

New Jersey Public Schools Autism Prevalence Report School Years 1992 - 2003

FightingAutism, November 2004

Introduction: The Individuals with Disabilities Education Act (IDEA) requires each state's Department of Education and the U.S. Department of Education to record specific childhood disabilities, including autism, for each school year. This report analyzes the IDEA data by quantifying and characterizing trends over time in autism prevalence for each specific state or nationally.

The autism disability category was added as a reporting requirement in 1991. However, it was not until the 1992 school year that most states actually started reporting data for the autism disability category. States have different eligibility criteria for the autism disability category. This report uses the term *autism* to represent the students meeting the states eligibility criteria for each respective year.

As of writing this report the 2003 school year is the last released set of data. We expect to be able to update this report in late December 2005 with the data for the 2004 school year.

This report and additional autism prevalence reports for other states are available at www.fightingautism.org.

Context: Concern has been raised about the increase in the prevalence of autism. However, no systematic analysis of public school system IDEA data has been conducted on a national and state level.

Objectives: To quantify and characterize the prevalence of autism among students enrolled in the public school system for each state and for the nation as a whole. To identify peak point prevalence and any significant time trends in the prevalence of autism.

Design, Setting, and Population: Study the number of children with autism and autism prevalence among children aged 3 to 22 years in the 50 states and nationally for school years 1992 to 2003.

New Jersey Results:

- The increase in autism prevalence is systemic across the US. (Fig 1).
- 5,503 children with autism in 2003 (Fig 2).
- 911% cumulative growth rate of autism from 1992 to 2003 (Fig 3).
- 22% average annual growth rate for autism from 1992 to 2003 (Fig 4).
- Autism prevalence compared to CA and U.S. (Fig 5).
- 1 out of 179 (56/10,000) children has autism in 2003.(Fig 6).
- Increase in autism prevalence, in 2003, is attributed to younger autistic children (ages 3-8). (Fig 7).
- Autism prevalence time trend steadily increased from 1992 to 2003. (Fig 8).

Conclusion: The increase in autism prevalence is systemic across the entire United States and should be a urgent public health concern. The majority of the increase is attributed to young children. The increasing prevalence time trend provides additional evidence that disease frequency is, and has been, increasing in the United States. The disease frequency of autism now surpasses that of all types of cancer combined.

Number of Cases: Number of cases of autism is the total number of autistic students recorded in the autism disability category between ages 3-22 recorded by the state. In order to be recorded in the autism disability category the student must require special academic support because of their disability and meet the eligibility criteria for the autism disability category set by the school administrators for each specific state. Therefore number of autism cases is an extremely good measure of the economic burden of autism on the state via the additional cost to the educational system.

There are, however, some children with autism who are not included in these counts, such as children who attend private school or placement, or who are home schooled, or do not meet the eligibility criteria for the autism disability category, or who are in regular education classes. One study in Brick Township reported that only 50% of children with an ASD and 66% of those with autistic disorder had autism listed as their special education designation for services.[6] Another recent study in Atlanta reported that of those children with ASD only 41% were recorded in the autism eligibility category.[5] Therefore, the number of children with autism and autism prevalence shown in this report are an under reporting of the actual disease frequency.

Autism Incidence: Autism incidence is the rate of *newly* diagnosed students with autism during the specific school year. It is not possible to assess changes in actual disease incidence with the IDEA data, because the IDEA data only includes child counts by disability and age. It does not include details about specific students such as year of first service or age of diagnosis. However, a *crude* incidence can be calculated by subtracting two consecutive school year's prevalence rates.

Autism Prevalence: Autism point prevalence is the total number of autistic students in the autism disability category stratified by age (birth year) and divided by either the number of:

- Births in that specific birth year, which provides units of *incidence per 10,000 births*. The advantage of normalizing by

births is that the prevalence for ages 3-22 can be calculated. The disadvantage is there can be an immigration bias introduced in states that have a growing population.

- Public school K-12 grade enrollment, which provides units of *incidence per 10,000 public school enrollment*. The grade enrollment data is adjusted by grade level plus 6 years to match the specific birth year. The advantage of normalizing by grade enrollment is that there is no immigration bias in the calculation. The disadvantage is the prevalence calculations are limited to ages 6-18.

Point prevalence allows comparison between different states or other diseases like cancer. For example, the National Cancer Institute reports that the cancer prevalence rate of all types of cancer peaked in 1992 at a rate of 51.1 per 10,000 (diagnosis, not mortality). Since 1992 the prevalence of a cancer diagnosis has fallen to 47.6 per 10,000.[7] The CDC reports the autism prevalence rate to be 1 out of 166 children or 60.2 per 10,000.[8] Therefore, autism is more prevalent than all types of cancer combined.

