

# Rising Prevalence of Autism

*What are the implications?*

*Dennis Rogers  
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Member NARPAA  
August 5, 2011*

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Ohio Public Schools  
Autism Prevalence Report  
School Years 1992-2003

Ohio Autism Task Force  
Launched by Gov. Taft (June 2003)

Prevalence of Autism  
in Brick Township, NJ  
Center for Disease Control &  
Prevention (2000)

**Demand for Special Ed on the Rise**

*... schools wonder how they'll cover costs*  
Atlanta Constitution (Jan 2006)

US Department of Education  
IDEA 2004/2005 Statistics –  
1 child in 166 has ASD

Autism Challenges Eastern  
Connecticut Schools  
(Jan 2006)

Autism 2001 –  
The Silent Epidemic (UK)

Autism – the Hidden Epidemic  
*... as autism cases soar – a search for clues*  
MSNBC Feb 2005

Autism in America –  
Disorder That's Defining an Era  
Child Magazine

Autism Spectrum Disorders –  
Changes in the California Caseload  
1987-2002

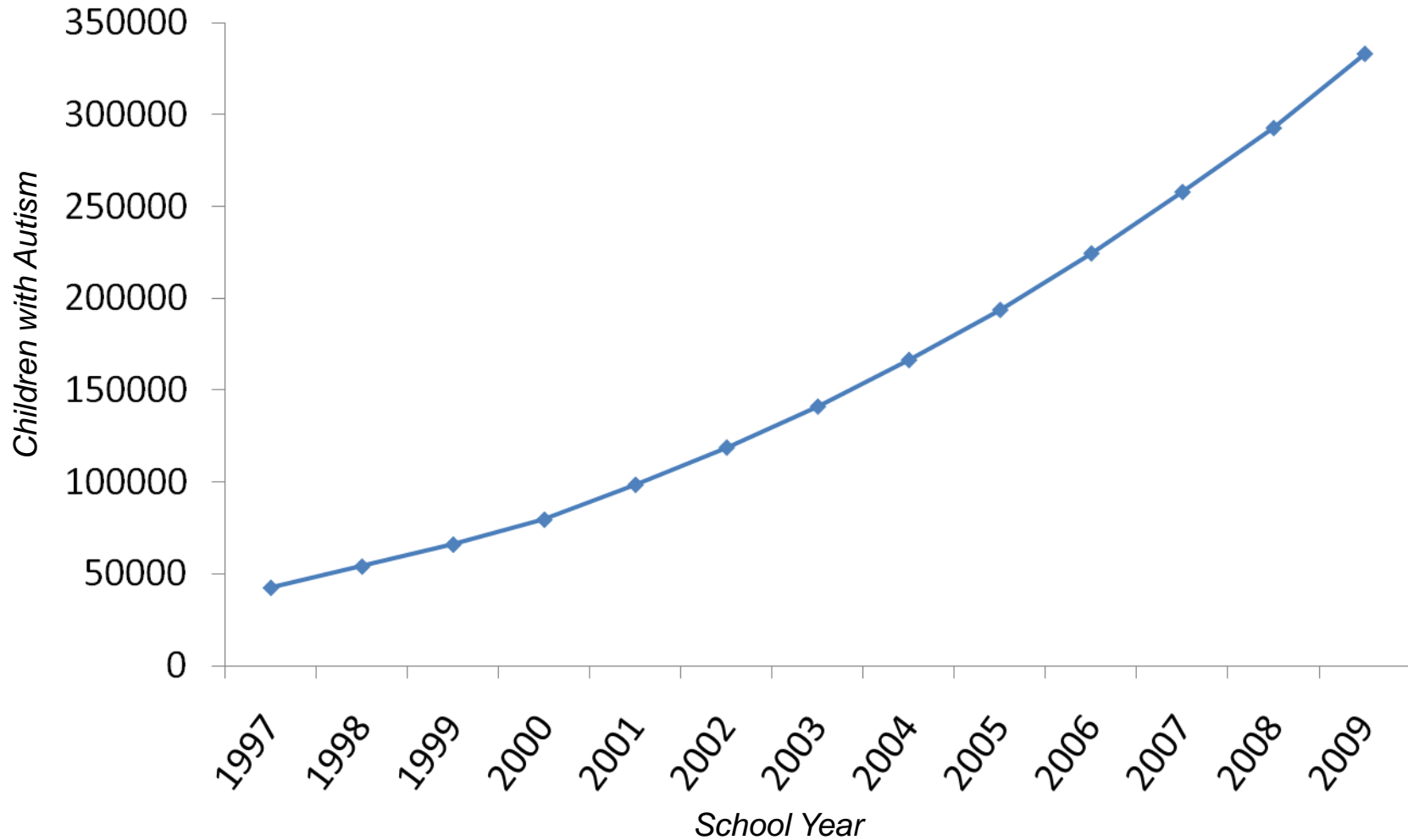
Autism Society of America –  
The National Crisis in Adult Services  
for Individuals with Autism  
*... a call to action*

Autism Up: Schools Stressed  
*Schools scrambling to fill special needs*

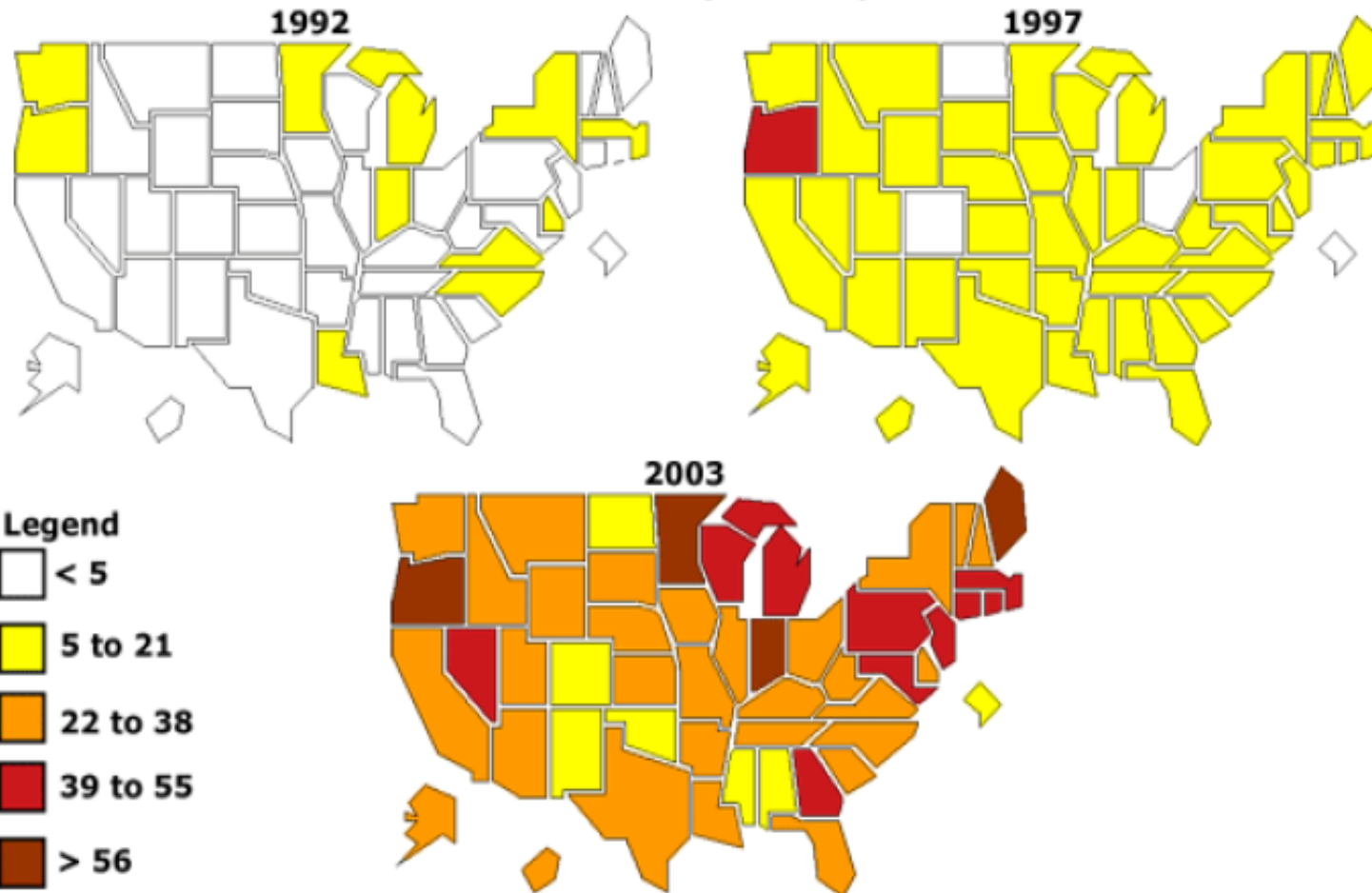
**Autism has become a world-wide epidemic!**

