



# State Autism Insurance Reform Initiatives

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# State Autism Insurance Reform Initiatives

Autism Speaks is the nation's largest autism science and advocacy organization, dedicated to funding autism research, increasing awareness of autism, and to advocating for the needs of individuals with autism and their families.



# State Autism Insurance Reform Initiatives

- What is the impact of autism on family finances, employment and time?
  - Relative to children with other special health care needs, a disproportionate number of children with autism live in families that have large out-of-pocket expenditures, experience financial problems, and report a need for additional income.
  - Parents of more than half of children with autism reduce or stop work to care for their child.
  - Parents of more than 25% of children with autism spend 10 or more hours weekly providing or coordinating their child's care.



# State Autism Insurance Reform Initiatives

- What are the health insurance experiences of families who have a child with autism? Compared to families who have a special needs child without mental health care needs, families who have a child with autism
  - are over three times more likely to report that health insurance does not meet their child's needs;
  - are over two times more likely to report that costs not covered by insurance are unreasonable;
  - are over three times more likely to report that insurance does not allow their child to see a needed provider.



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- Many policies restrict autism coverage. For example, section 3.01.006 of the CareFirst BlueCross BlueShield Medical Policy Reference Manual provides as follows:

“Medical and mental health services for the treatment of pervasive developmental disorders are considered **not medically necessary**, as no medical or mental health treatments have been proven effective for the primary diagnosis of pervasive developmental disorders.”



# State Autism Insurance Reform Initiatives

- Are there in fact no effective treatments for autism? In 1999, the Surgeon General of the United States stated that “[t]hirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”



# State Autism Insurance Reform Initiatives

- Just last week, the journal *Pediatrics* published the results of a randomized control trial assessing the efficacy of the Early Start Denver Model, a comprehensive developmental behavioral intervention, for improving outcomes of toddlers with autism.
- The intervention, which was initiated when children were less than 21/2 years, resulted in significant improvements in IQ, language, adaptive behavior, and autism diagnosis.

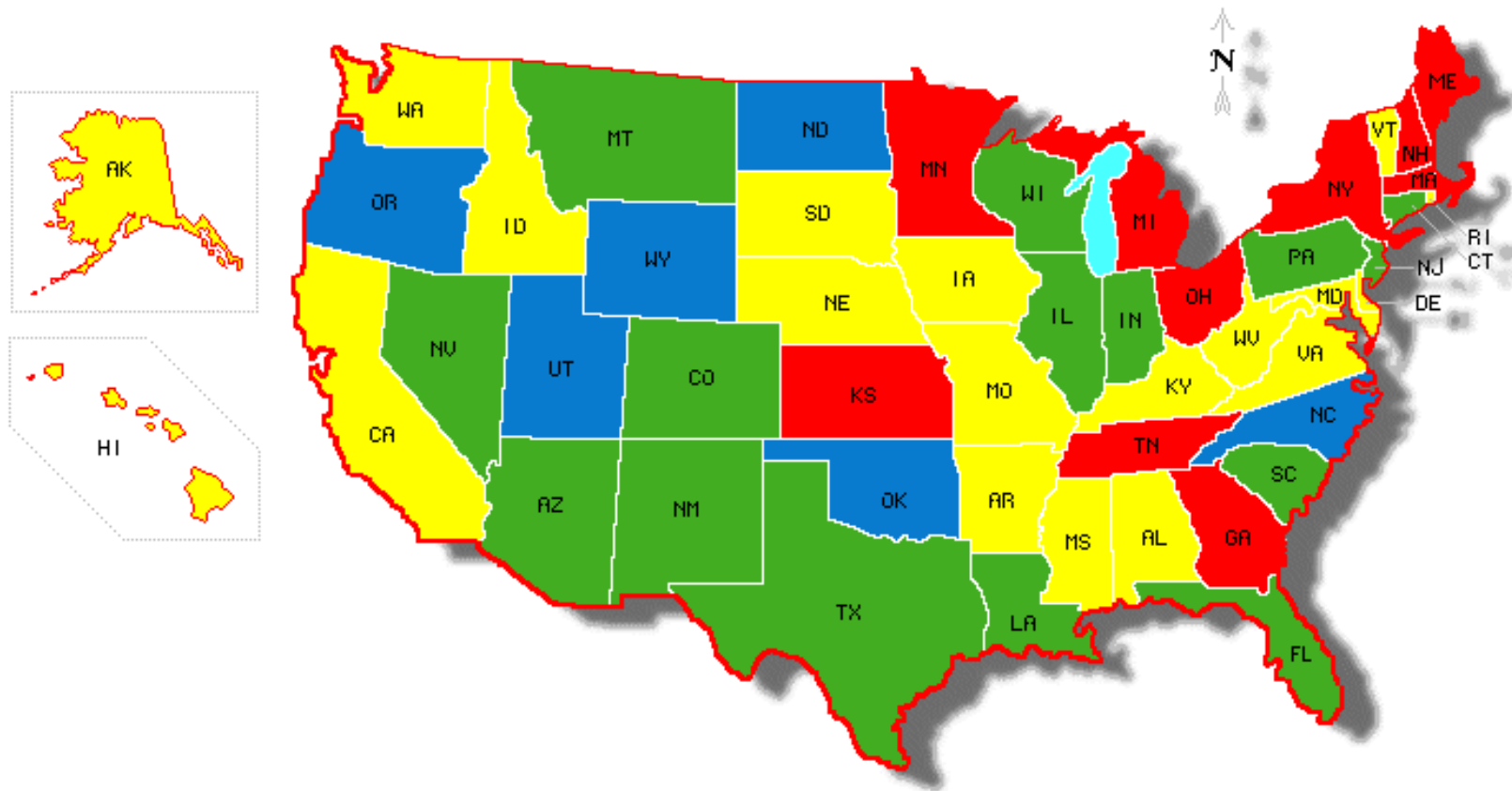


# State Autism Insurance Reform Initiatives

- How have states responded to the health care experiences of families and the body of evidence of treatment efficacy?