Autism Prevalence Time Trend: Autism prevalence time trend, by holding age constant over time, is the gold standard for determining if the prevalence rate is rising, falling, or holding constant over time. A rising or falling prevalence trend would implicate environmental factors in the causality of autism and hopefully trigger an appropriate response from the public health officials. A steady prevalence time trend would implicate genetic factors in the causality of autism.

One recent review study, the most thorough and comprehensive to date reviewing 54 published reports and studies, showed a 10 fold increase in autism prevalence rates in the United States that cannot be explained by changes in diagnostic criteria or improvements in case ascertainment. Reported rates of autism increased from < 3 per 10,000 children in the 1970s to > 30 per 10,000 children in the 1990s. The reported rates for the full spectrum of autistic disorders rose from 5 to 10 per 10,000 range to the 50 to 80 per 10,000 range.[4]

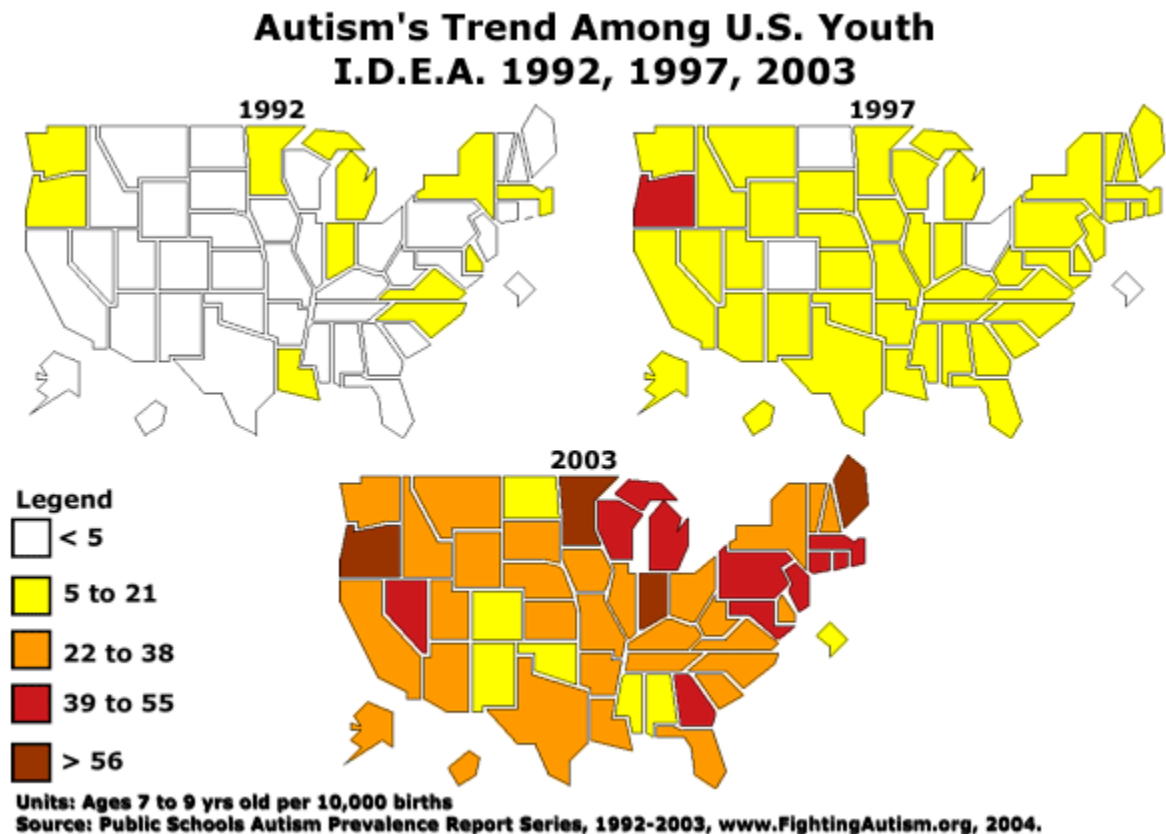


Figure 1 – Autism prevalence trend among United States Youth for IDEA 1992, 1997, 2002.

