

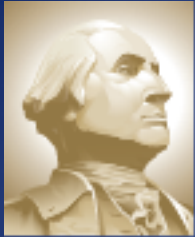


Update on Autism Spectrum Disorders



Lorri Shealy Unumb, Esq.

Vice President, State Government Affairs, [Autism Speaks](#)



**THE GEORGE
WASHINGTON
UNIVERSITY**
WASHINGTON, DC

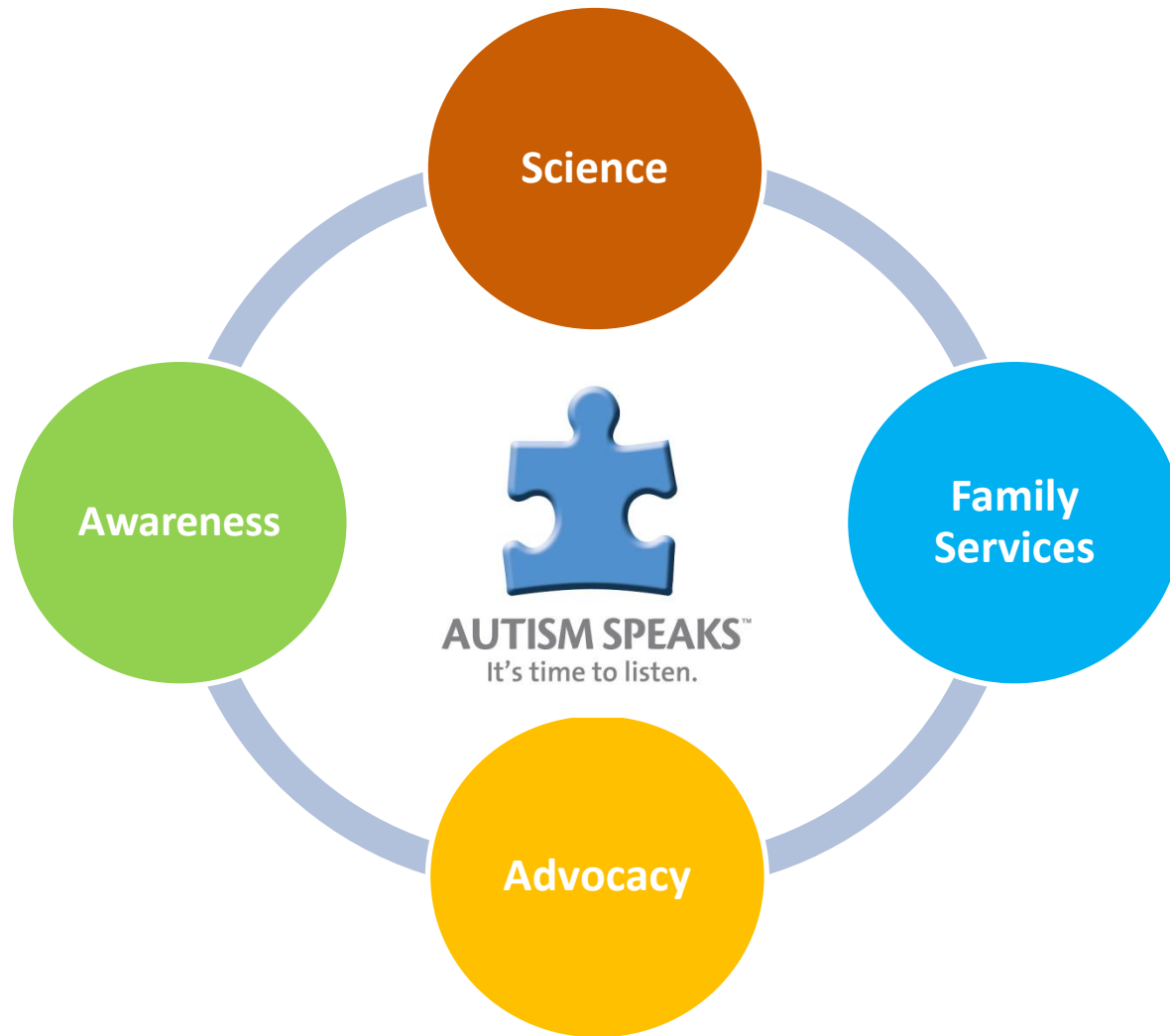


Autism and the Law

Cases, Statutes, and Materials

by Lorri Shealy Unumb & Daniel R. Unumb

Carolina Academic Press



Autism Speaks Government Relations



Autism Speaks
- Headquartered
in New York

**Autism Speaks
Government
Relations**
- Headquartered
in D.C.

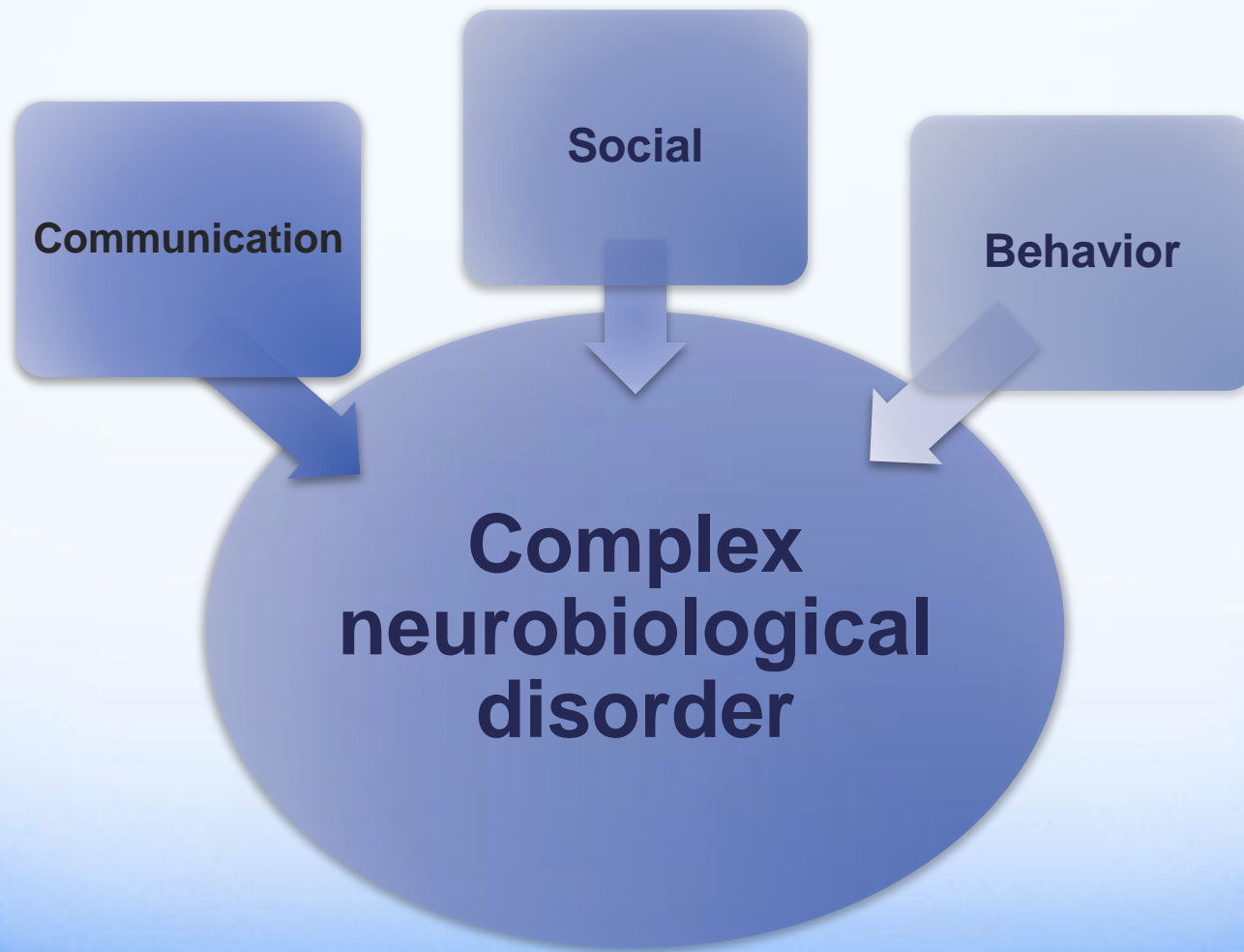


Autism Spectrum Disorder



- A medical condition, brought on through no apparent fault of family
- Diagnosed by doctor or psychologist; often a developmental pediatrician
- Four-five times more common in boys than girls

What is Autism?

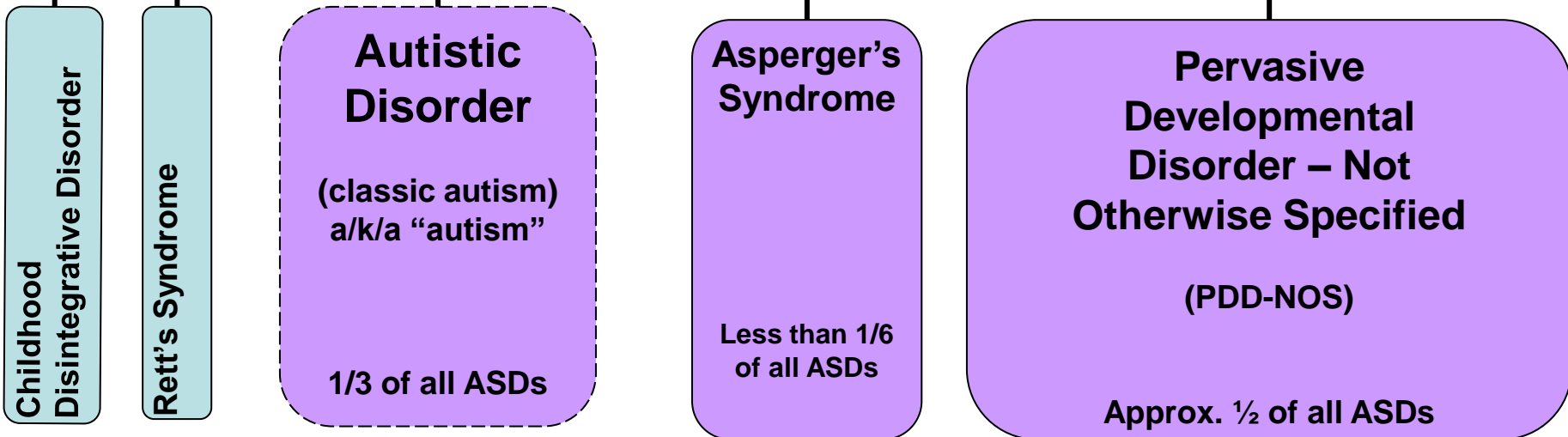


Pervasive Developmental Disorders

(the umbrella category in the DSM-IV)

There are 5 Pervasive Developmental Disorders (PDDs).