# Autism in US Schools - IDEA Data

*Ages 6-21*



## Autism's Trend Among U.S. Youth I.D.E.A. 1992, 1997, 2003



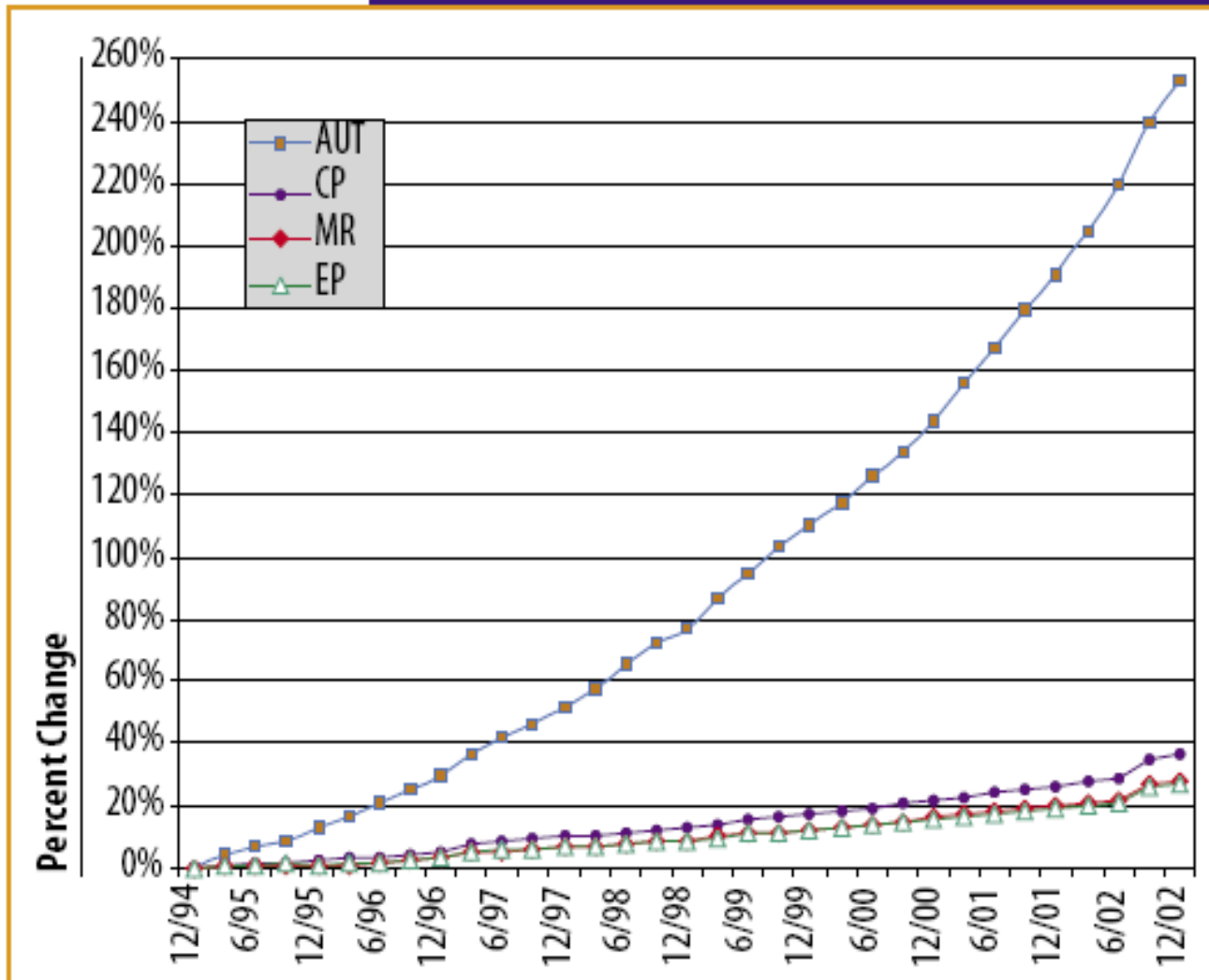
Units: Ages 7 to 9 yrs old per 10,000 births

Source: Public Schools Autism Prevalence Report Series, 1992-2003, [www.FightingAutism.org](http://www.FightingAutism.org), 2004.

Autism prevalence trend among United States Youth for IDEA 1992, 1997, 2002.

# California

**Figure 2 - Percent Change in All Disabilities from 1994 through 2002**



“Autism Spectrum Disorders, Changes in the California Caseload, An Update: 1999-2002”  
(published in April 2003 by the California Dept. of Developmental Services)

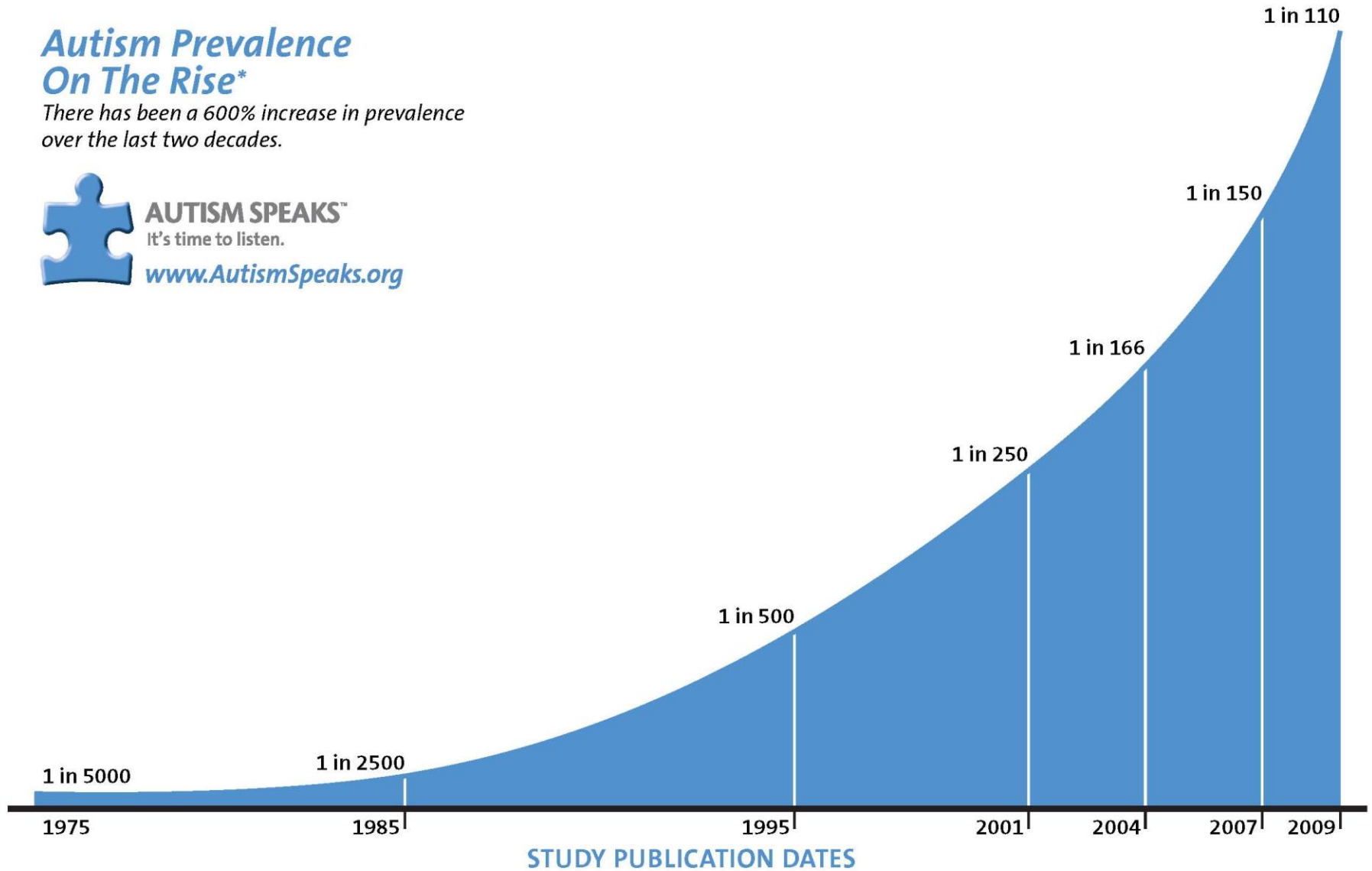
# Autism Prevalence On The Rise\*

There has been a 600% increase in prevalence over the last two decades.



