

Presented to the Interagency Autism Coordinating Committee January 18, 2011 by Stuart Spielman Senior Policy Advisor and Counsel Autism Speaks 5

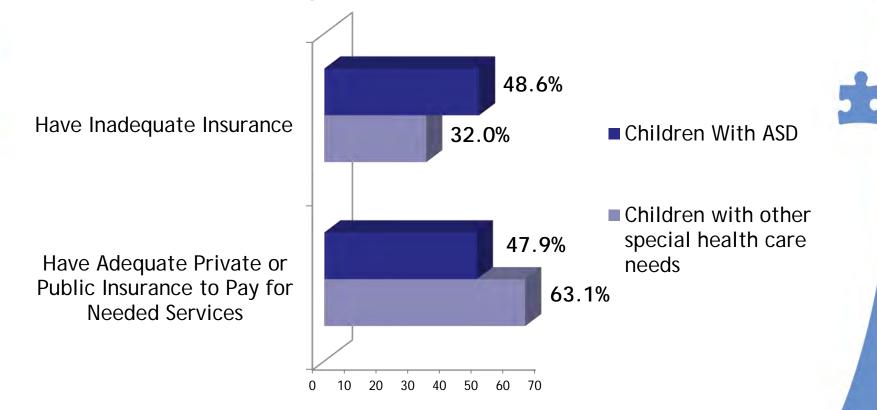
Background

Individuals with Autism Spectrum Disorders (ASDs) have historically experienced difficulty with health insurance coverage.

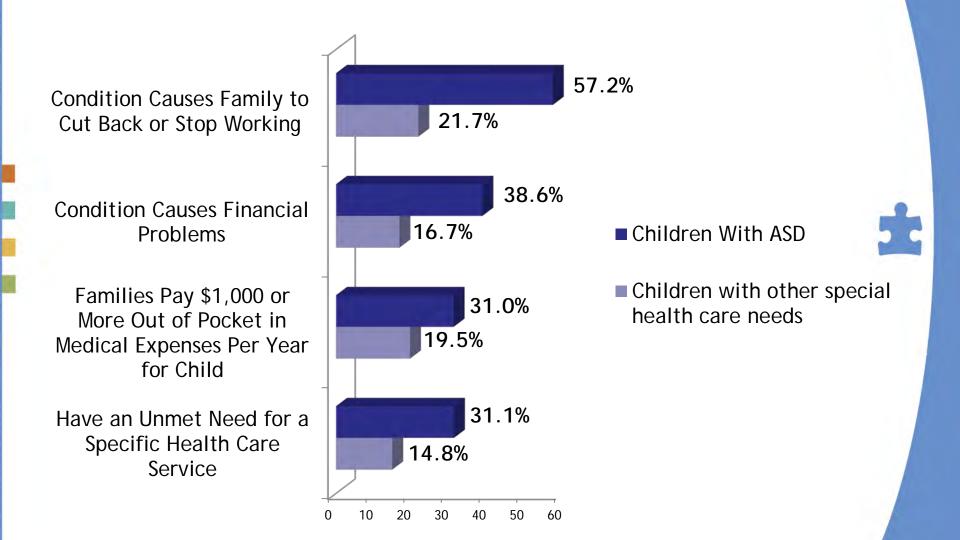
 In a 2002 study of diagnostic exclusions in private behavioral health care plans, researchers who examined 46 employmentbased behavioral health plans covering a total of 496,911 lives found that autism was a diagnostic exclusion in *all* of the plans.

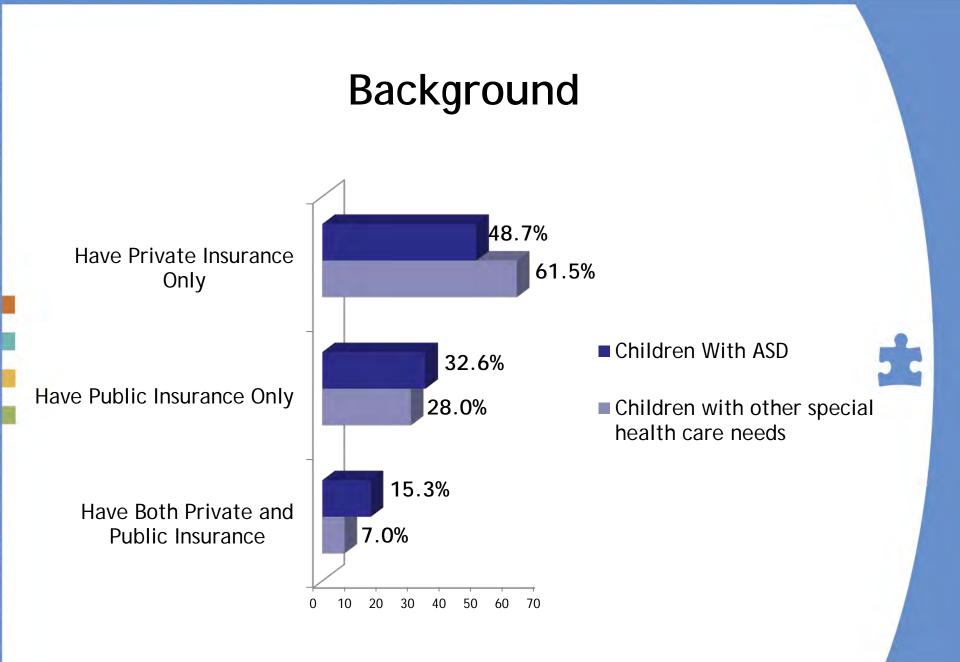
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• According to the 2005/06 National Survey of Children with Special Health Care Needs,