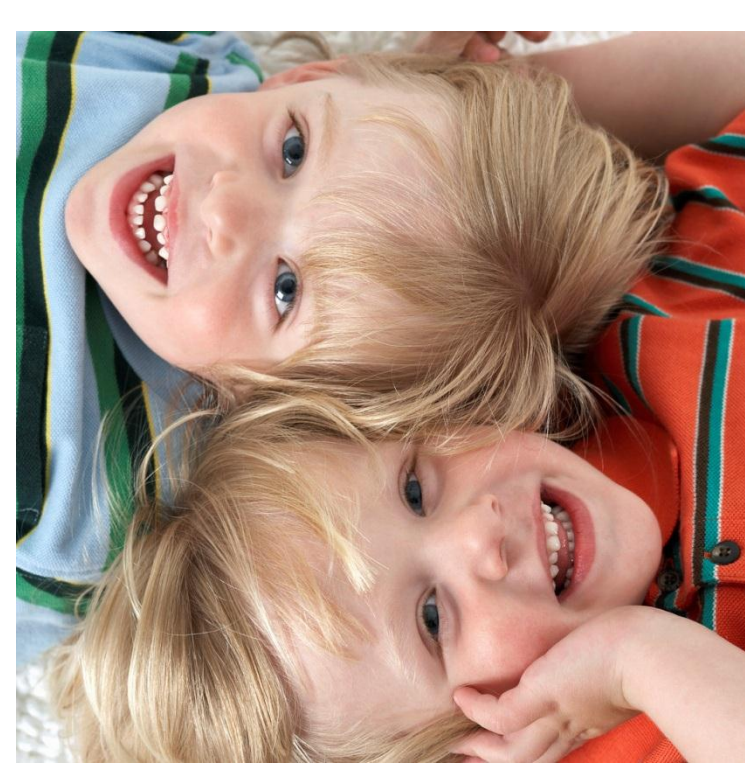
Within the 5 PDDs, there are 3 **Autism Spectrum Disorders** (ASDs), shown in purple below.



Cause(s)?

An 30-year-old study looked at 21 pairs of twins, at least one of each pair being affected by autism. It compared identical twins, who share all of their genetic makeup, with fraternal twins, who share around half their genes. It found that when one identical twin had autism, so did the other 83 percent of the time. By contrast, this was true of only 10 percent of the fraternal twins. For decades, it was taken as fact that the causes of autism were almost completely genetic.

That changed this past year with the [largest ever autism twin study](#). A Stanford University study found a significantly lower autism concordance between identical twins—just 70 percent. They also found a much higher than expected overlap between fraternal twins—around 35 percent, considerably higher than the 15 percent or lower concordance we know exists between siblings who are not twins. This strongly suggests that environmental influences play a significant role in autism -prenatal influences being among the most likely.

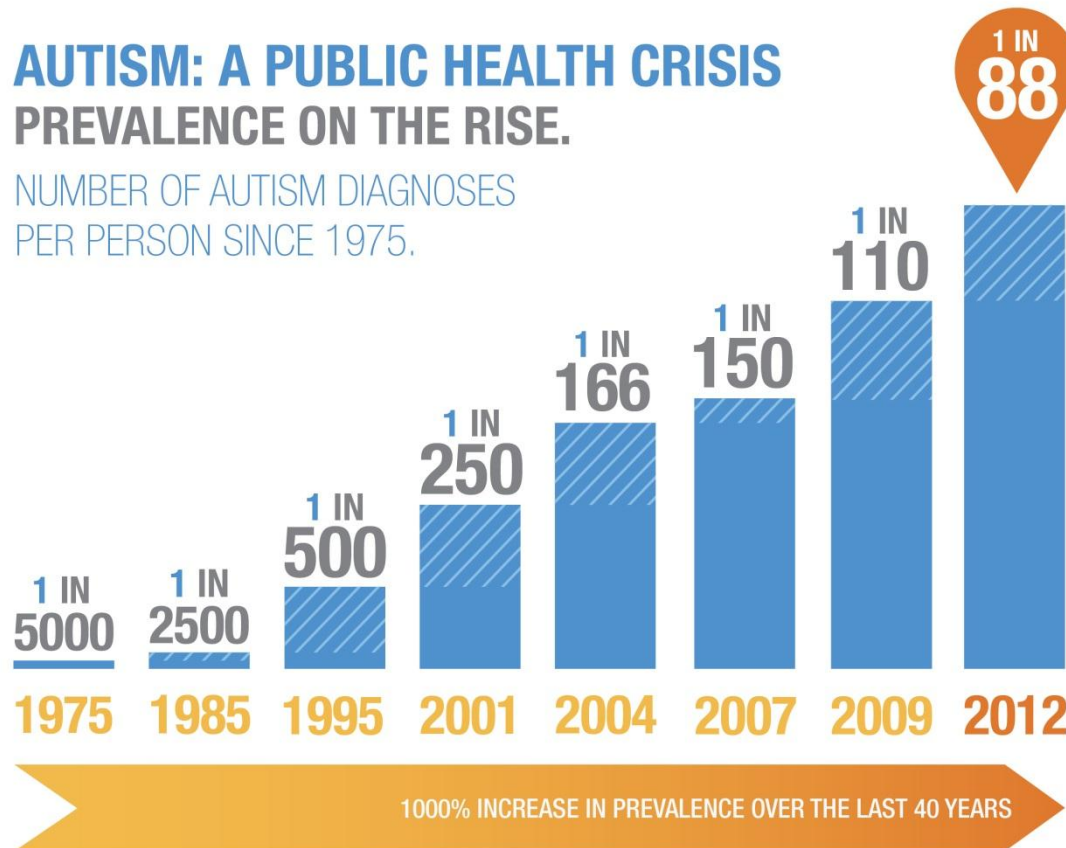




AUTISM: A PUBLIC HEALTH CRISIS

PREVALENCE ON THE RISE.

NUMBER OF AUTISM DIAGNOSES
PER PERSON SINCE 1975.

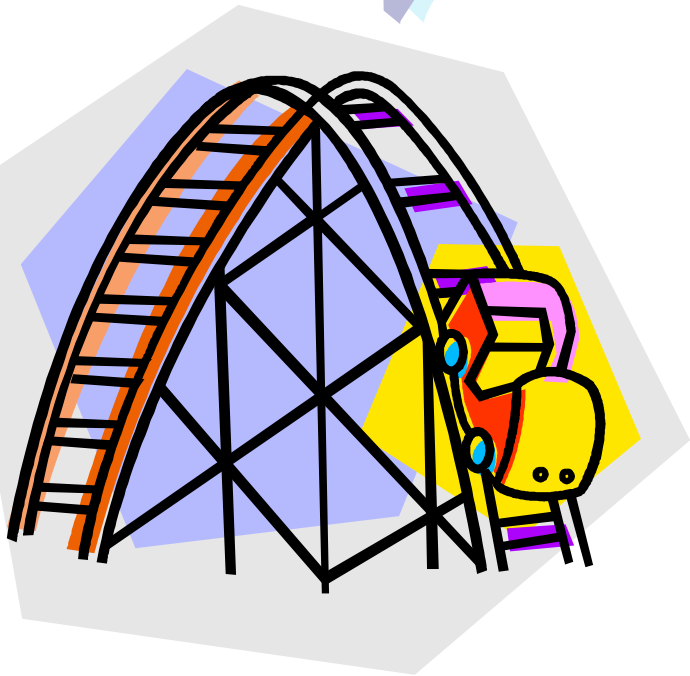


 % INCREASE FROM PREVIOUS YEAR

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Johns Hopkins University's Kennedy Krieger Institute
Children's National Medical Center
Georgetown University Hospital



Applied Behavior Analysis (ABA Therapy)

- One-on-one therapy
- Up to 40 hours/week
- Uses behavioral stimuli & consequences to produce significant improvement in human behavior
- Breaks down into discrete components the skills that neuro-typical children acquire naturally
- Trains child to acquire skills through repetition, prompting, and positive reinforcement



Applied Behavior Analysis: Sample Therapy Structure

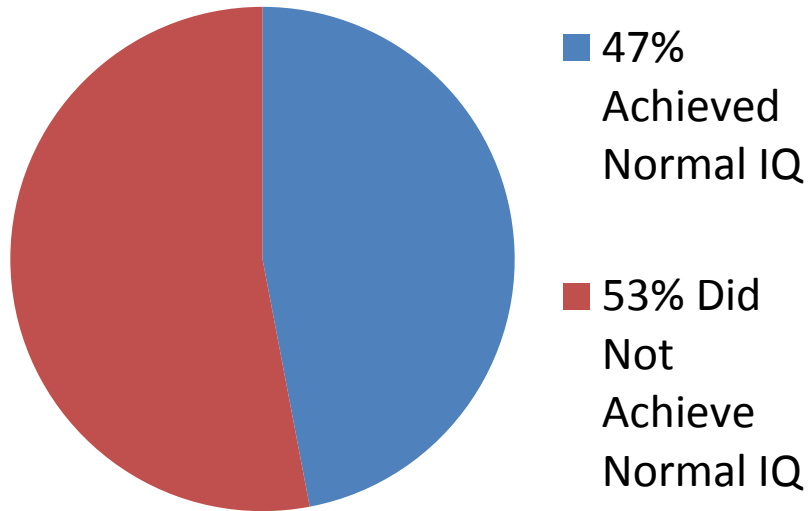
- Consultant
 - Highly educated and trained in ABA
 - Board certified in ABA
 - Evaluates, designs, trains
 - 3-6 hours per month
- Mid-level supervisor (lead therapist)
 - Educated and trained
 - May be board certified
 - Updates programming; trains; oversees
 - 6 hours per week
- Line therapists
 - Trained & supervised by above
 - Provide 40 hours per week of direct therapy, usually in 3-hour shifts



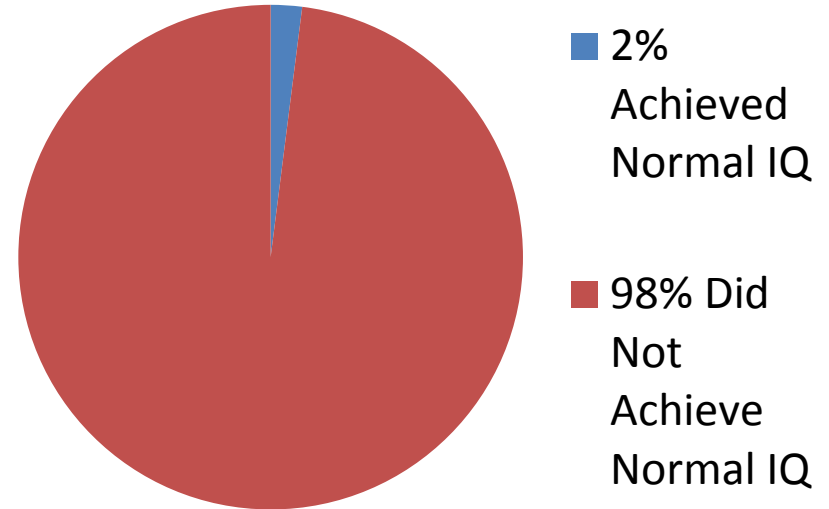
Efficacy of ABA Therapy

Outcome of 1987 UCLA Lovaas Study

ABA Group



**Other Intervention
(Control) Group**



Applied Behavior Analysis: Cost of a Sample Therapy Program

- Consultant
 - 3-6 hours per month
 - \$100-\$150/hour
 - 6 hours x \$150 = \$900/month
 - \$900 x 12 months = **\$10,800**
- Mid-level supervisor (lead therapist)
 - 6 hours per week
 - \$30-\$60/hour
 - 6 hours x \$60 = \$360/week
 - \$360/week x 52 weeks = **\$18,720**
- Line therapists
 - 40 hours per week
 - \$20 - \$30/hour
 - 40 hours x \$20 = \$800/week
 - \$800/week x 52 weeks = **\$41,600**
- $\$10,800 + \$18,720 + \$41,600 = \mathbf{\$71,120}$
- **How does a family pay for this?**
- **THANK GOODNESS FOR HEALTH INSURANCE!**





June 20, 2012

Testimony of
Vera F. Tait MD, FAAP

On behalf of the
American Academy of Pediatrics

Before the
**Subcommittee on Personnel,
Senate Armed Services Committee**

●“The effectiveness of ABA-based interventions in ASDs has been well documented through a long history of research in university and community settings. Children who receive early intensive behavioral treatment have been shown to make **substantial gains in cognition, language, academic performance, and adaptive behavior as well as some measures of social behavior**, and their outcomes have been significantly better than those of children in control groups.”



