

Arizona Autism Insurance Coverage: FAQ's

Q. What is autism?

- A. Autism, or Autism Spectrum Disorders (ASD) is a complex, lifelong, neurobiological disorder. "ASD" includes the three diagnoses of autistic disorder, Asperger's Syndrome, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS). 1 in 150 individuals born today in the US are diagnosed with ASD, making it more common than all types of pediatric cancer, diabetes, and AIDS combined. ASD crosses all racial, ethnic, and social lines, but is four times more common in boys than girls. ASDs result in impairments in a combination of communication, social, and behavior domains. Symptoms can range from very mild to quite severe.

Q. How is ASD diagnosed?

- A. ASD is usually diagnosed by a licensed psychologist or pediatrician, often a specialist such as a developmental pediatrician. Validated screening and diagnostic instruments such as the PEDS, mCHAT, ADI-R, and/or ADOS are typically used. Diagnostic assessments may take several hours to perform, and require specialized training. Parents generally report a speech delay or regression as the first warning sign, usually around 18 months of age, but this varies across demographic groups.

Q. How is ASD treated?

- A. There is no single treatment protocol for all children with autism. However, most children are treated with a combination of behavioral, physical, occupational, and speech therapies, and in some cases, medications for co-occurring symptoms or diagnoses such as irritability, bi-polar disorder, anxiety, or other disorders. Some of the most common and well-understood therapeutic interventions are based on applied Behavior analysis (ABA). As a theoretical umbrella, principles of ABA are often employed in behavioral, occupational, speech, and physical therapies. Behavioral therapy is generally the most highly utilized therapy for most children; while speech, occupational, and physical therapies might be prescribed for 1-2 hours per week, behavioral therapy may be required for up to 35 hours per week.

Q. Why is behavioral therapy used and how do we know it is effective in treating ASD?

- A. Behavioral therapy generally comprises the largest component of a child's treatment plan in terms of the number of hours. Research clearly demonstrates that most individuals respond best to highly-structured behavioral programs. The seminal article on this type of intervention was published by Ivar Lovaas at UCLA in 1987. This controlled, long-term study found that 47% of children with autism achieved normal intellectual educational functioning after treatment intensive behavioral treatment, compared to only 2% in the control group. Since the Lovaas article was published, 20 years of research and over 500 studies continues to support the effectiveness of behavioral therapy for autism. The National Institute of Child Health and Human Development, the National Research Council, the American Academy of Pediatrics, and other prominent groups all list ABA-based interventions among the recommended treatment for ASD.

Q. How much does ASD cost the US every year?

- A. Autism costs the US over \$90 billion per year, and that cost is expected to double by 2017 due to the growing population of those affected. (Autism Society of America)

Q. How much does treatment cost for one child with ASD?

- A. Over the lifespan, the average societal cost of caring for one person with autism is \$3.2 million. (Harvard School of Public Health, 2006) Comprehensive intervention programs for preschool aged children cost up to \$50,000 per year. (New York Times 2006) However, investing \$50,000 per child for 3 years before school entry saves \$1 million per person by age 55 in costs related to housing, income subsidy, employment assistance, health care, and other public programs. (Jacobson, et al., 1998)

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Q. How many children in Arizona have ASD?

A. Based on 2006 data from the Department of Education and 2007 data from the Centers for Disease Control, almost 6,800 students would be diagnosed with autism in Arizona public and charter schools. This excludes private schools, and adults and children under age five. Further, DDD does not currently publish data about the number of people served under the autism diagnosis in Arizona, nor do they serve individuals with Asperger's or PDD-NOS.

Q. Who currently pays for ASD treatment in Arizona?

A. There is no required private insurance coverage for the diagnosis or treatment of ASD in Arizona. The State of Arizona, through the Department of Economic Security acts as the "payor of last resort" (A.R.S. §36-2946[A]) for certain autism services (such as OT, PT, speech, music, and habilitation therapies). Services for children ages 0-3 are delivered through the Arizona Early Intervention Program (AzEIP), and services for children ages 3+ and adults are delivered through the Division of Developmental Disabilities (DDD).