Background





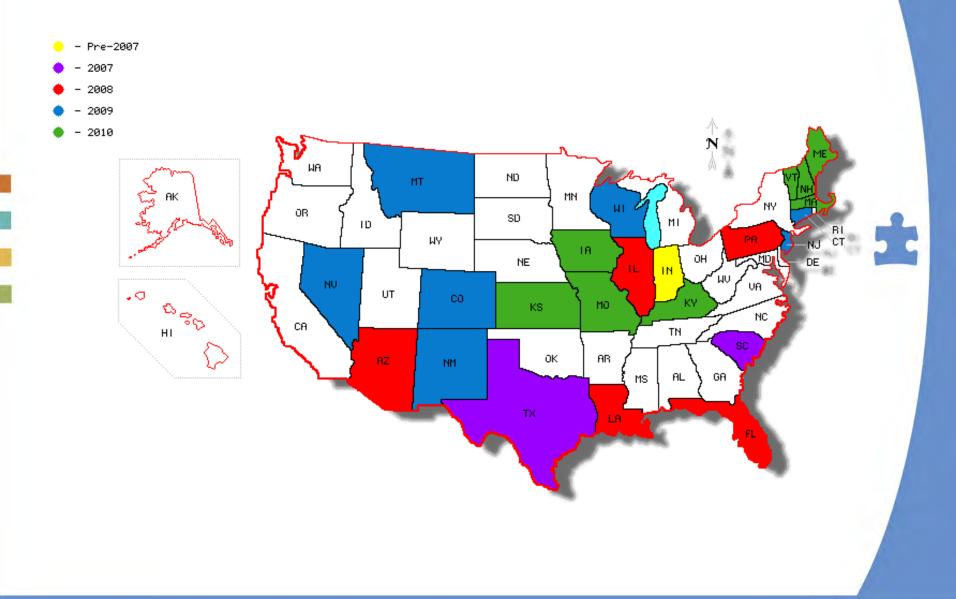
Concern about the healthcare needs of individuals with autism has prompted enactment of state autism insurance laws.

The first comprehensive statute dates back to 2001.



- In 2007, Autism Speaks started a nationwide campaign to encourage enactment of comprehensive coverage laws for people with ASDs.
- There are now 23 states that have enacted strong benefit laws:



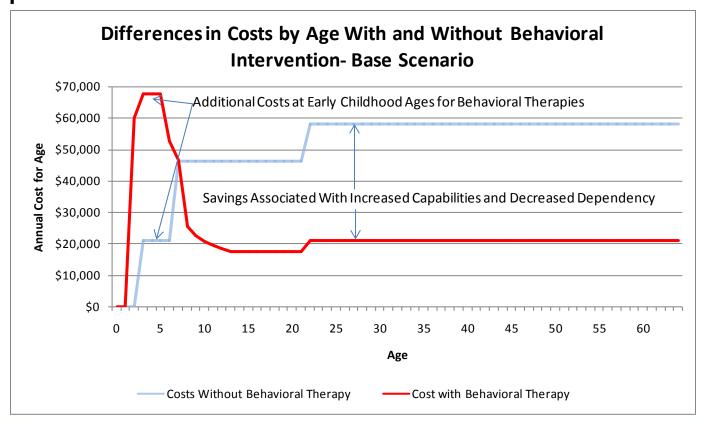


- Each of the state laws differs, but most have these features:
 - coverage for diagnosis;
 - coverage for habilitative care, including speech therapy and occupational therapy;
 - coverage for applied behavior analysis;
 - protection for services rendered under the Individuals with Disabilities Education Act.
- Detailed information on each state law is available at <u>www.autismvotes.org</u>