**AUTISM SPEAKS™**  
It's time to listen.

[www.AutismSpeaks.org](http://www.AutismSpeaks.org)



\*Recent research has indicated that changes in diagnostic practices may account for at least 25% of the increase in prevalence over time, however much of the increase is still unaccounted for and may be influenced by environmental factors.

# Wow ... this sounds bad!

*But what does it all mean for the future?*

*How many people with autism will need to be served by 2030?*



## A simple model will provide the answer



*From US Census*

*From CDC &  
other sources*



# USA Census – Every 10 Years



## 2000 USA Census

Age	# People	Birth Year
0	3,805,648	2000
1	3,820,582	1999
2	3,790,446	1998
3	3,832,799	1997
4	3,926,323	1996
5	3,965,103	1995
...		
21	3,841,082	1979
22	3,758,648	1978
23	3,673,582	1977
...		
84	801,329	1916
85+	4,239,587	< 1916
<b>Total</b>	<b>281,421,906</b>	

## Future Forecast



Model Constructed by  
US Census Bureau  
Based On:

- fertility rates (+)
- mortality rates (-)
- immigration rates (+)
- emigration rates (-)

## 2010 USA Forecast

Age # People Birth Year

## 2020 USA Forecast

Age # People Birth Year

## 2030 USA Forecast

Age # People Birth Year

US Census Bureau publishes forecasts for next 30 years, by age, by sex, by state, etc.