ABA is the Standard of Care

United States Surgeon General

(1999)

*“**Thirty years of research** demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”*

Centers for Medicare and Medicaid

(2011)

*“...**controlled trials have shown both the efficacy** of programs based in the principles of ABA and that certain individual characteristics (age, IQ, and functional impairments) are associated with positive outcomes.”*

National Institute of Mental Health

(2011)

*“One type of a **widely accepted treatment** is applied behavior analysis (ABA). The goals of ABA are to shape and reinforce new behaviors, such as learning to speak and play, and reduce undesirable ones.”*



ABA is the Standard of Care

Centers for Disease Control and Prevention (2012)

*“A notable treatment approach for people with an ASD is called applied behavior analysis (ABA). ABA has become **widely accepted** among health care professionals...”*

NATIONAL INSTITUTE OF NEUROLOGICAL (2012) DISORDERS AND STROKE

*“Therapies and behavioral interventions are designed to remedy specific symptoms and **can bring about substantial improvement**...Therapists use highly structured and intensive skill-oriented training sessions to help children develop social and language skills, such as Applied Behavioral Analysis”*



ABA is the Standard of Care

AMERICAN PSYCHOLOGICAL ASSOCIATION (2012)

*“The field of applied behavior analysis has grown substantially in the past decade, enabling more children with autism and their families to obtain needed services. This growth appears to be related to an increase in the number of children diagnosed with an autism spectrum disorder and to the **recognition of the effectiveness of behavior analytic services.**”*

The U.S. Office of Personnel Management (2012)

*“The OPM Benefit Review Panel recently evaluated the status of Applied Behavior Analysis (ABA) for children with autism. Previously, ABA was considered to be an educational intervention and not covered under the FEHB Program. The Panel concluded that there is now **sufficient evidence to categorize ABA as medical therapy.** Accordingly, plans may propose benefit packages which include ABA.”*

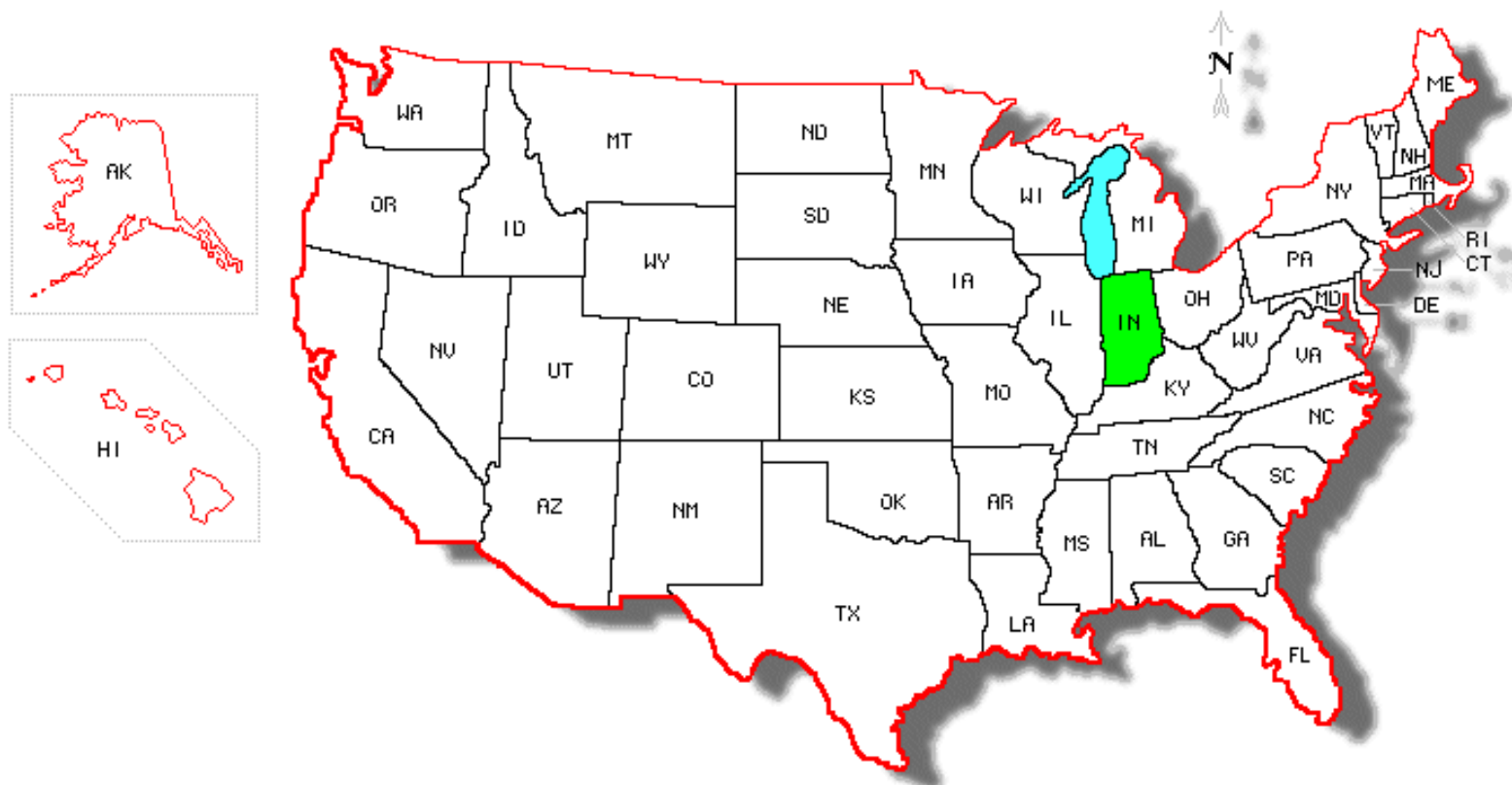


Cost of Autism to Society/State

- **Without appropriate treatment**, the lifetime societal cost has been estimated to be **\$3.2 million** per child with ASD (Ganz, 2007)
 - special education
 - adult services
 - decreased productivity
- State estimated lifetime cost **savings** of providing appropriate treatment are \$1 million per child (Jacobsen et al, 1998)