# State Autism Insurance Reform Initiatives



**Green** – States with comprehensive autism insurance laws

**Red** – States with pending autism insurance bills

**Yellow** – States developing autism insurance legislation

**Blue** – States not currently pursuing autism insurance legislation

# State Autism Insurance Reform Initiatives

- Fifteen states have enacted comprehensive autism insurance laws:
  - 2001: Indiana
  - 2007: South Carolina, Texas
  - 2008: Arizona, Florida, Louisiana, Pennsylvania, Illinois
  - 2009: New Mexico, Montana, Nevada, Colorado, Connecticut, Wisconsin, New Jersey



# State Autism Insurance Reform Initiatives

- The state laws vary considerably. Here's an excerpt from the Indiana enactment:

27-8-14.2-4. Group policies -- Coverage for pervasive developmental disorder required.

(a) An accident and sickness insurance policy that is issued on a group basis must provide coverage for the treatment of a pervasive developmental disorder of an insured. Coverage provided under this section is limited to treatment that is prescribed by the insured's treating physician in accordance with a treatment plan. . . .



# State Autism Insurance Reform Initiatives

- Note that the Indiana law covers treatment prescribed by an insured's treating physician in accordance with a treatment plan. The Indiana Department of Insurance has interpreted this mandate to mean that behavioral therapies such as applied behavior analysis may not be subject to limitations that apply to physical, occupational, or speech therapy. The department has further concluded that claims may not be denied on the basis that a provider of applied behavior analysis does not hold a license.



# State Autism Insurance Reform Initiatives

- Pennsylvania takes a somewhat different approach than Indiana. Here are some excerpts from that state's law:

40 P.S. § 764h. Autism spectrum disorders coverage



A health insurance policy or government program covered under this section shall provide to covered individuals or recipients under twenty-one (21) years of age coverage for the diagnostic assessment of autism spectrum disorders and for the treatment of autism spectrum disorders. . . .

# State Autism Insurance Reform Initiatives

"Treatment of autism spectrum disorders" shall be identified in a treatment plan and shall include any of the following medically necessary pharmacy care, psychiatric care, psychological care, rehabilitative care [which includes applied behavioral analysis and other treatment provided by an autism service provider to produce socially significant improvements in human behavior or to prevent loss of attained skill or function]and therapeutic care that is:



# State Autism Insurance Reform Initiatives

(i) Prescribed, ordered or provided by a licensed physician, licensed physician assistant, licensed psychologist, licensed clinical social worker or certified registered nurse practitioner.

(ii) Provided by an autism service provider.

(iii) Provided by a person, entity or group that works under the direction of an autism service provider.



# State Autism Insurance Reform Initiatives

- Pennsylvania clearly takes a more detailed and prescriptive approach to coverage than Indiana. It's noteworthy that the Pennsylvania law spells out treatments and treatment providers, as well as other service features.



# State Autism Insurance Reform Initiatives

- One commonality among the newer state measures such as Pennsylvania's is the statutory enumeration of applied behavior analysis and other evidence-based treatments.
- For more information on individual state measures, both enacted and introduced, as well as other noteworthy policy items, go to <http://www.autismvotes.org>



# State Autism Insurance Reform Initiatives

What is the relationship between the state autism insurance reform initiatives and services available through the Individuals with Disabilities Education Act (IDEA)?

- New Jersey § 17B:26-2.1cc. Individual health insurance policy to provide benefits for treatment of autism or other developmental disability [Effective February 9, 2010] :



# State Autism Insurance Reform Initiatives

The provisions . . . of this section shall not be construed to require that benefits be provided to reimburse the cost of services provided under an individualized family service plan or an individualized education program, or affect any requirement to provide those services; except that the benefits provided pursuant to those subsections shall include coverage for expenses incurred by participants in an individualized family service plan through a family cost share.



# State Autism Insurance Reform Initiatives

- In New Jersey and elsewhere, insurance benefits are intended to complement rather than supplant IDEA services.
- The state autism insurance reform initiatives recognize the challenges that schools face in providing services.
- Educational services provided inside the school and health services provided outside the school may differ considerably in scope, nature, and intensity. Some challenges may only be presented outside the school environment.



# State Autism Insurance Reform Initiatives

What's the cost?

- Many of the state statutes are too new for cost data.
- Estimates by state vary. Here are a few cost projections:
  - South Carolina: \$48/year
  - Louisiana: \$13.42 to \$46.47 per policy/year
  - Pennsylvania: \$1 per plan member/month



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What are the likely savings?

- The lifetime cost of caring for a person with autism has been estimated to be \$3.2 million, and the cost of caring for all persons with autism born in a given year has been estimated to be \$35 billion.
- Broad societal savings are more difficult to calculate.