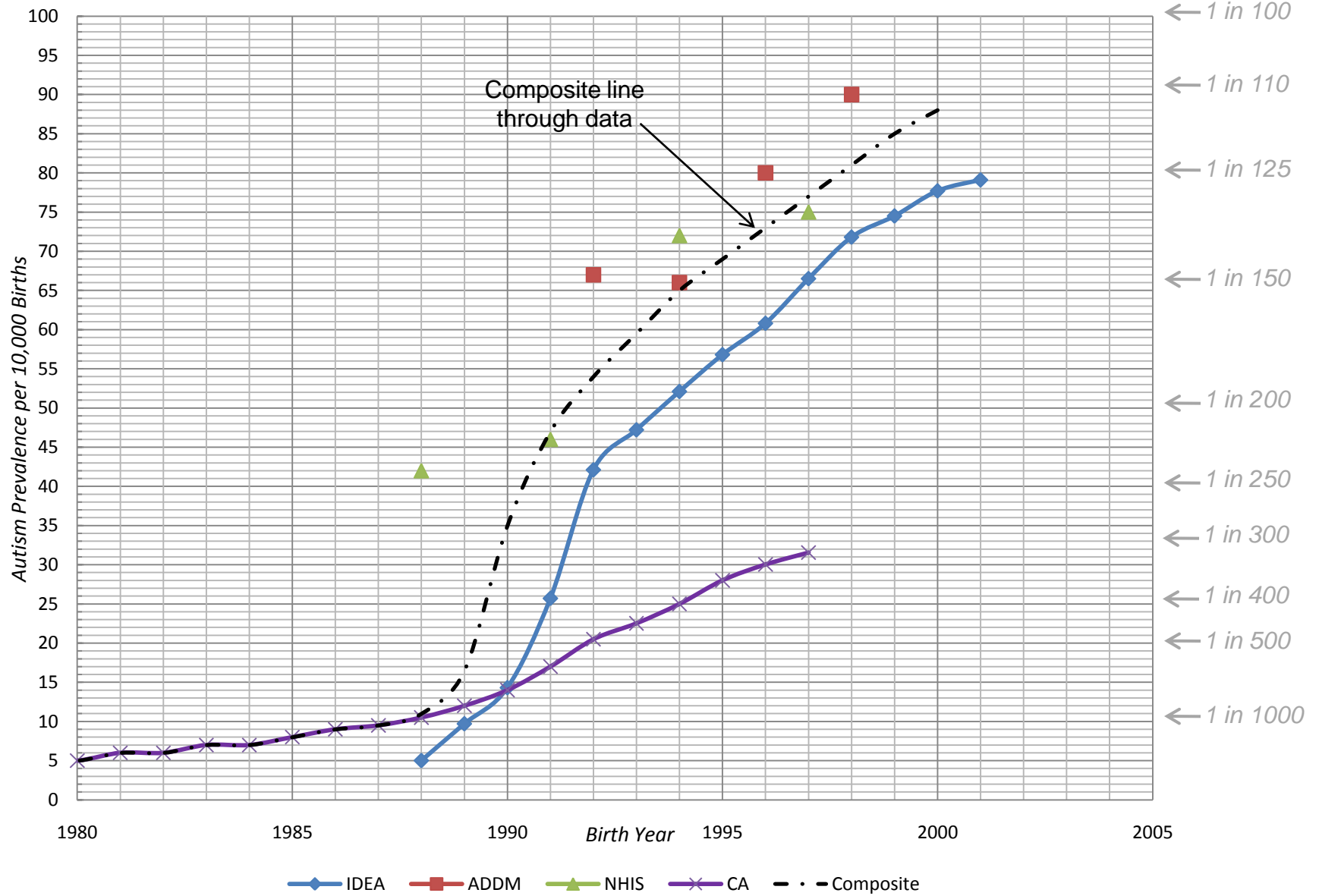


# ASD prevalence data sources used in this presentation

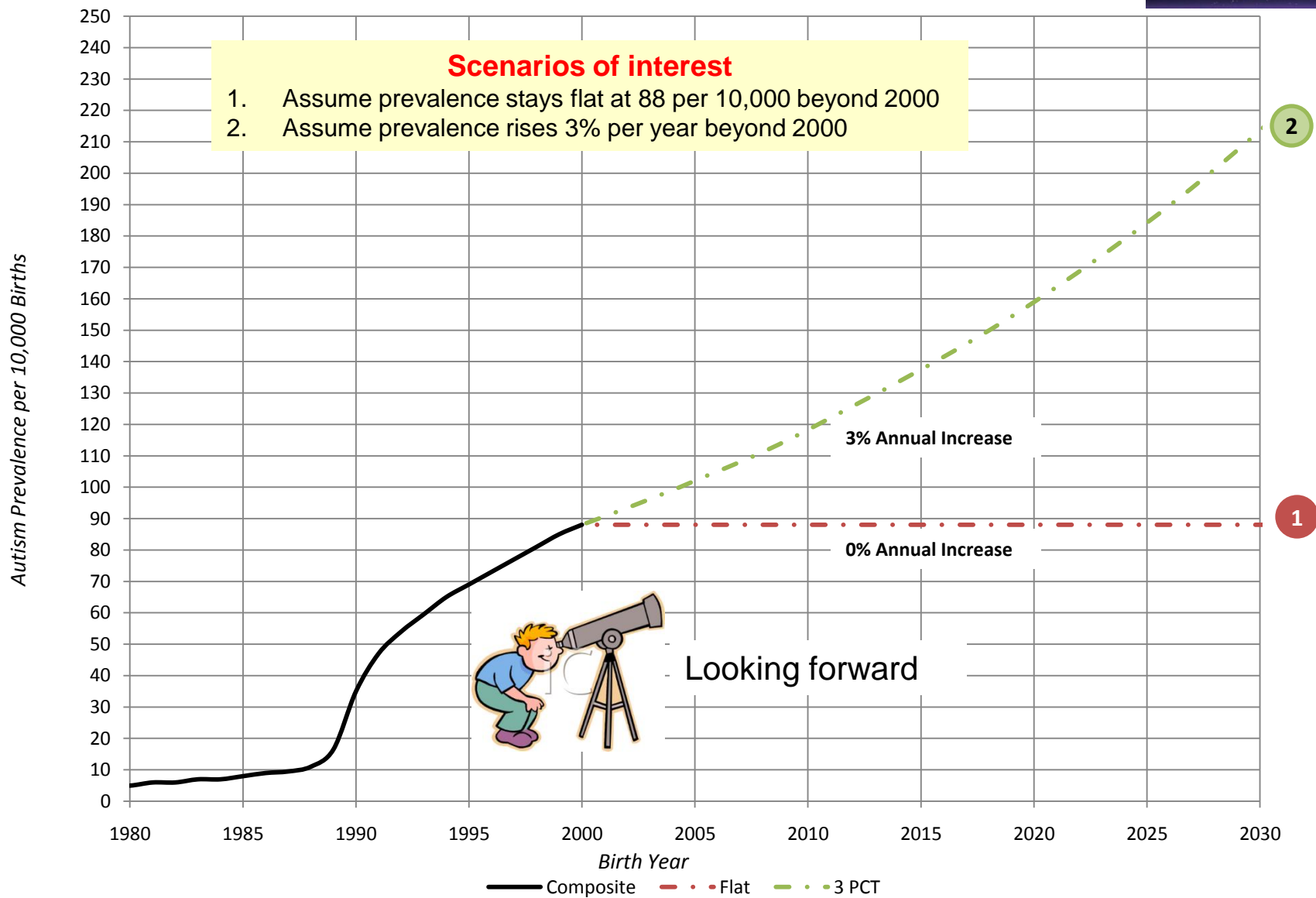
- California Department of Developmental Services Data – autism prevalence 1987-2002 *(note: does not include Asperger's or PDD-NOS)*
- IDEA School Data – students with ASD by birth year, 2009 data
- CDC surveys – National Health Interview Survey & National Survey of Children's Health - Parent Survey Data of 4-17 year olds, 2003/2004
- CDC ASD prevalence studies of 8 year olds – Autism and Developmental Disabilities Monitoring Network Data for 2000, 2002, 2004, 2006

*(see references at back of presentation)*

# Autism Prevalence Data Sources



# Autism Prevalence Extrapolation Assumptions



# Determination of Number of People with Autism in USA *(example)*

For Year 2000

Age	Number of People	Birth Year	Autism Rate per 10,000 Births	Number with Autism
0	3,805,648	2000	88	33,490
1	3,820,582	1999	85	32,475
2	3,790,446	1998	81	30,703
3	3,832,799	1997	77	29,436
4	3,926,323	1996	73	28,662
5	3,965,103	1995	69	27,359
	<i>Etc. for each age</i>			
83	883,063	1917	4	353
84	801,329	1916	4	320
85+	4,239,587	1915 & before	4	1,696
<b>Total</b>	<b>281,421,906</b>			

## Calculation Methodology

- **Column 2:** For a given year, determine the population by age from census data projections
- **Column 3:** Determine the birth year for each age for that year – someone who is 2 years old in 2000 was born in 1998, etc.
- **Column 4:** Determine the autism rate from prevalence curve for that birth year:

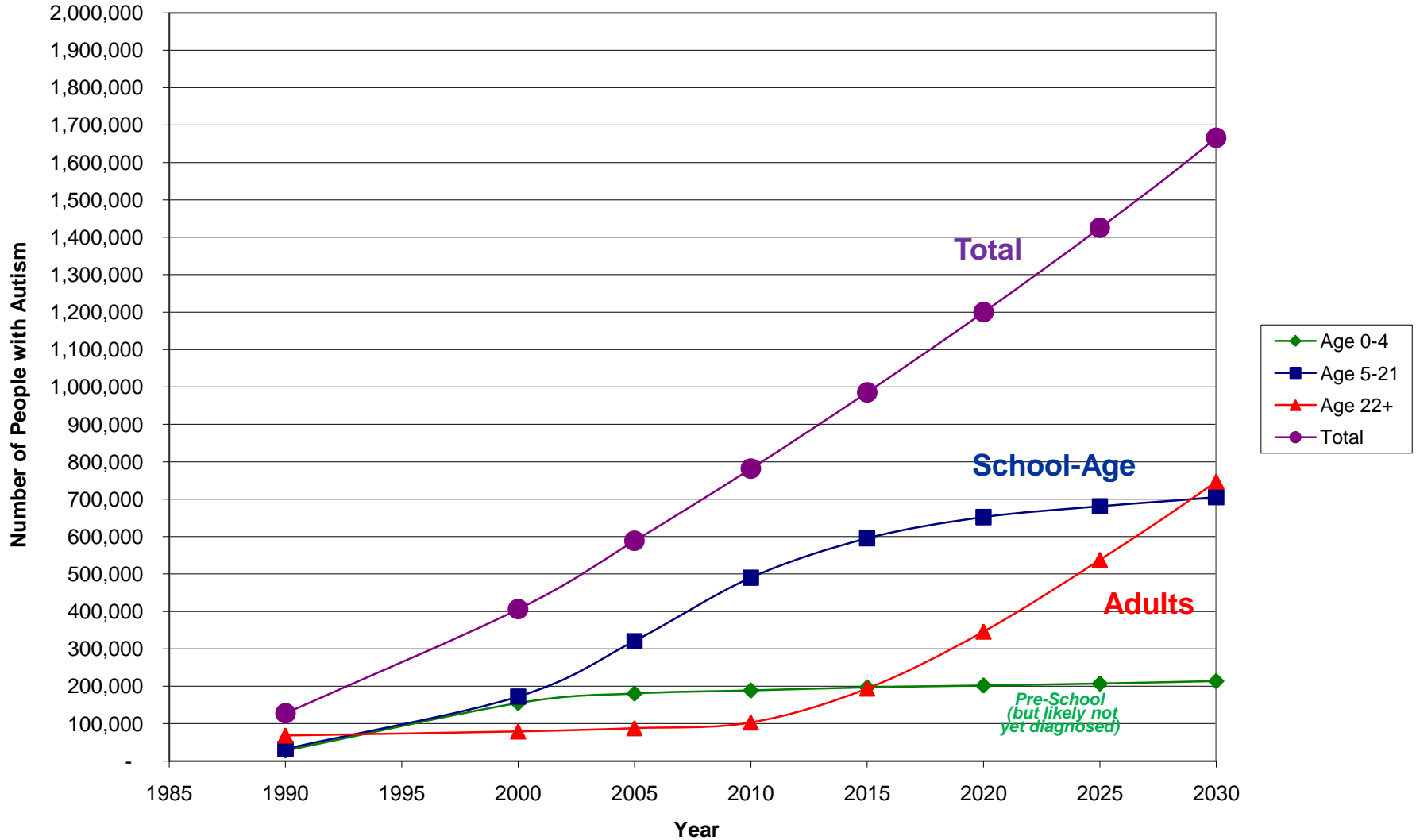


- **Column 5:** Calculate: Number with autism = (Number of People)/10,000 x Autism Rate  
*example for age 2 in year 2000:*  
 Number with Autism = 3,790,446/10,000 x 81 = 30,703

- ❖ Do a similar calculation for every age in every year to predict number of people with autism in USA now and in the future
- ❖ Repeat using census data and population forecast from every state