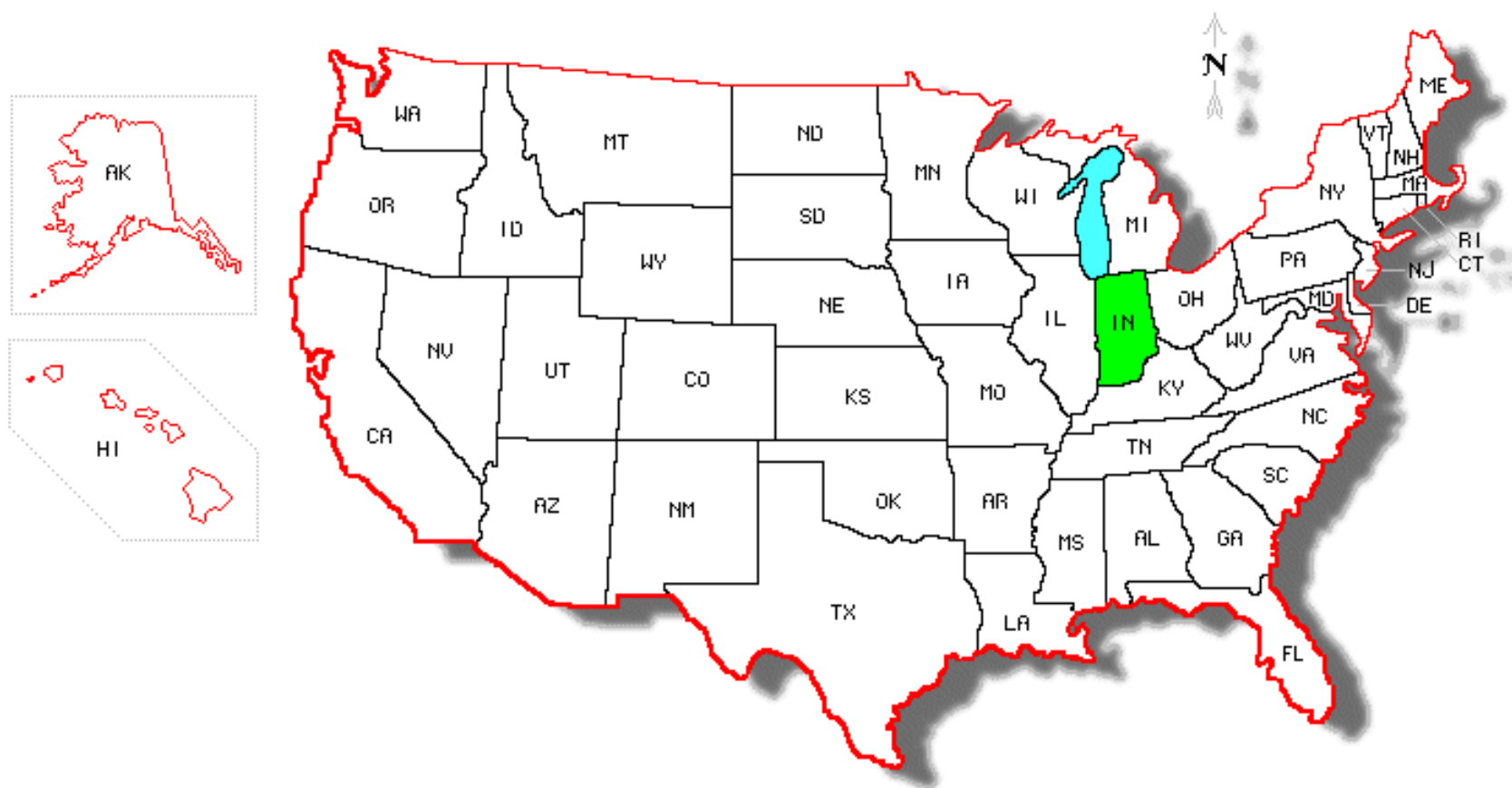


2001 Snapshot



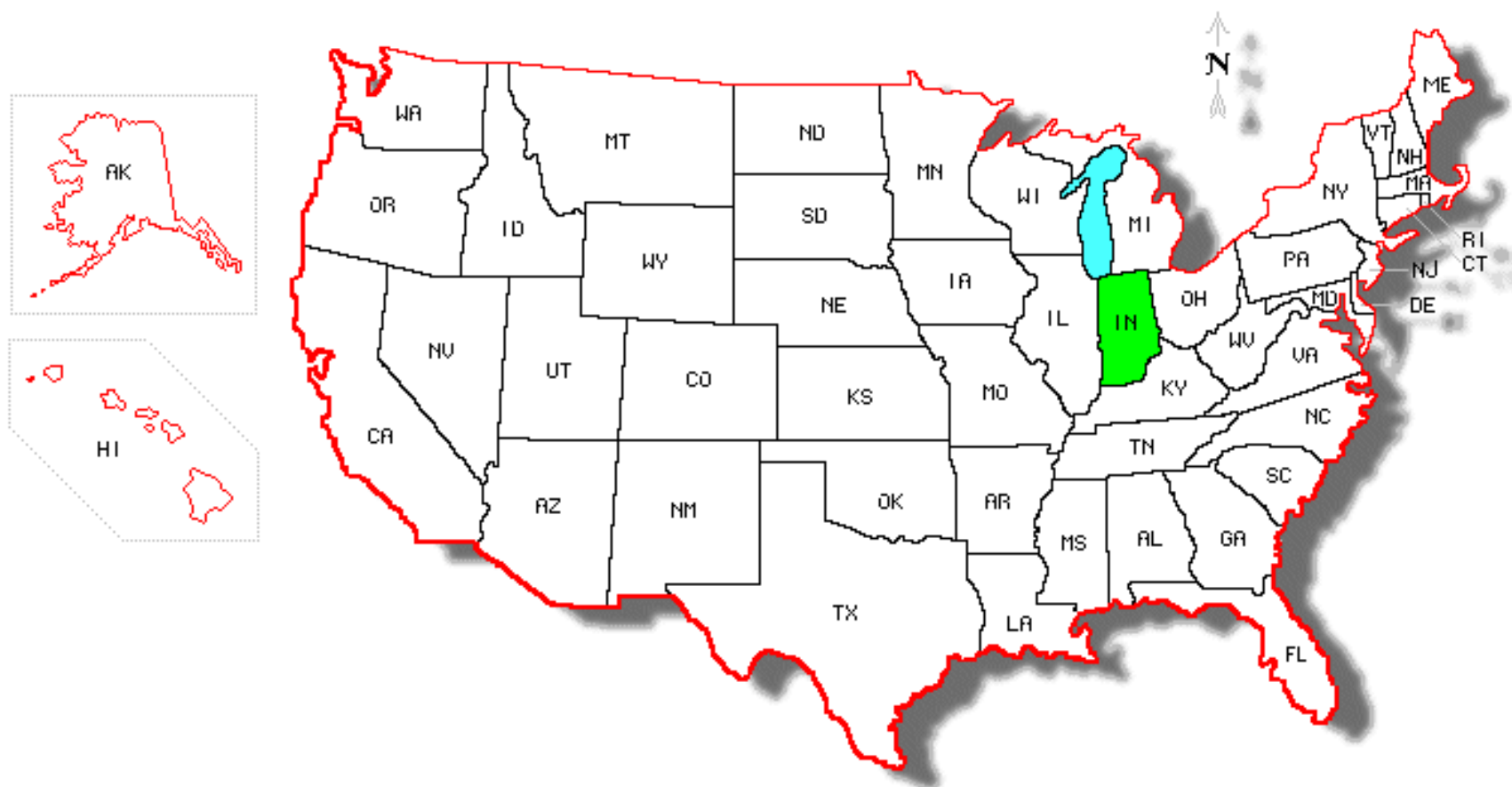
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2002 Snapshot



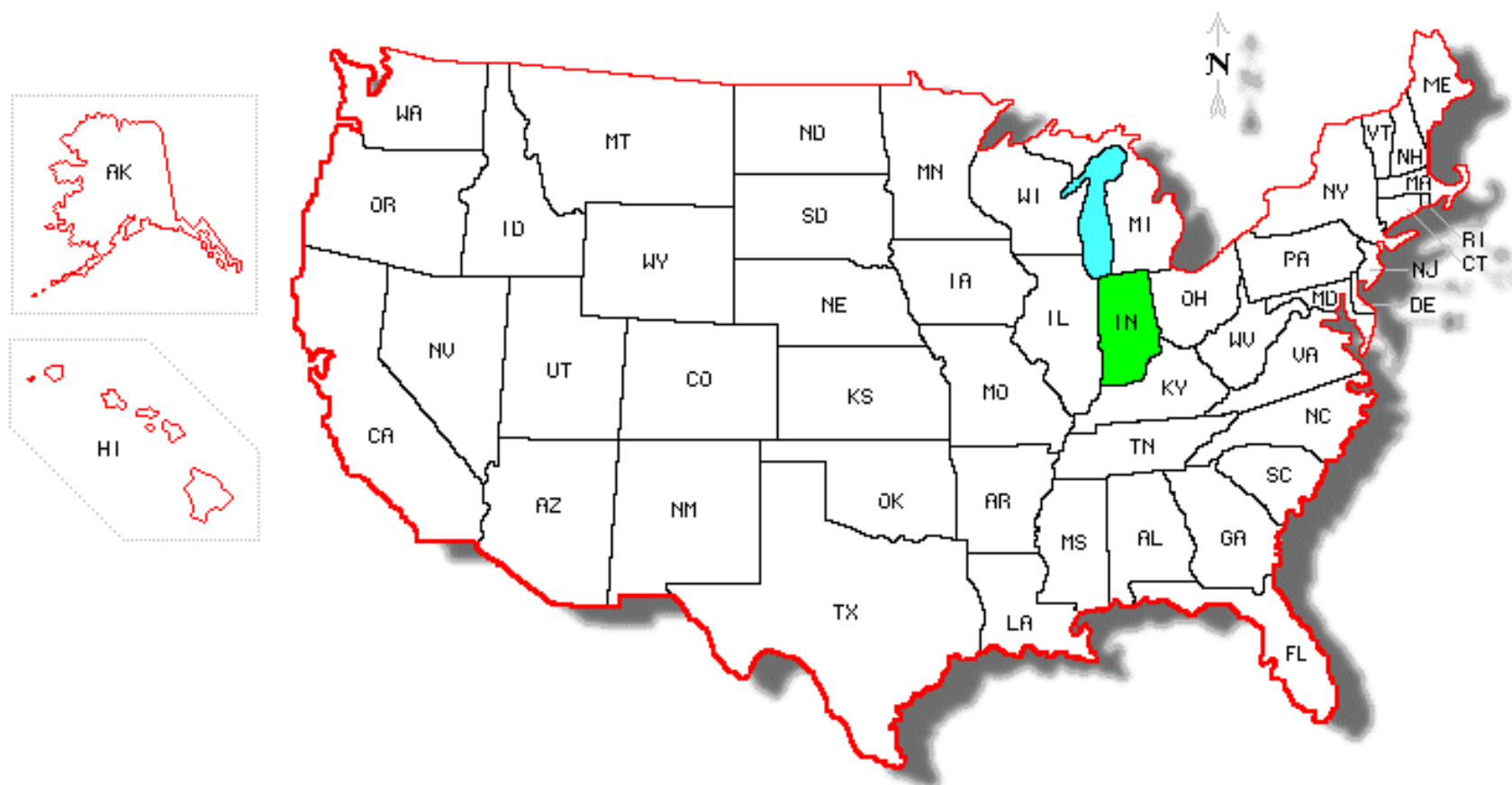
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2003 Snapshot



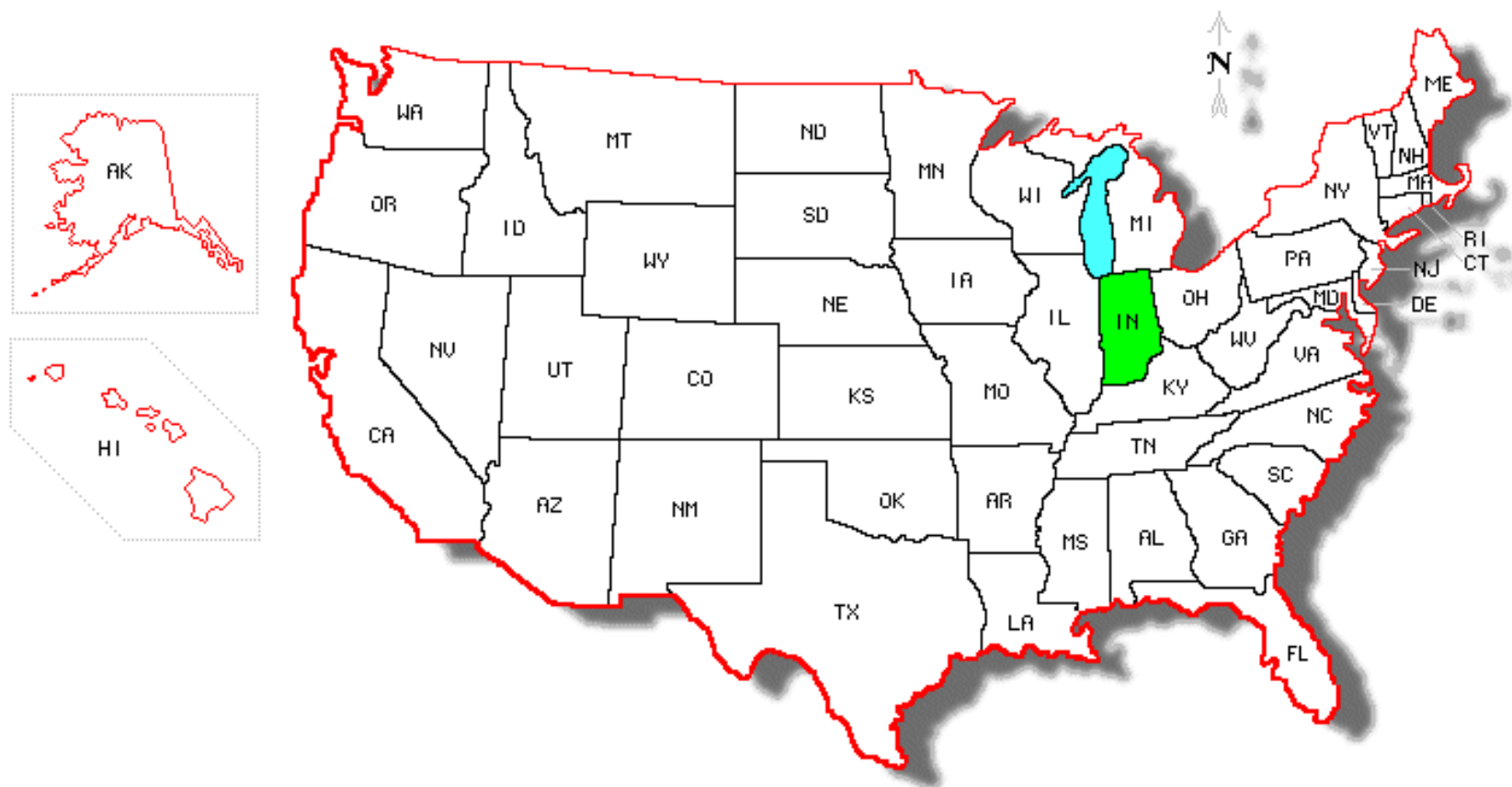
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2004 Snapshot