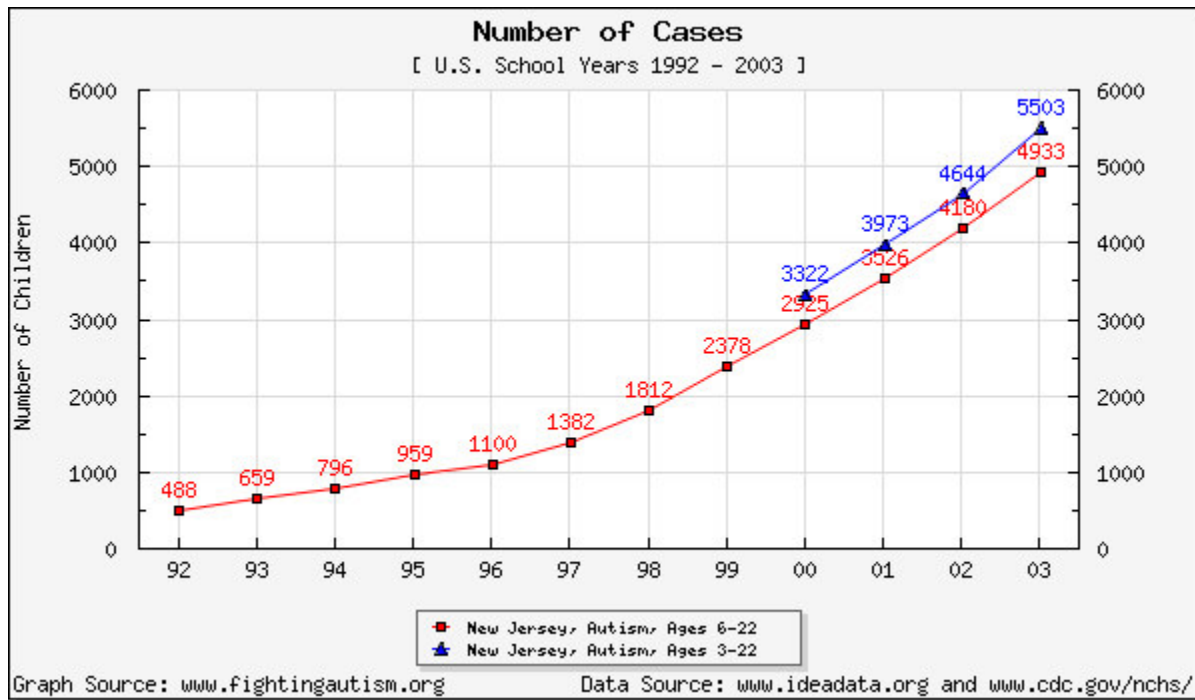


Figure 2 – Number of students with autism in New Jersey starting from 1992 to 2003.

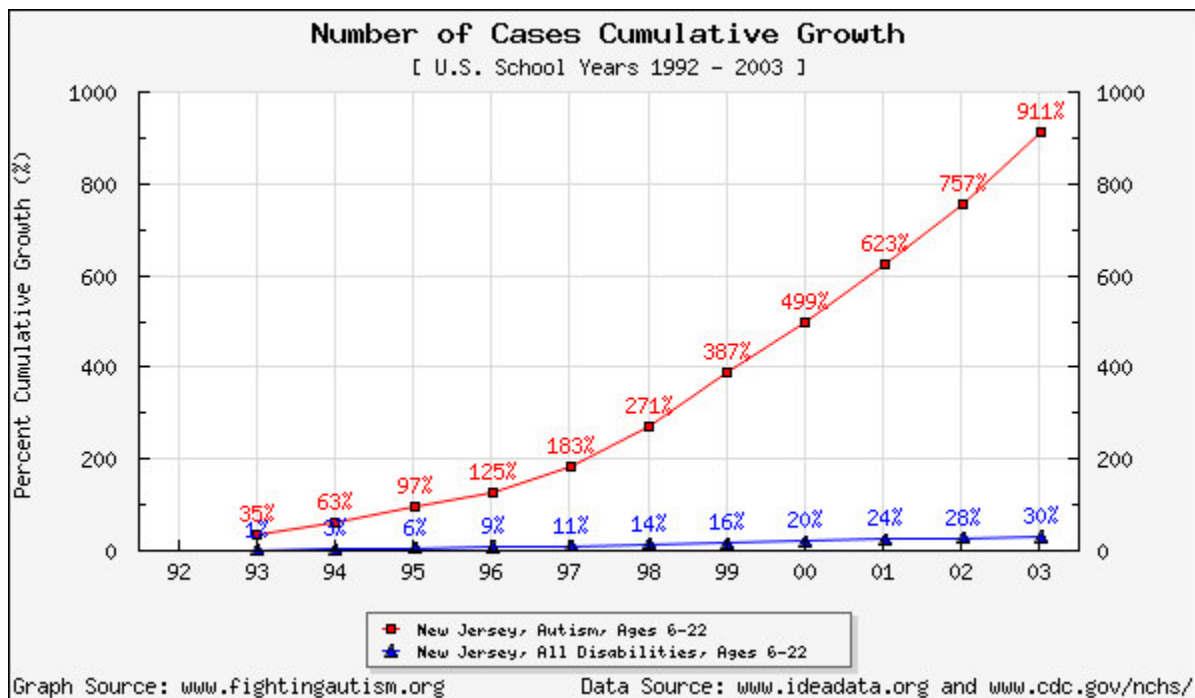


Figure 3 – Cumulative growth rate of the number of children with autism from 1992 to 2003 for ages 6-22 in New Jersey compared to all disabilities (including autism).