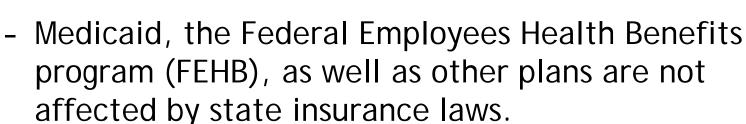
 The effect of these new laws on premiums is expected to be small. A national actuarial consulting firm estimates that state autism insurance laws may increase premiums by 0.3% to 0.6%:

		Avg. Annual		Annual Premium	
	% Diagnosed Under	AB A Program	Avg. Annual	Increase per	Premium Increase
Scenario	Age 6 Starting ABA	Cost (Ages 2-7)	non-ABA Cost	Person	(% of Premium)
Low	40.0%	\$35,000	\$2,050	\$11.20	0.28%
Middle	50.0%	\$42,500	\$3,075	\$16.90	0.42%
High	66.7%	\$49,496	\$4,100	\$25.60	0.64%

It is expected that these cost increases will be offset by savings associated with decreased dependence.



- Although millions of Americans have benefited from them, the reach of state insurance laws is limited:
 - 59% of covered workers are in a self-funded plan. The Employee Retirement Income Security Act of 1974 (ERISA) exempts self-funded plans from state insurance laws.



- About 1 in 6 Americans is uninsured.



- The health care of people with autism is not solely a concern of state policymakers.
- In 2009 the Autism Treatment Acceleration Act (ATAA) was introduced in Congress. Sen. Richard Durbin (IL) sponsored the bill in the Senate and Rep. Mike Doyle (PA) sponsored a companion measure in the House.
- The bill reflected the commitment and interest of candidate and then President Obama in addressing ASD and its challenges:



 "Barack Obama and Joe Biden will seek to increase federal ASD funding for research, treatment, screenings, public awareness, and support services to \$1 billion annually by the end of his first term in office. They will mandate insurance coverage of autism treatment and will also continue to work with parents, physicians, providers, researchers, and schools to create opportunities and effective solutions for people with ASD."

- Both versions of the ATAA bill contained a comprehensive autism coverage provision, which defined ASD and required coverage for diagnosis and certain treatments, including the following:
 - Medications
 - Occupational therapy, physical therapy, and speech therapy
 - Services provided by a psychologist or psychiatrist
 - Applied behavior analysis
 - Augmentative communication devices.

- Both the House and Senate bills would have required coverage by self-funded and fully funded plans, as well as plans issued in the individual market.
- Notwithstanding the breadth of its congressional support - 21 cosponsors in the Senate and 86 in the House - ATAA was not enacted into law, as Congress' attention shifted to broad health care reform.

Federal Initiatives - the Patient Protection and Affordable Care Act

- Although the Patient Protection and Affordable Care Act (PPACA) does not specifically mention autism, it will have a profound effect on people with ASDs.
- Regulations under the act require group and individual coverage for certain preventive services, with no cost-sharing requirements. Covered services include the following:
 - Screening for developmental delays and disabilities during regular well-child doctor visits at 9 months, 18 months, 24 or 30 months, and additional necessary visits
 - Autism-specific screening during regular well-child doctor visits at 18 months, 24 months, and additional necessary visits



Federal Initiatives - the Patient Protection and Affordable Care Act

- Section 1302 of the PPACA describes 10 general categories of essential health benefits. One category is "Mental health and substance use disorder services, <u>including behavioral</u> <u>health treatment</u>."
- This last phrase was introduced as an amendment in the House by Rep. Mike Doyle (PA), Congressional Autism Caucus co-chair, and Sen. Robert Menendez (NJ) in the Senate, where there was a lively debate.

Federal Initiatives – the Patient Protection and Affordable Care Act



Federal Initiatives - the Patient Protection and Affordable Care Act

- The Institute of Medicine (IOM) has been charged with making recommendations to the Secretary regarding the criteria and methods for determining the essential health benefits package.
- In separate letters to the President of the IOM, Senator Menendez, joined by Senators Durbin and Casey, and Representative Doyle confirmed that Congress intended to include applied behavior analysis in the essential health benefits.

Conclusion

 During the debate over the PPACA and beyond, Autism Speaks has vigorously argued for comprehensive health coverage for people with ASDs. We believe that the lives of people with ASDs can be significantly benefitted if this critical moment is seized and a decadeslong pattern of discrimination in health care comes to an end.