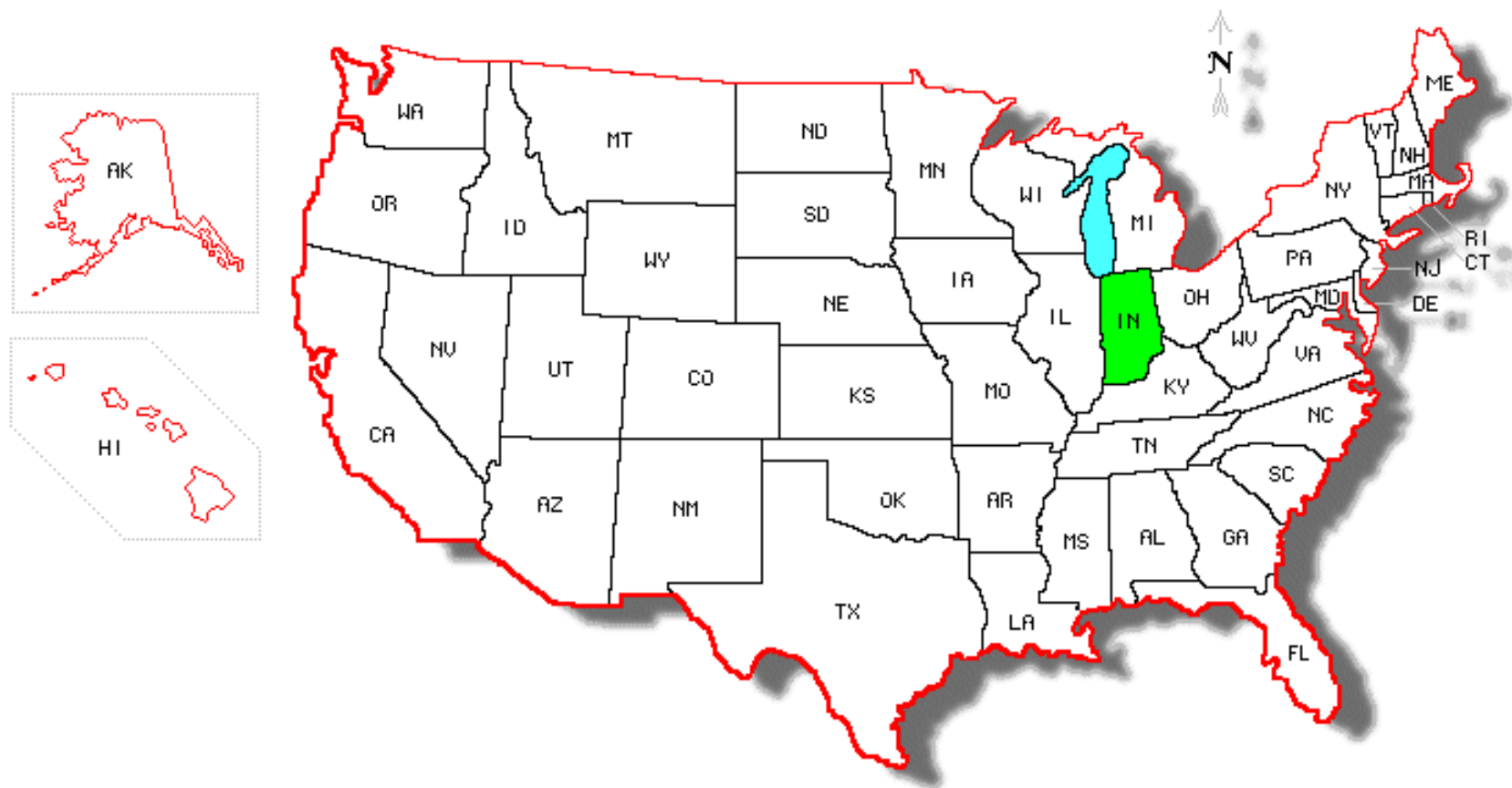


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2005 Snapshot

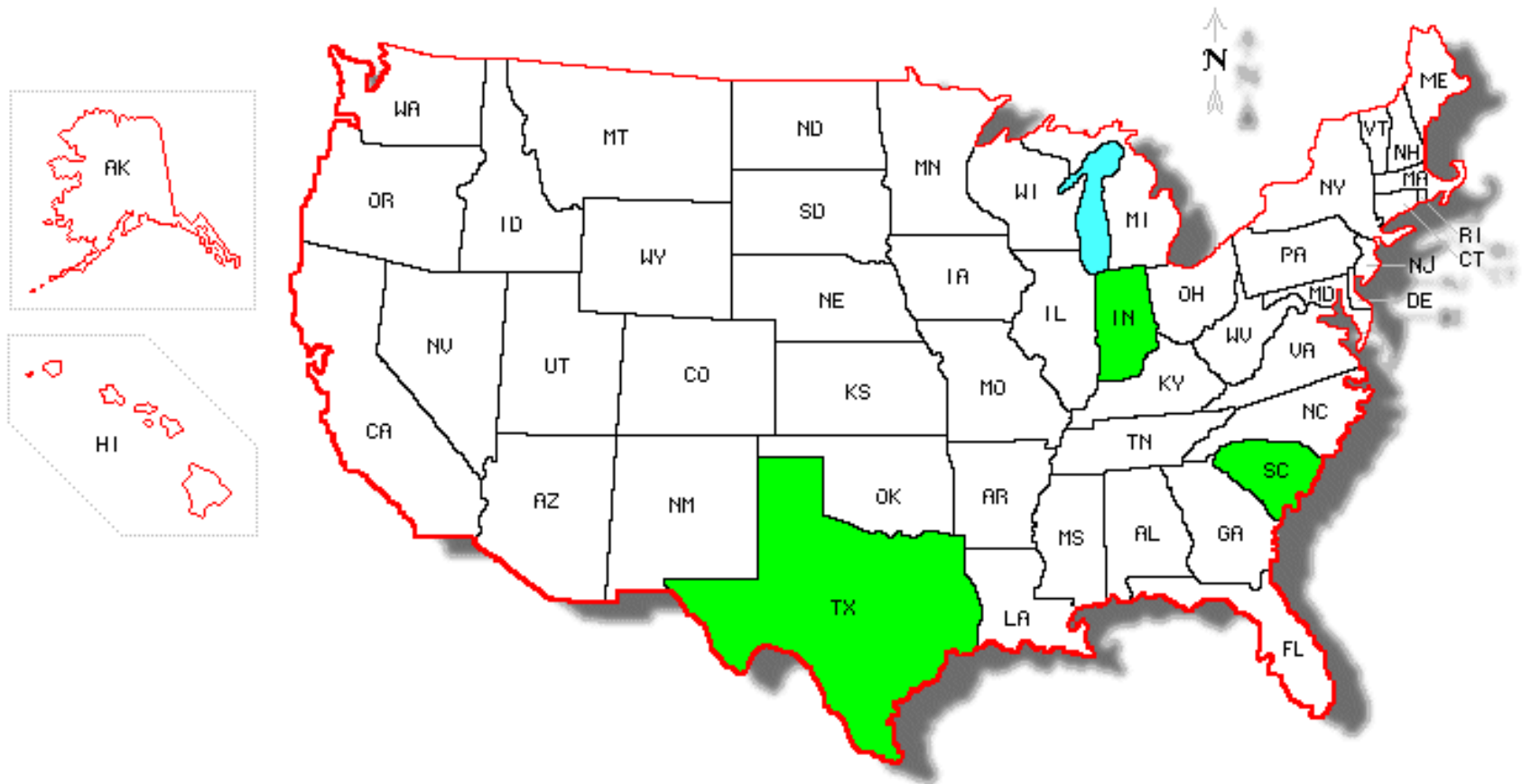


2006 Snapshot



2007 Snapshot

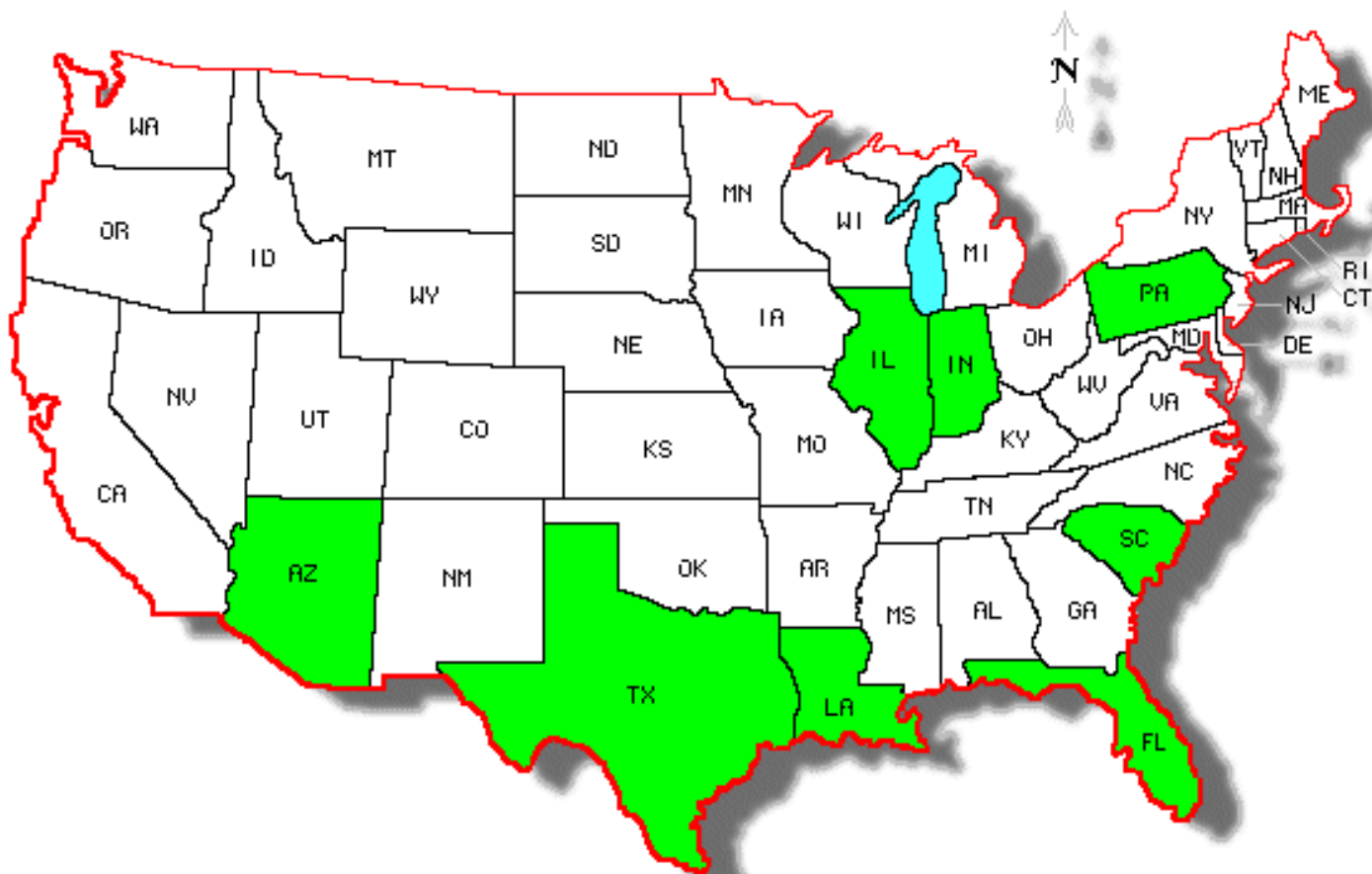
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5-29-10