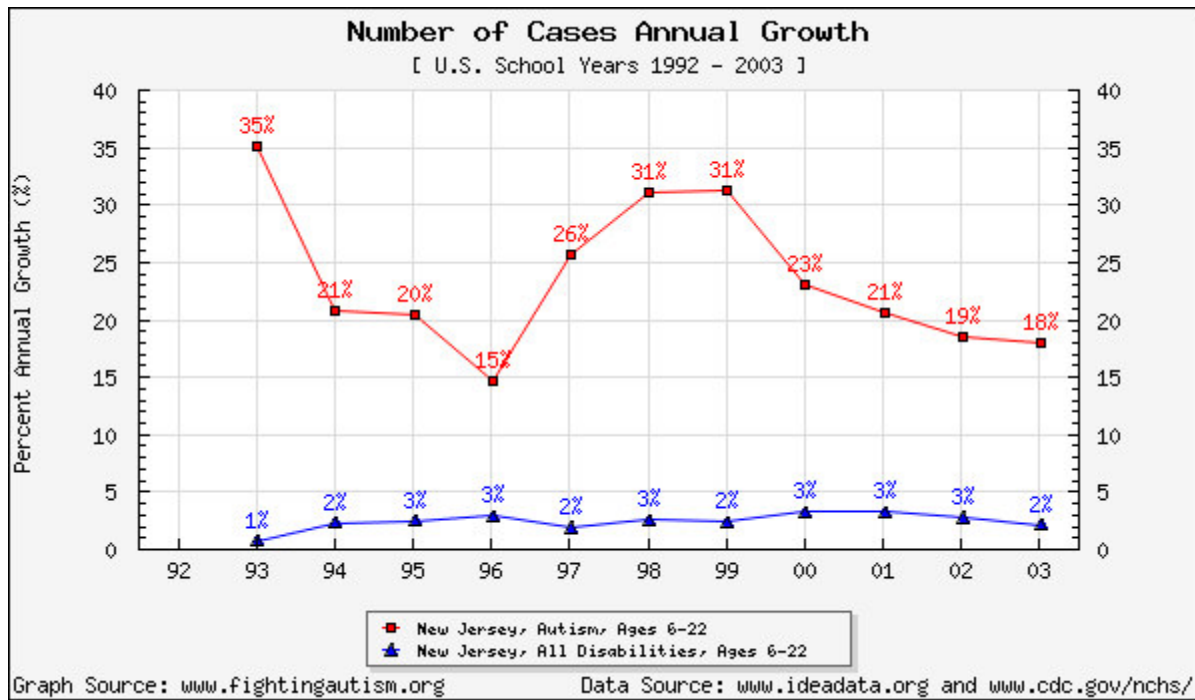


Figure 4 – Annual growth rate of the number of students with autism in New Jersey compared to the growth rate of all disabilities from 1992 to 2003.