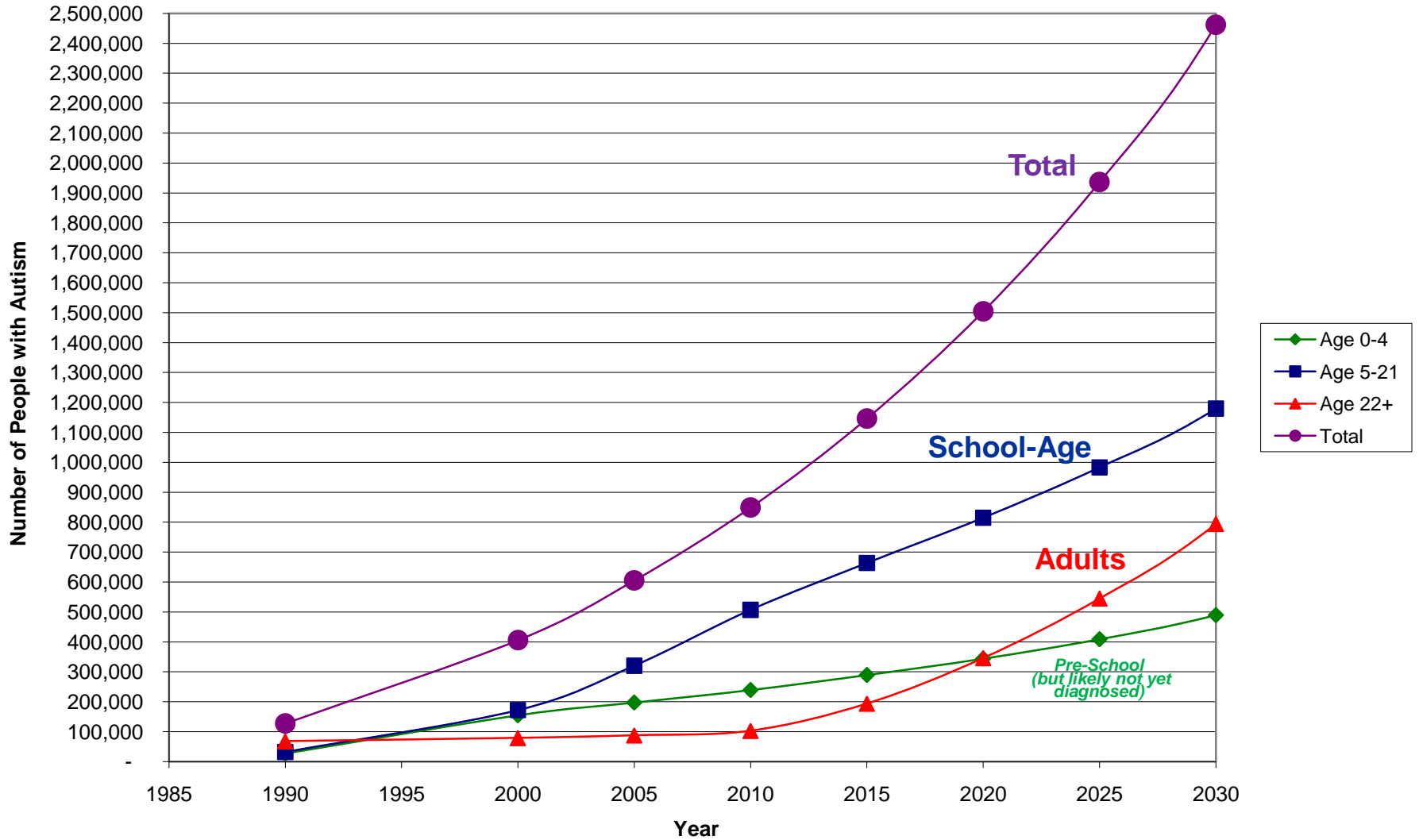
# Autism Population Forecast - USA

*with flat extrapolation assumption*



# Autism Population Forecast - USA

*with +3% per year extrapolation assumption*



# Forecast of Number of Individuals with Autism in USA for 2000-2030

*flat  
extrapolation  
assumption*

Age Group	Year				% Change 2030 vs. 2010
	2000	2010	2020	2030	
Pre-School (0-4)	154,842	188,550	201,802	213,593	+13%
School Age (5-21)	171,988	489,955	651,973	705,464	+44%
Adults (22+)	79,067	103,002	345,927	747,124	<b>+625%</b>
Total	405,897	781,507	1,199,702	1,666,181	+113%

*+3% per year  
extrapolation  
assumption*

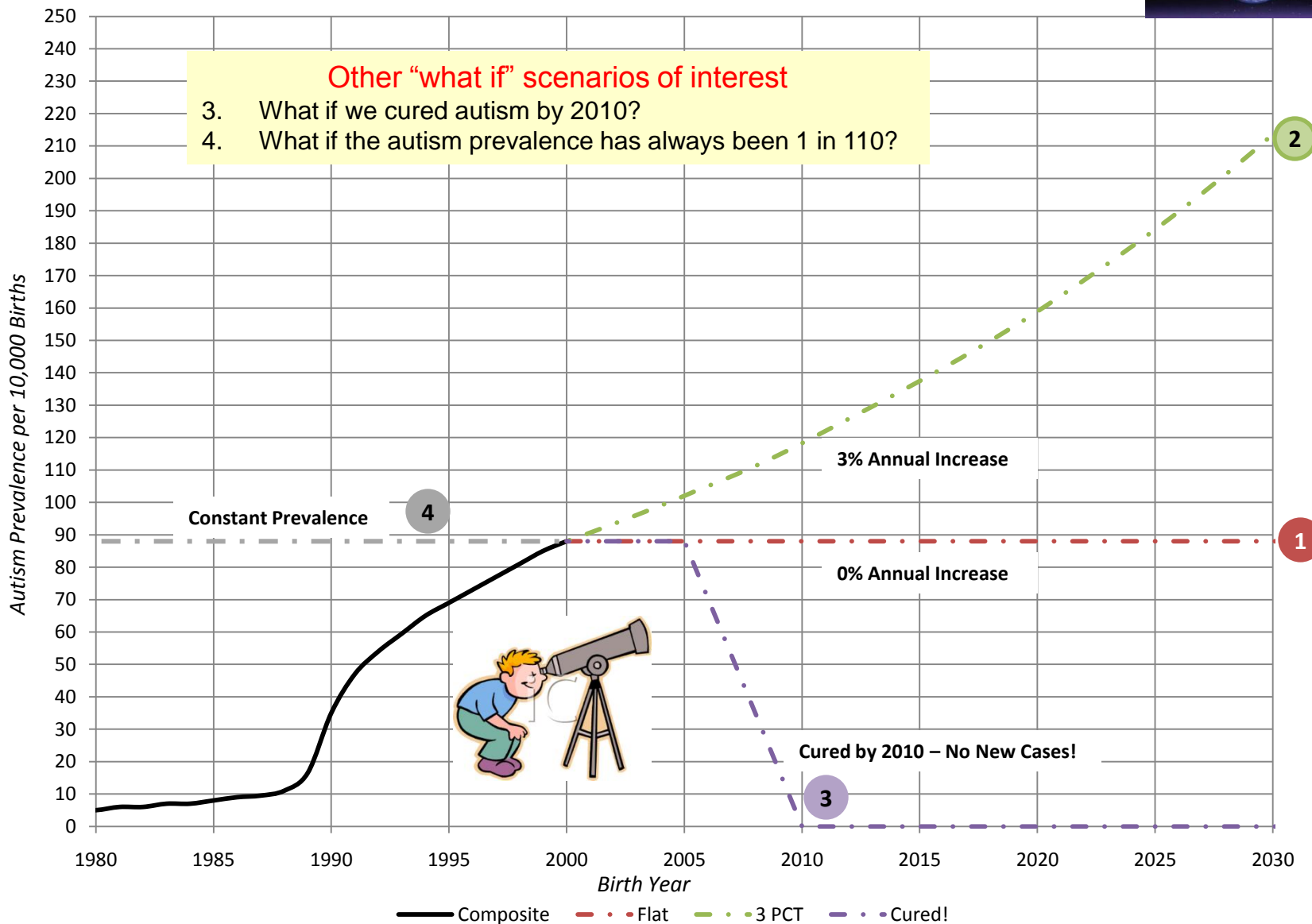
Age Group	Year				% Change 2030 vs. 2010
	2000	2010	2020	2030	
Pre-School (0-4)	154,842	239,173	343,907	489,242	+105%
School Age (5-21)	171,988	507,074	814,800	1,179,382	+133%
Adults (22+)	79,067	103,002	345,927	793,906	<b>+671%</b>
Total	405,897	849,249	1,504,634	2,462,530	+190%

# Other “What If” Extrapolation Scenarios of Interest

3. What if we cured autism in 2010? What would the impact be on future service needs? This is the best possible assumption!
4. What if the autism prevalence isn't really rising? We have widened the definition, assigned a name to the disorder, trained doctors and parents to recognize it, etc. So the apparent rise in autism prevalence is simply due to better diagnosis and awareness. The current rate is correct, but the past rates were significantly under represented due to the above factors.