2008 Snapshot

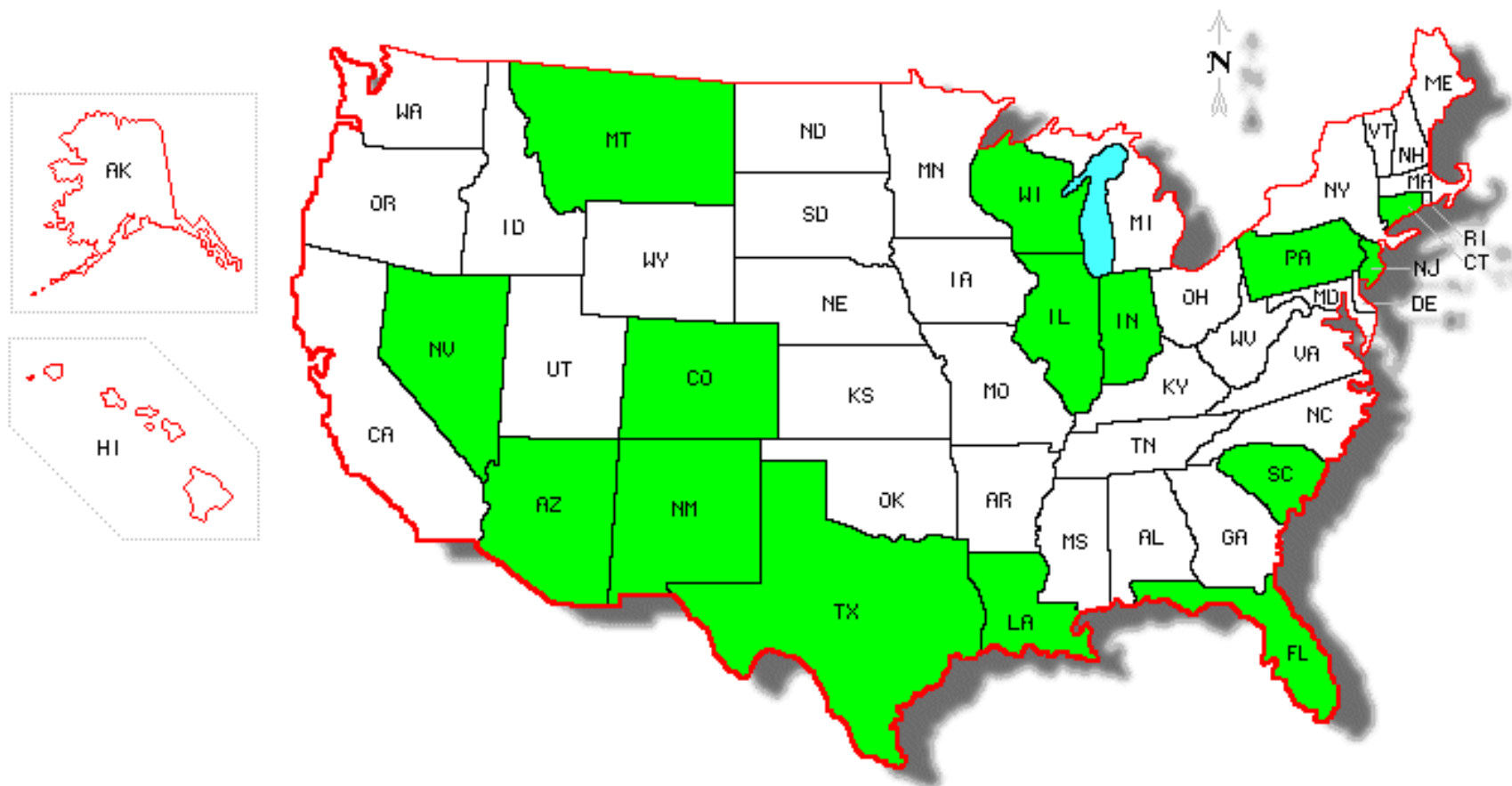
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5-29-10

2009 Snapshot

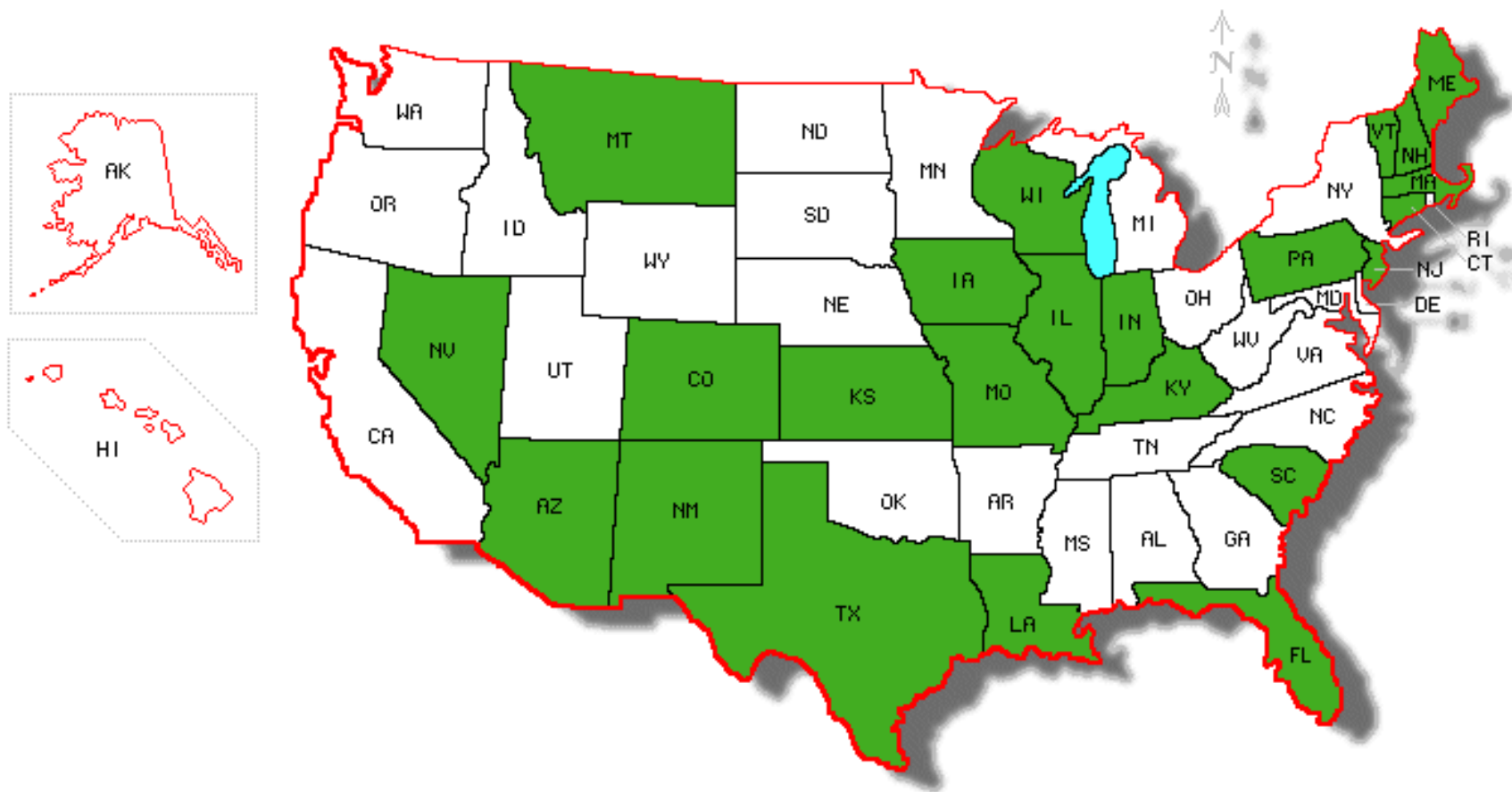
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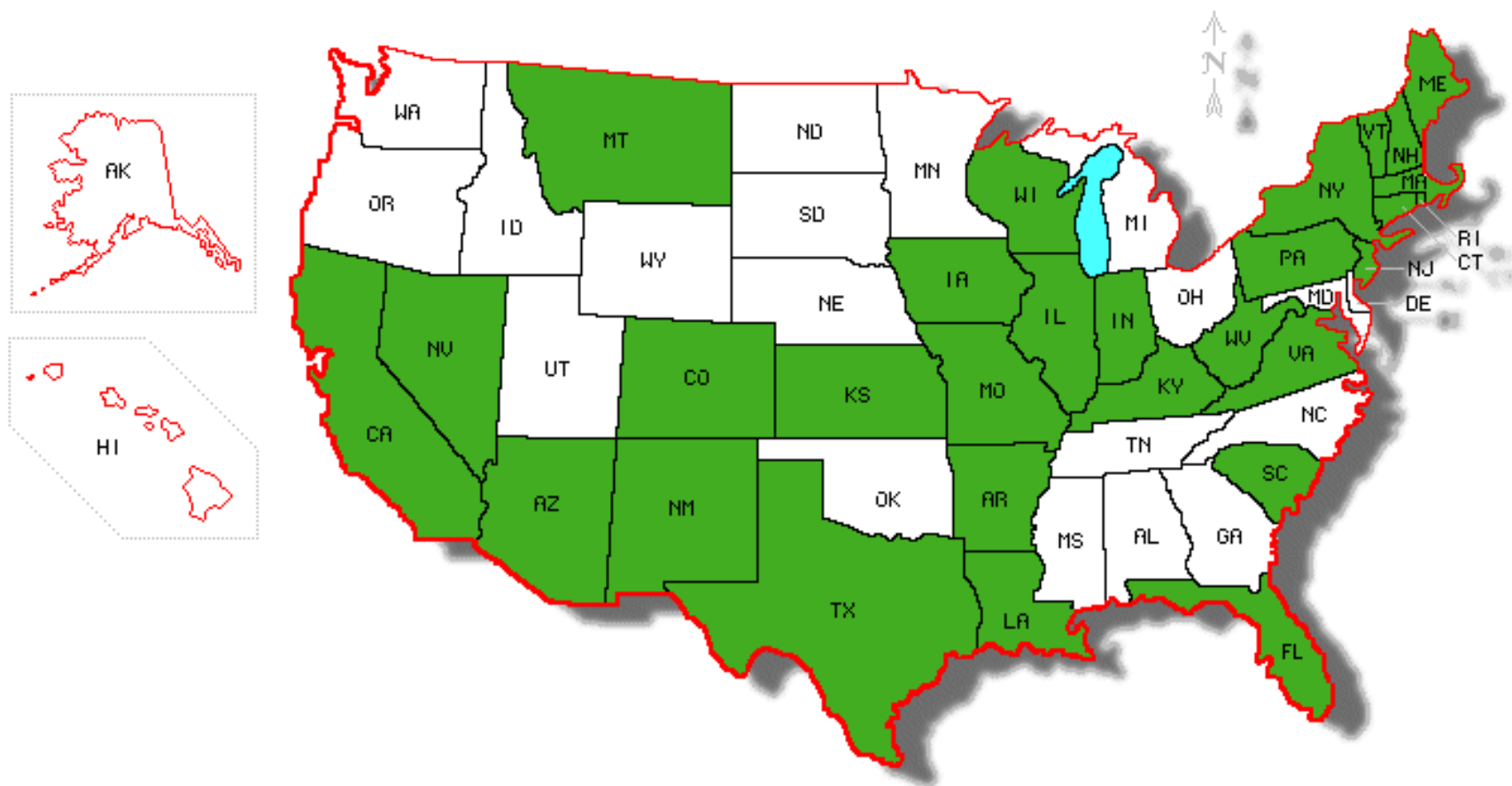
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2010 Snapshot

