical domains (neurodevelopmental pediatrics, psychology,

speech, occupational and physical therapy, ophthalmology, audiology). If a child exhibits any of the “red flags” (i.e., no babbling, pointing or gestures by 12 months, no single words by 16 months, no two-word spontaneous phrases by 24 months, ANY loss of ANY language or social skills at ANY age), an *Ages & Stages* screening tool is administered.

Only those children who “fail” the screening are referred for developmental assessment consisting of a record review, objective observation, parent interviews and administration of additional assessment tools such as the *Modified Checklist for Autism in Toddlers* or *Autism Screening Questionnaire*.

Only those children who “fail” the developmental assessment are referred for a comprehensive evaluation in Anchorage at The Children’s Hospital at Providence. Staff collect records and data, including a parent questionnaire, developmental interview, history and neurological evaluation and with a release of information also collects private occupational, speech and physical therapy and psychological testing notes; early intervention, school, medical, vision and hearing records; and behavioral and mental health assessments. The multi-disciplinary team reviews the records as a team and orders additional testing as needed (i.e., vision, hearing, occupational therapy, physical therapy, speech and language, psychological, dental, neurology).

A diagnosis of autism is only given after the comprehensive evaluation indicates that the child meets specific medical criteria for autism and other possible genetic or medical disorders are ruled out.

Question: How can I help?

Answer: Join the grassroots advocacy coalition now!

- Contact the Governor’s Council on Disabilities & Special Education at 1-888-269-8990 or 269-8990 (Anchorage) or <http://hss.state.ak.us/gcdse/Contacts/default.htm>
- Respond to action alerts
- Talk to your legislators
- Spread the word about HB 187 Autism Insurance Reform with friends, therapists, doctors, school district staff and anyone who would benefit from passage of autism insurance reform