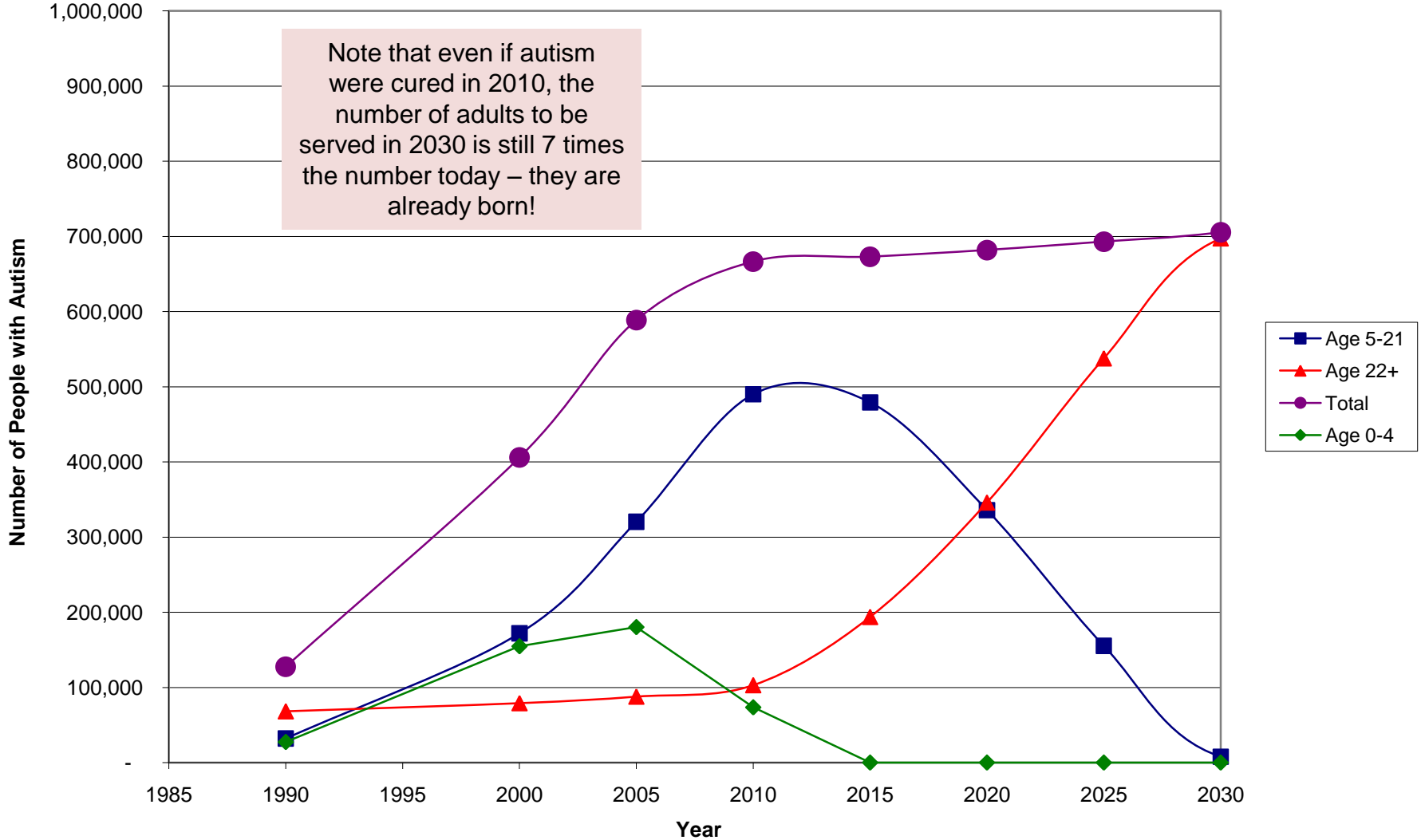
# Autism Prevalence Extrapolation Scenarios



# Autism Prevalence Trends - United States Total

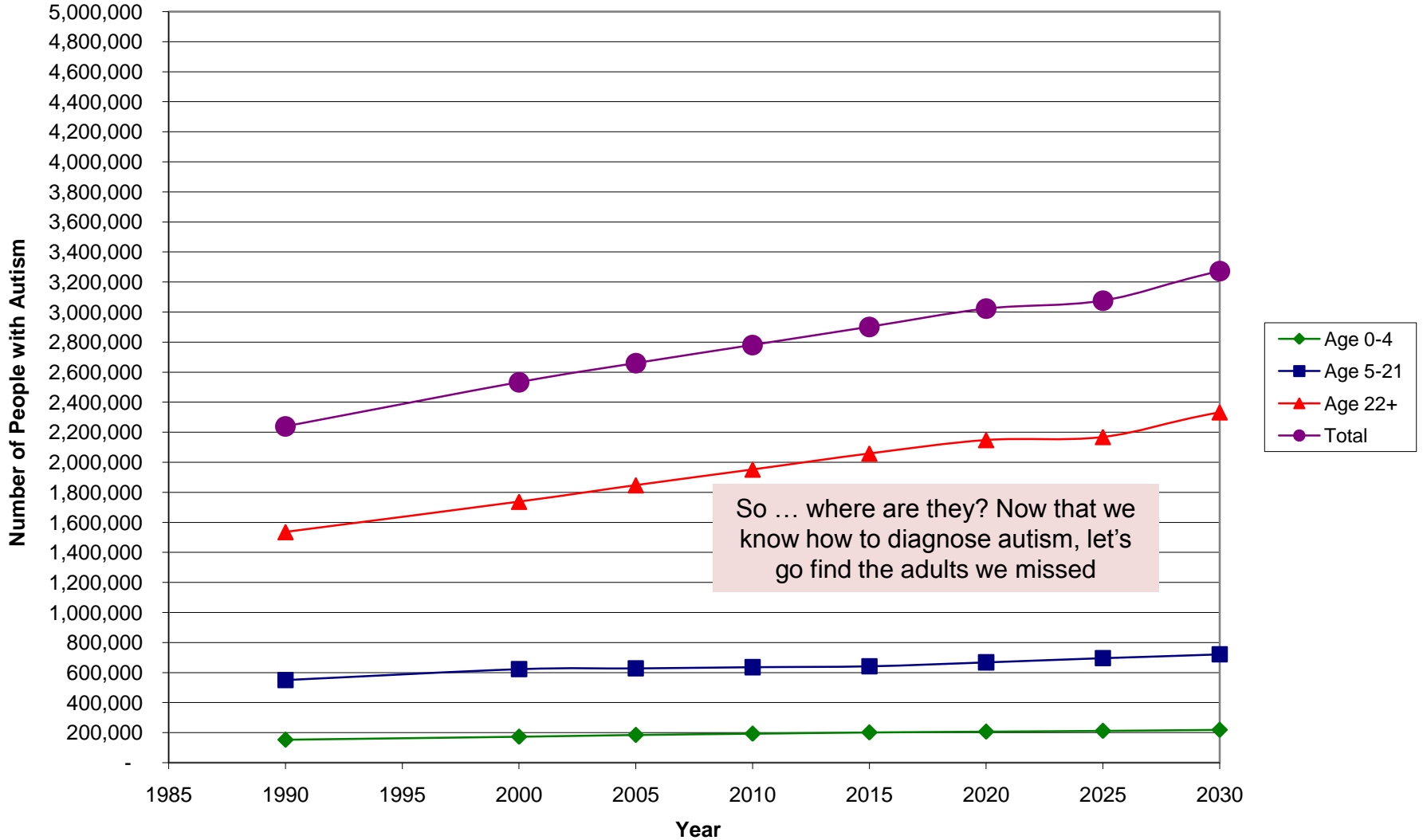
Cured by 2010!