23



2011 Snapshot



States with Autism Insurance Reform



2001 - Indiana

2007 - South Carolina

2007 - Texas

2008 - Arizona

2008 - Florida

2008 - Louisiana

2008 - Pennsylvania

2008 - Illinois

2009 - Colorado

2009 - Nevada

2009 - Connecticut

2009 - Wisconsin

2009 - Montana

2009 - New Jersey

2009 - New Mexico

2010 - Maine

2010 - Kentucky

2010 - Kansas

2010 - Iowa

2010 - Vermont

2010 - Missouri

2010 - New Hampshire

2010 - Massachusetts

2011 - Arkansas

2011 - West Virginia

2011 - Virginia

2011 - Rhode Island

2011 - California

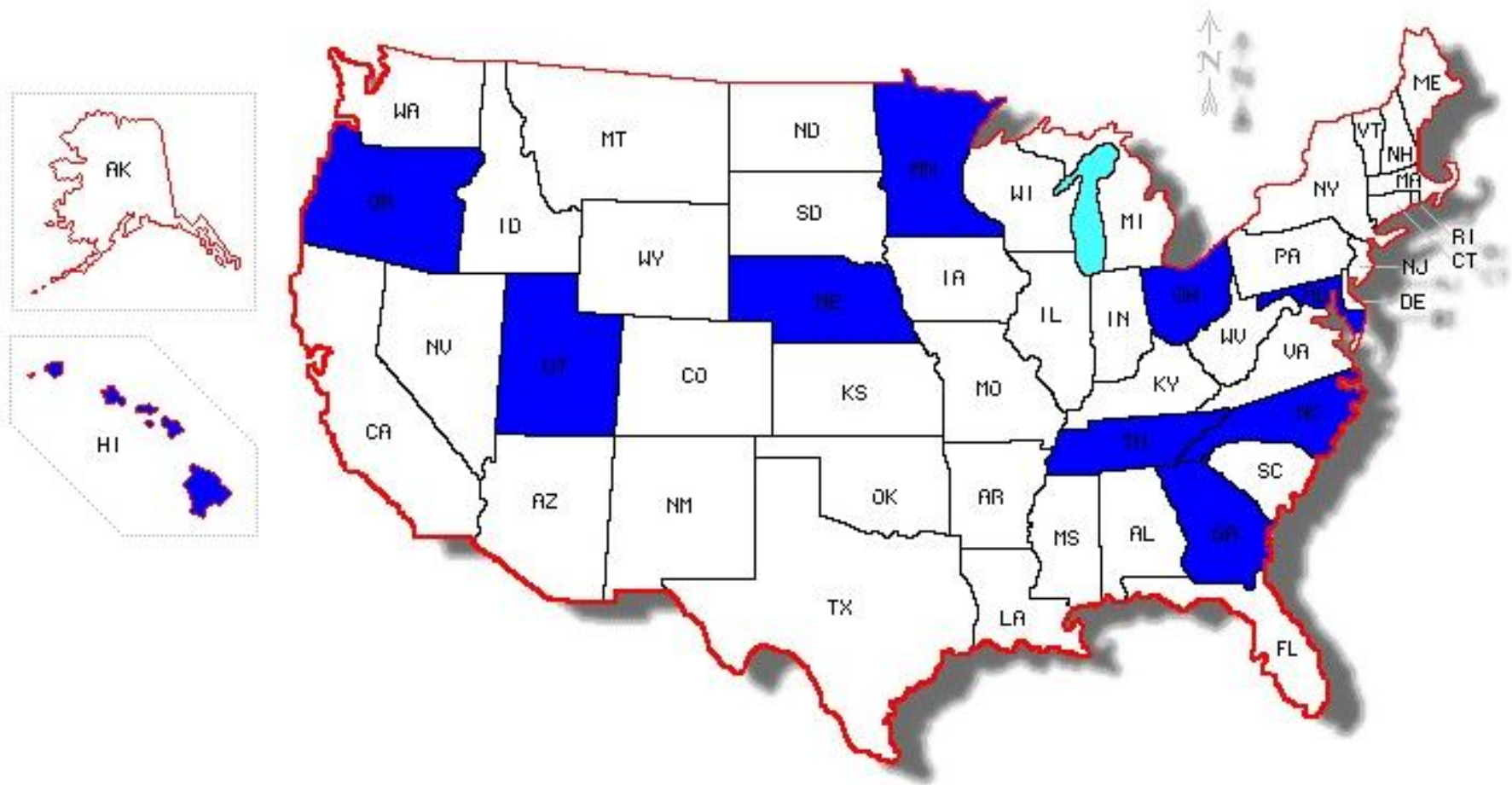
2011 - New York

2012 - Michigan

2012 - Alaska

2012 - Delaware

Considering Autism Insurance Reform in 2013



South Carolina State Employee Plan



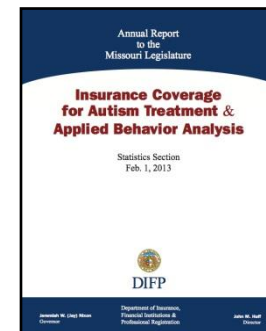
- Dates
 - Applicable to state health plan as of 1-1-09
- Population
 - State health plan has 350-390,000 members
- Terms
 - \$50,000 cap on ABA
 - To age 16
- Projected Cost
 - Original: \$18.9 million
 - Revised: \$9 million
- Actual cost
 - 2010: \$2,042,392
 - PMPM - 44 cents
 - PEPM – 75 cents
 - (228,048 employees/subscribers;
79 kids accessing coverage)

Actual Claims Data

Missouri (2012)



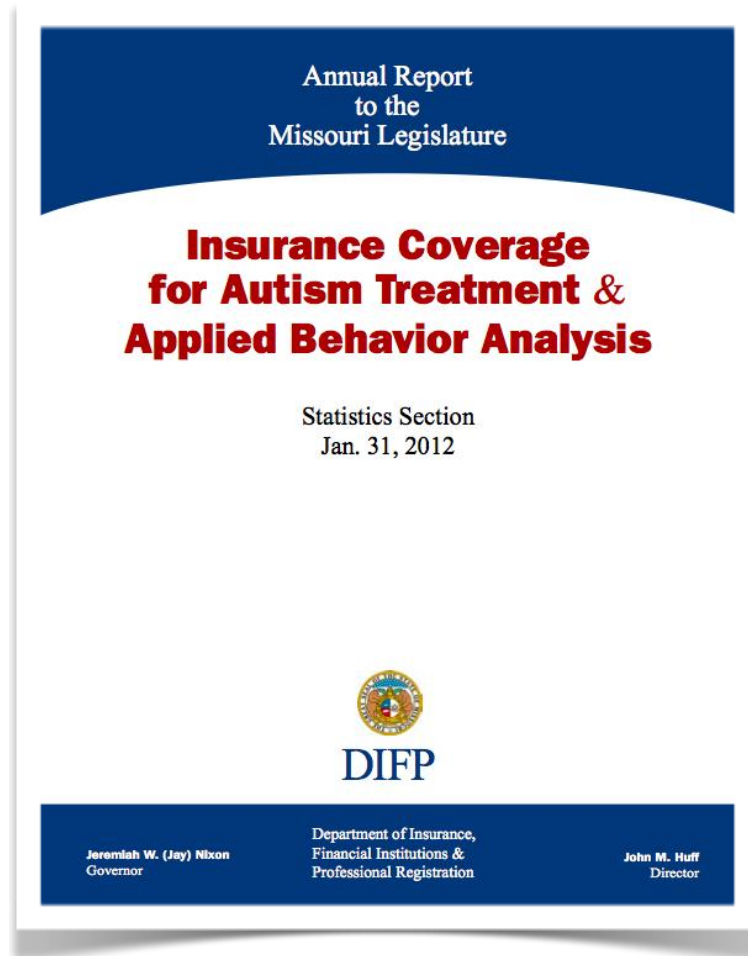
- Implemented Jan 2011
 - Terms
 - \$40,000/yr (cap only applies to ABA)*
 - until age 18*
-
- Total claims paid = \$6,555,602
 - Total covered lives** = 1,429,153
 - Unique claimants = 2,508
 - PMPM cost = **38 ¢**



* Caps can be exceeded if deemed medically necessary

** Member months of policies with ASD coverage = 17,149,845

Effect on Premiums



- Claims incurred for treatment of ASD represent **0.1% of total claims**
- “While claims costs are expected to grow somewhat in the future, it seems very unlikely that costs for autism treatment will have an appreciable impact on insurance premiums.”



Cost of Autism Insurance Reform

	Year of coverage	Number of Covered Lives	Total Claims	PMPM cost
South Carolina	2	397,757	\$2,042,394	\$0.43
Illinois	2	170,790	\$197,290	\$0.10
Louisiana	2	149,477	\$722,828	\$0.40
Florida	2	386,203	\$1,748,849	\$0.38
Arizona	2	130,000	\$388,662	\$0.25
Missouri	2	1,429,153	\$6,555,602	\$0.38
Kansas	2	100,000	\$266,077*	\$0.24
	Average second year cost			\$0.31

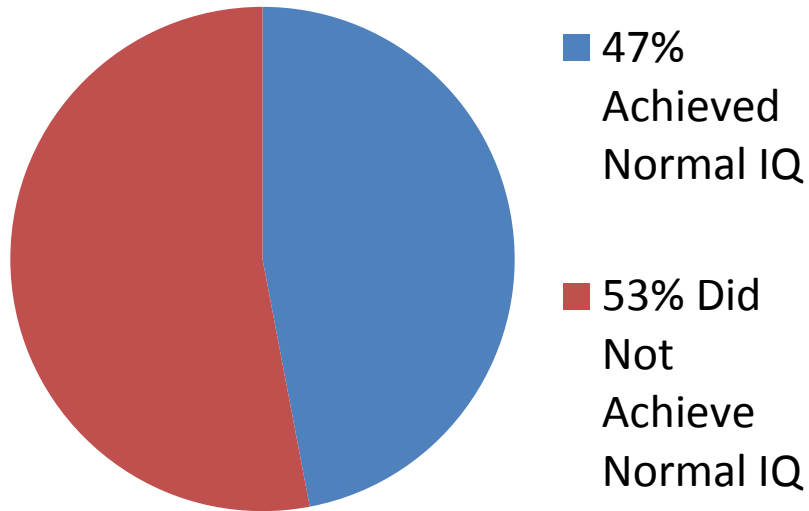
* 11 months (Jan-Nov 2012)

References: Data collected by Autism Speaks from State agencies responsible for administering State Employee Health Benefits Programs (2011); Missouri Department of Insurance, Financial Institutions and Professional Registration (2012); and the Kansas Department of Health and Environment (2012)

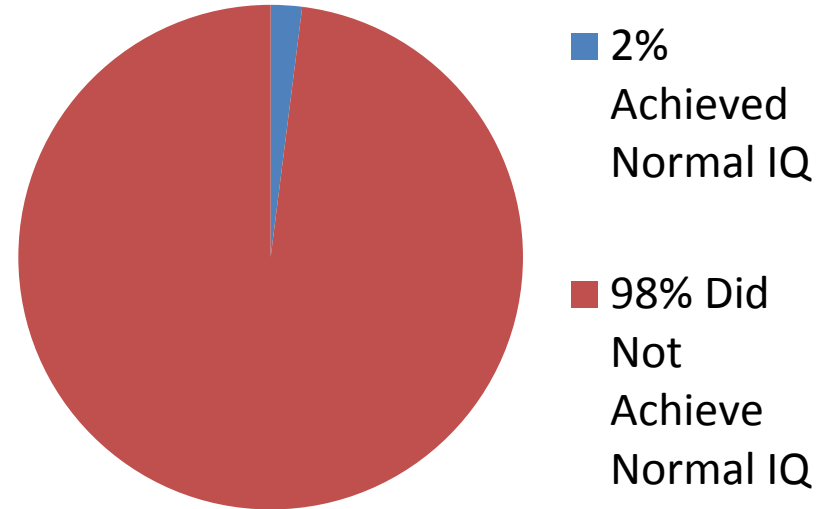
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Outcome of 1987 UCLA Lovaas Study