In 2006, AzEIP paid an average of \$5,927.40 in 2006 per child for early intervention for children with autism age 0-3 [DES 2006]). However, this figure does not capture the true cost of services for multiple reasons, including:

- Many children with ASD are not diagnosed and receiving services prior to age three.
- There is a shortage of providers in AZ, and some therapies are not available without long waiting lists, especially in rural areas.
- Not all children receive the same number of therapy hours, and criteria used to determine a child's treatment plan are subjective.

AHCCCS/Arizona Long Term Care System (ALTCS) contracts with DES through the Division of Developmental Disabilities (DDD) for services for children ages 3+, including OT, PT, speech, music, and habilitation therapies. **There is no coverage at all for Asperger's Syndrome or PDD-NOS under DDD** (see A.R.S. §36-551[18a]), and many children with an autism diagnosis fail to qualify for services as well due to eligibility requirements. In November 2007, AHCCCS reported annual expenditures of approximately \$44.5M (total funds) related to services for approximately 5,090 individuals with autism (\$8,700/person). As of 1/18/08, DDD pays the following rates for one hour of therapy:

DDD Service	Hourly Rate	
	Low	High
[Behavioral] Habilitation	20.53	N/A
Assessment & Supervision-Hab Bach/Masters	40.00	60.00
Speech Therapy – Clinic*	62.80	86.28
Speech Therapy – Natural*	77.94	116.91
Occupational Therapy*	62.80	86.28
Physical Therapy*	62.80	86.28

* Tiered by zip code

Because Arizona law does not require insurance coverage for ASD treatment, families that do not qualify for AzEIP and/or DDD services pay for services out of pocket, often tens of thousands of dollars per year. Families that cannot afford to do so may go without crucial interventions. Bearing this burden often results in divorce and even bankruptcy.

Q. What happens in other States?

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A. In contrast to Arizona, 19 states and the District of Columbia have enacted some form of insurance coverage for autism, including CA, CO, CT, GA, IL, IN, IA, KS, KY, ME, MD, NH, NY, OR, RI, SC (Ryan's Law), TN, TX, VA. Laws specifically requiring coverage of ABA-based interventions are found in IN, MN (legal action), SC, and TX. Additional bills are pending in FL, OH, OK (Nick's Law), MA, MI, and PA.

Q. What would change if Arizona required insurance companies to pay a share of the treatment costs related to ASD?

A. DDD would save money because as the payor of last resort, DDD would pay for far fewer claims related to autism treatment. The quality of services would improve, because insurance companies will create standards for reimbursable providers. Providers would be able to offer higher salaries to therapists, and offer more oversight, training, and expertise to their line therapists. Improved coverage would likely generate more small businesses, as well as draw and retain providers in the state of Arizona. Families would not bear the often ruinous financial strain of exorbitant out-of-pocket cost. More children would enter school ready and able to learn in a mainstream classroom.

Q. What is covered under the proposed legislation in Arizona?

A. The bill as introduced would provide coverage for the following:

- Diagnosis of ASD
 - By a licensed Arizona psychologist
 - By a medical doctor (MD) or doctor of osteopathy (DO) in Arizona
- Treatment for ASD
 - Autism, Asperger's Syndrome, and PDD-NOS
 - Speech, Occupational, Physical, Behavioral therapies
 - Psychiatric and Psychological care
 - Rehabilitative and Habilitative care
 - Children birth-18 years of age
 - Behavioral Therapy subject to annual limit of \$50,000, but NOT subject to limit on the number of annual visits
- Excludes small employers (<50 employees) and AHCCCS Health Plans
- Effective for contracts, policies, or evidences of coverage issued or renewed after 6/30/09

Q. Will the Arizona bill significantly increase insurance premiums for employers and/or employees?

A. The Arizona bill would generate an estimated **impact of .501% on claim cost** in Arizona, or about **\$1.50 per member insured per month** (\$18.00 per year). This is consistent with other states, in which the effect on claims has been less than 1% per year.¹ Further, the primary drivers of health care costs are NOT insurance mandates, but rather, increased spending on prescription drugs and hospital care.²

Q. What can I do to help?

A. Contact your senator and representatives and ask them to support the autism insurance bill. Attend the candlelight vigil on January 29, 2008, 6pm at the state capital, 1700 W. Washington, Phoenix, AZ 85007. Still have questions? Visit www.azautismsinsurance.org for updates and information!

¹ See www.CAHI.org

² See "Too Great a Burden: Arizona's Families at Risk." Publication No. 07-112AZ. Families USA, December 2007.