Note that even if autism were cured in 2010, the number of adults to be served in 2030 is still 7 times the number today – they are already born!



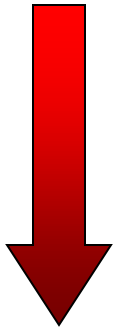
# Autism Prevalence Trends - United States Total

Constant Prevalence



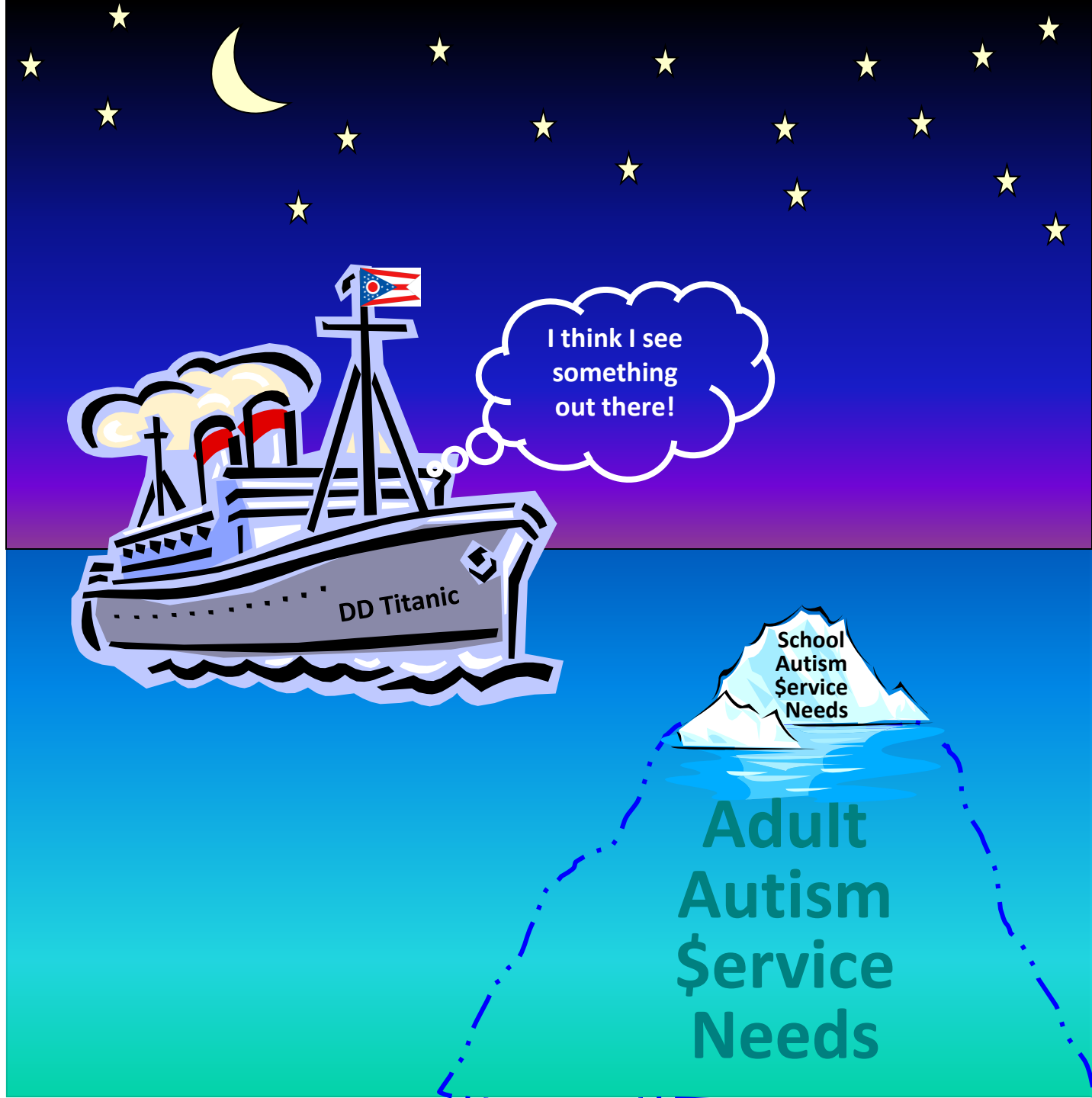
# Cost of Care

- Annual cost to educate students with disabilities  
= \$12,474 per school year
- Annual cost to support an adult with autism in supported living setting  
= \$50,000-\$100,000
- In school for 16 years (ages 5-21)
- In adult services for 60+ years!
- Significant rise in number of adults with autism will severely strain funding sources



***“The Tip  
of the  
Iceberg”***

Dennis Rogers 2006



# Conclusions

- Simple model created to help us see the future of autism, based on:
  - ✓ USA census population forecasts
  - ✓ Historical autism prevalence trends (*looking backward*)
  - ✓ Assumed future autism prevalence trends (*looking forward*)
- Model shows by 2030
  - ✓ Number of **students** with autism is forecast to increase
    - 44% (*with flat extrapolation*)
    - 133 % (*with +3% per year extrapolation*)
  - ✓ Number of **adults** with autism is forecast to increase by over 600% with any extrapolation assumption – they are already born!



“The era of procrastination,  
of half measures, of soothing and  
baffling expedients and delays  
is coming to a close.

In it's place we are entering a  
period of **consequences**.”

*Sir Winston Churchill*



# Reference Information



# Census & Autism Prevalence Data used in this Presentation

## US Census Data

1. State Interim Population Projections by Age and Sex: 2004 – 2030 (Download File3). Released in March 2004.  
Source: U.S. Census Bureau, Population Division  
<http://www.census.gov/population/www/projections/projectionsagesex.html>

## California Department of Developmental Services Data

2. Changes in the population of persons with autism and pervasive developmental disorders in California's Developmental Services System: 1987 through 1998. A report to the Legislature. Sacramento, CA: California Health and Human Services Agency, Department of Developmental Services; 1999.  
[http://www.dds.ca.gov/Autism/docs/autism\\_report\\_1999.pdf](http://www.dds.ca.gov/Autism/docs/autism_report_1999.pdf)
3. Autistic spectrum disorders: changes in the California caseload. An update: 1999 through 2002. Sacramento, CA: California Health and Human Services Agency, Department of Developmental Services; 2003.  
<http://www.dds.ca.gov/Autism/docs/AutismReport2003.pdf>

## IDEA School Data

4. Originally obtained from [www.fightingautism.org](http://www.fightingautism.org), which later moved to [www.thoughtfulhouse.org](http://www.thoughtfulhouse.org), now moved to [www.johnson-center.org/index.php/research/page/techlabs](http://www.johnson-center.org/index.php/research/page/techlabs) but currently inactive (coming soon)