ABA Group

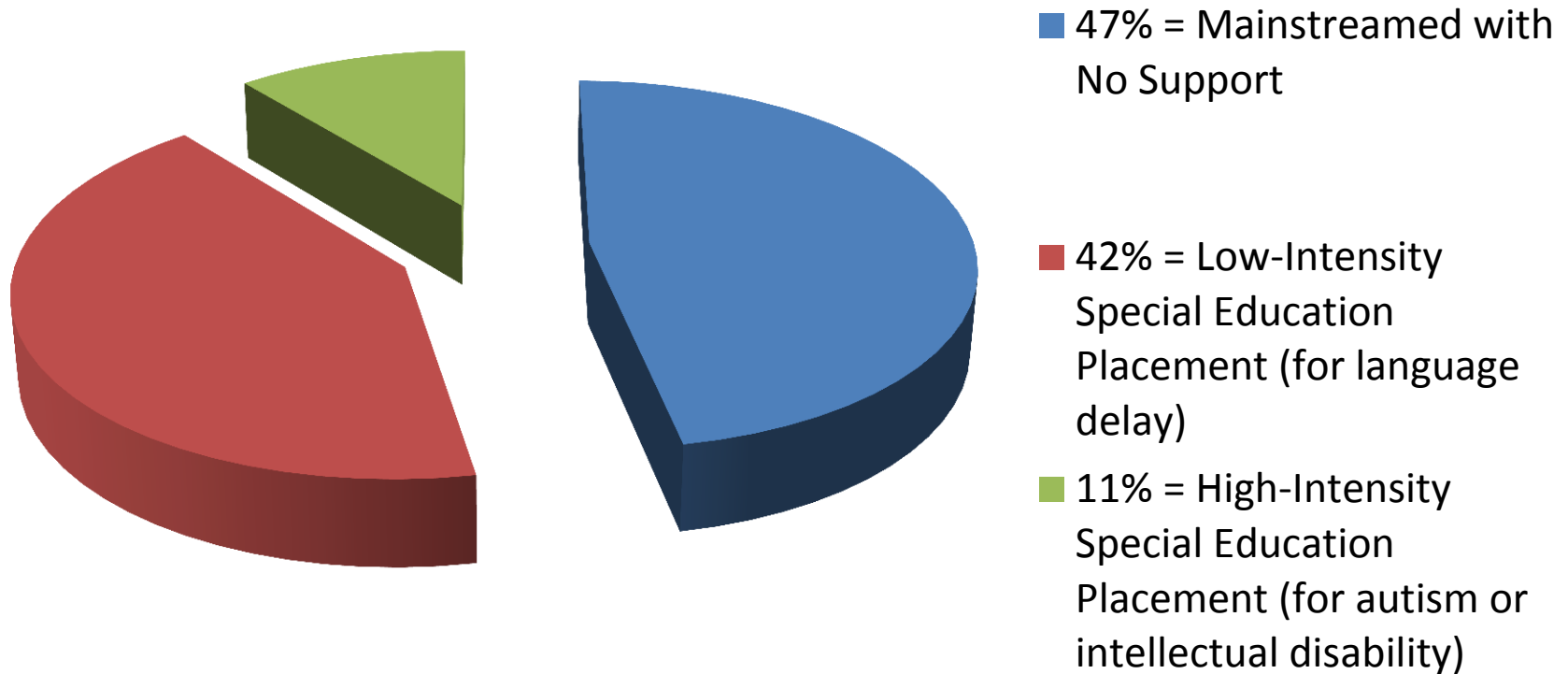


**Other Intervention
(Control) Group**

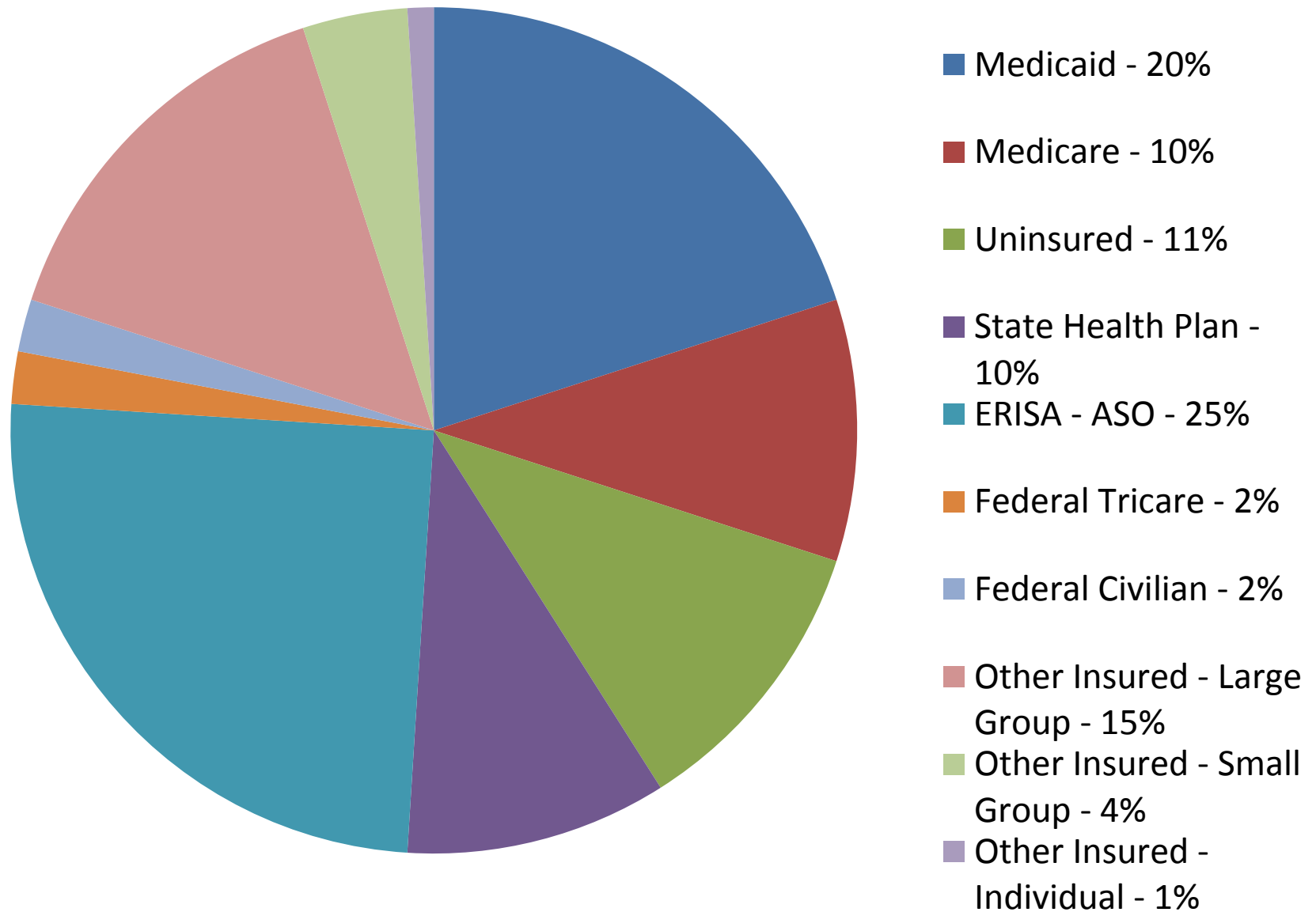


Outcome of 1987 UCLA Study

Educational Placements for Group That Received ABA



Sources of Health Care Coverage



Self-Funded “ERISA” Plans That Cover ABA

- Arnold & Porter
- Eli Lilly
- Ohio State University
- Global Foundries
- Blackbaud
- Lahey Clinic
- Indiana University
- Partners Healthcare
- Wells Fargo
- Capitol One
- White Castle
- Pacific Gas & Electric
- CH2MHill
- Stanford University
- University of Minnesota
- Progressive Group
- Greenville Hospital System
- Symantec
- DTE Energy
- Cerner
- State Street Financial
- Children’s Mercy
- EMC
- Sisters of Mercy
- Princeton University
- Pinnacle Casinos
- Squire Sanders & Dempsey
- Newell Rubbermaid
- And many more . . .



State Autism Insurance Reform & Exchanges



State	Year Enacted	State Population	Annual Dollar Cap	Age Cap	State E'ees?	Small Group?
Indiana	2001	6,484,000	None	None	Yes	Yes
South Carolina	2007	4,625,000	\$50K	16	Yes	No
Texas	2007	25,146,000	None	<10	No	No
Arizona	2008	6,392,000	\$50K: 0-8, \$25K: 9-16	16/17	Yes	No
Louisiana	2008	4,533,000	\$36K (\$144K lifetime)	<17	Yes	No
Florida	2008	18,801,000	\$36K (\$200K lifetime)	<18	Yes	No
Pennsylvania	2008	12,702,000	\$36K	<21	Yes	No
Illinois*	2008	12,831,000	\$36K	<21	Yes	Yes
New Mexico*	2009	2,059,000	\$36K (\$200K lifetime)	19/22	No	Yes
Montana	2009	989,000	\$50K: 0-8, \$20K: 9-18	18	Yes	Yes
Nevada	2009	2,701,000	\$36K	18/22	Yes	Yes
Colorado	2009	5,029,000	\$34K: 0-8, \$12K: 9-19	<20	Yes	Yes
Connecticut*	2009	3,574,000	\$50K: 0-8, \$35K: 9-12; \$25K: 13-14	<15	Yes	No
Wisconsin	2009	5,687,000	\$50K for 4 yrs, \$25K after	None	Yes	Yes
New Jersey*	2009	8,792,000	\$36K	21	Yes	Yes
Ohio & Minnesota***						

State Autism Insurance Reform & Exchanges



State	Year Enacted	State Population ¹	Annual Dollar Cap	Age Cap	State E'ees?	Small Group?
Maine	2010	1,328,000	\$36K	<6	Yes	Yes
Kentucky	2010	4,339,000	\$50K: 0-7, \$1000/mo: 7-21	1-21	Yes	Yes
Kansas	2010	2,853,000	\$36K: 0-7, \$27K: 8-19	<19	Yes only	No
Iowa	2010	3,046,000	\$36K	<21	Yes only	No
Vermont	2010	626,000	None	1 ½ - 6	Yes	Yes
Missouri	2010	5,989,000	\$40K	19	Yes	Yes
New Hampshire	2010	1,316,000	\$36K: 0-12, \$27K: 13-21	21	Yes	Yes
Massachusetts	2010	6,548,000	None	None	Yes	Yes
Arkansas	2011	2,916,000	\$50K	<18	Yes	No
West Virginia	2011	1,853,000	\$30K for 3 yrs; \$24K up to 18	3-18	Yes	Yes
Virginia	2011	8,001,000	\$35K	2-6	Yes	No
Rhode Island	2011	1,053,000	\$32K	15	Yes	No
New York	2011	19,378,000	\$45K	None	Yes	No
California	2011	37,254,000	None	None	No	No
Michigan	2012	9,836,640	\$50K if <7, \$40K if 7-12, \$30K if 13-18	18	Maybe	Yes
Alaska	2012	722,718	None	21	Yes	>20
Delaware	2012	907,135	\$36,000	21	Yes	Yes

Behavior Analyst Licensure Laws



ND has state “certification”

- May 27, 2010 at 5:08pm
- Subject: thanks
- I just wanted to say thank you for accomplishing what many people would not have attempted. I live in Charleston, SC. My husbands insurance is self funded so we are having to give up custody of our autistic 2 year old to my parents because their insurance is better. ABA is really helping and there is nothing I wouldn't do for him. You are inspirational to me and a hero. God bless you.





“[N]o
disability
claims
more
parental
time and
energy
than
autism.”

New York Times,
12/20/04