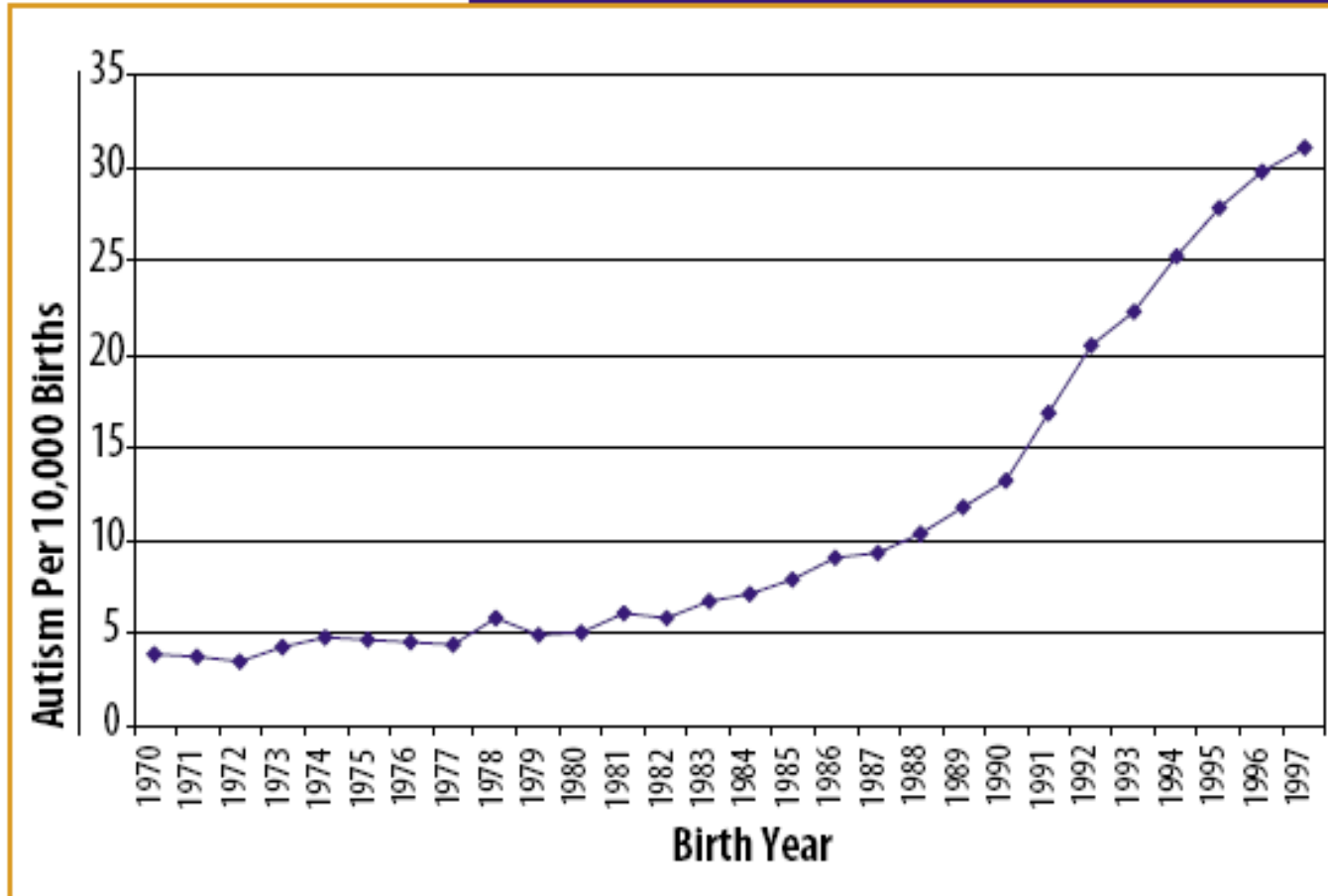
## CDC - NHIS & NHCS Parent Survey Data

5. Mental Health in the United States: Parental Report of Diagnosed Autism in Children Aged 4--17 Years --- United States, 2003—2004. Published May 5, 2006. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5517a3.htm>

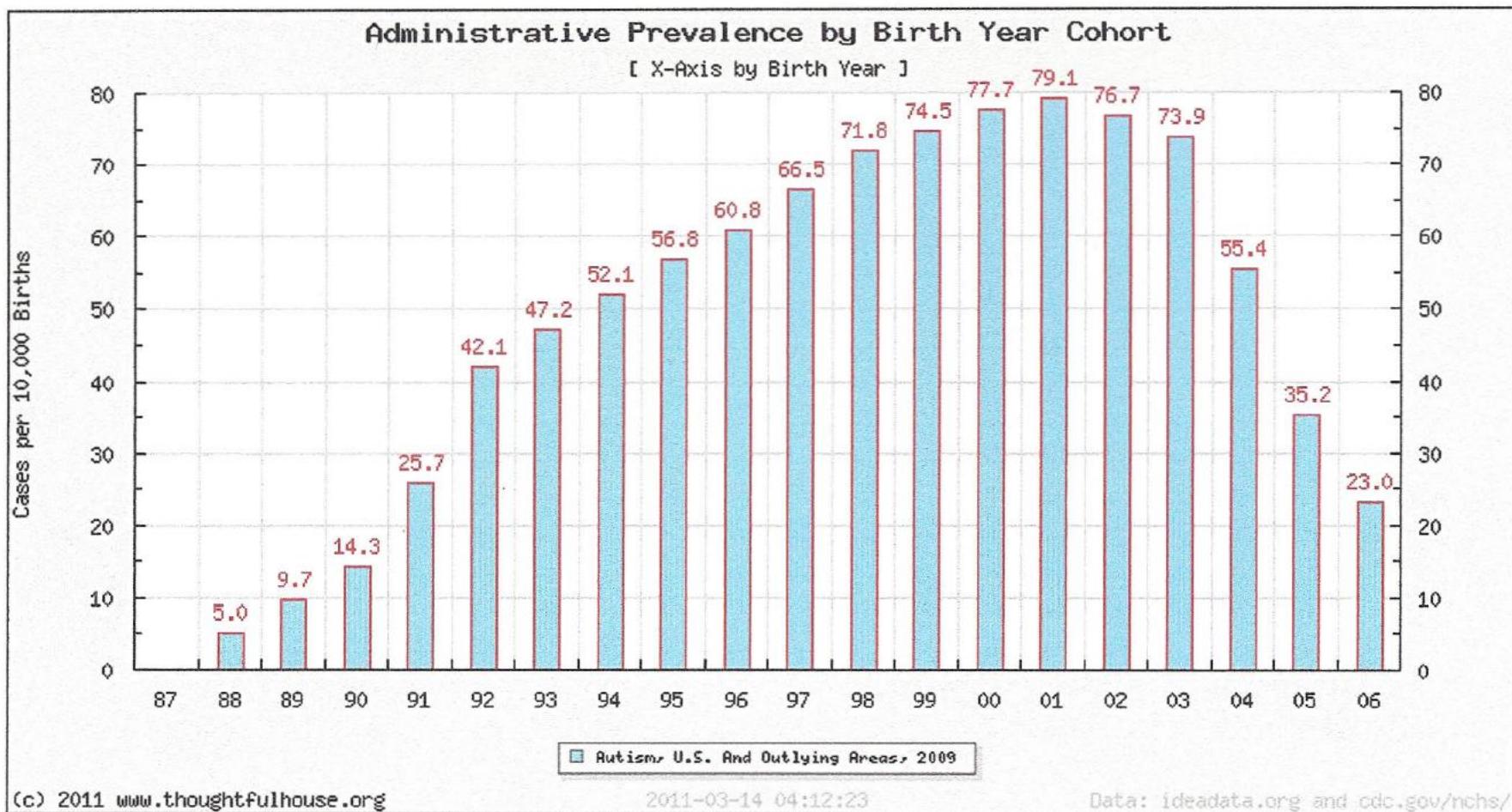
## CDC – ADDM Monitoring Network Data

6. Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2000 and 2002. *Community Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network*. Published February 9, 2007. <http://www.cdc.gov/mmwr/pdf/ss/ss5601.pdf>
7. Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2004 and 2006. *Community Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network*. <http://www.cdc.gov/ncbddd/autism/states/ADDMCommunityReport2009.pdf>

**Figure 3 - Uncorrected Birth Year  
Prevalence Rates from 1970 through  
1997 for the 2002 Population of  
Persons with Autism (Codes 1 & 2)**



# IDEA Autism Data for USA



┌──────────────────┐  
Data immature, not used  
– too young

# CDC Autism Prevalence Studies



2003/2004  
National Health Interview Survey  
18,885 surveyed

Age	Prevalence per 10,000	
4-5	48	<i>Not used*</i>
6-8	75	
9-11	72	
12-14	46	
15-17	42	

*\*Data immature – too young*

2003/2004  
National Survey of Children's Health  
79,590 surveyed

Age	Prevalence per 10,000
4-5	44
6-8	76
9-11	68
12-14	43
15-17	41

## ADDM Monitoring Network *(of 8 year olds)*

Year Surveyed	# States	# Surveyed	Prevalence per 10,000	Year Published
2000	6	187,761	67	2007
2002	14	407,578	66	2007
2004	8	172,335	80	2009
2006	11	308,038	90	2009