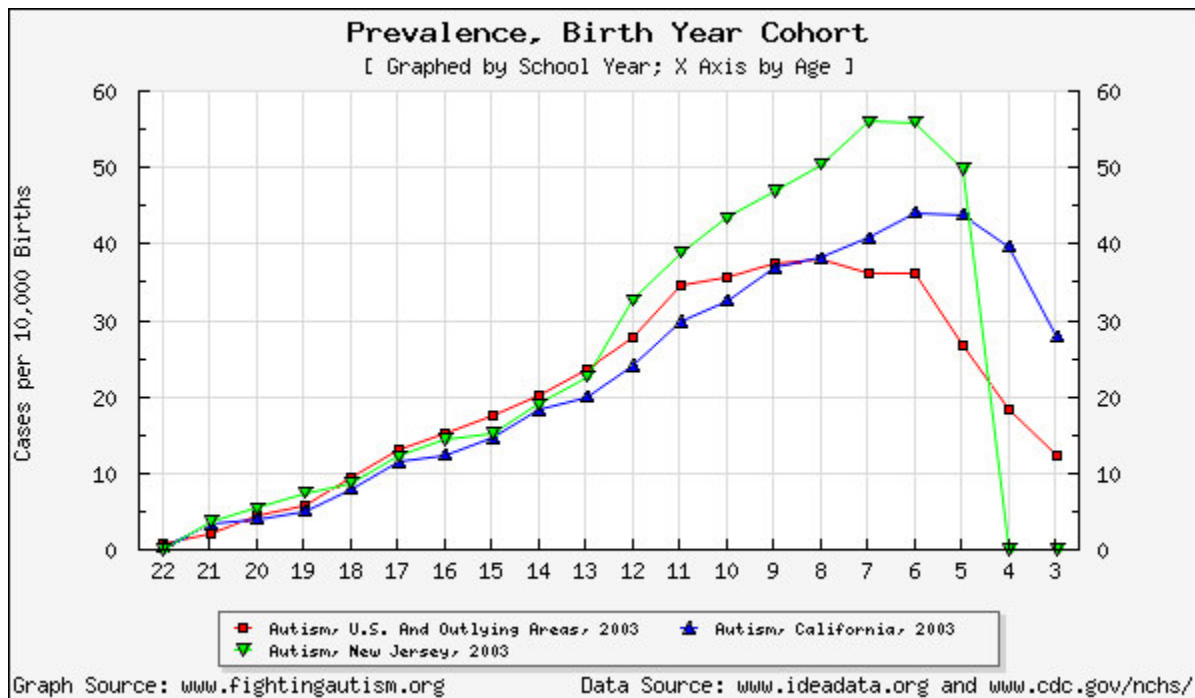


Figure 5 – Autism prevalence rate in New Jersey, CA and US for the 2003 school year. Not surprisingly, younger children (ages 3-7) have lower prevalence rates than older children since many young children have not yet have come to the attention of professionals.

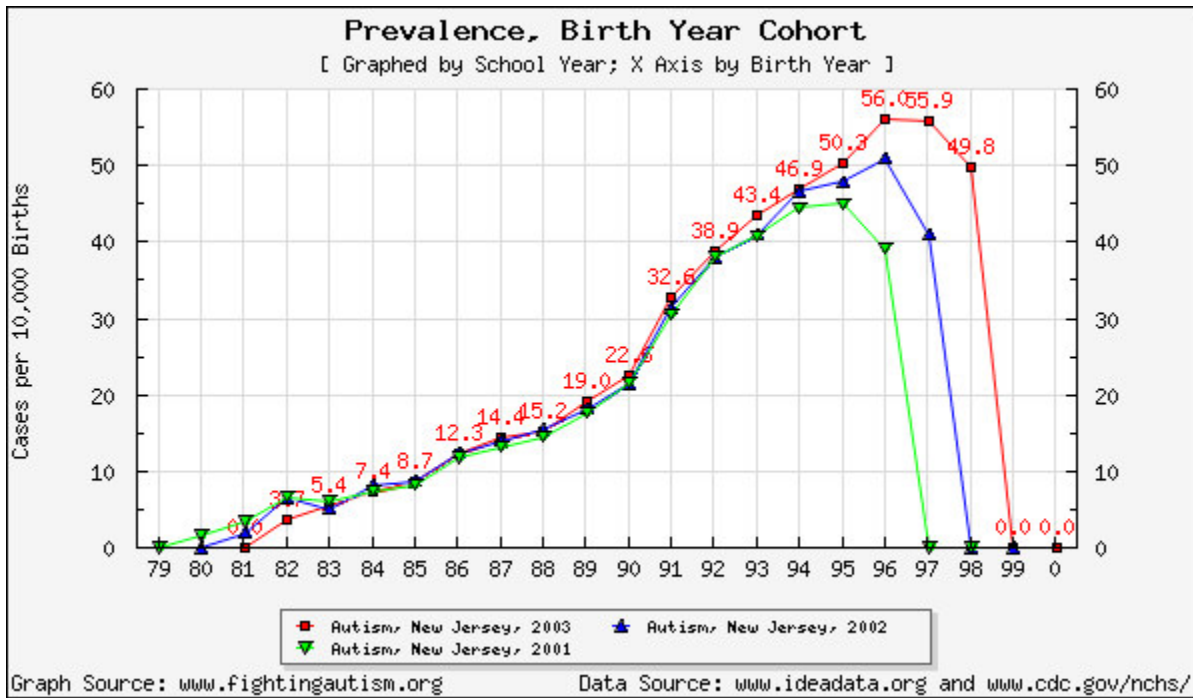


Figure 6 – Autism prevalence rate in New Jersey from 2000 to 2003. Each line represents the prevalence rate graphed by school year. Graph concept adapted from MF Blaxill. [9]

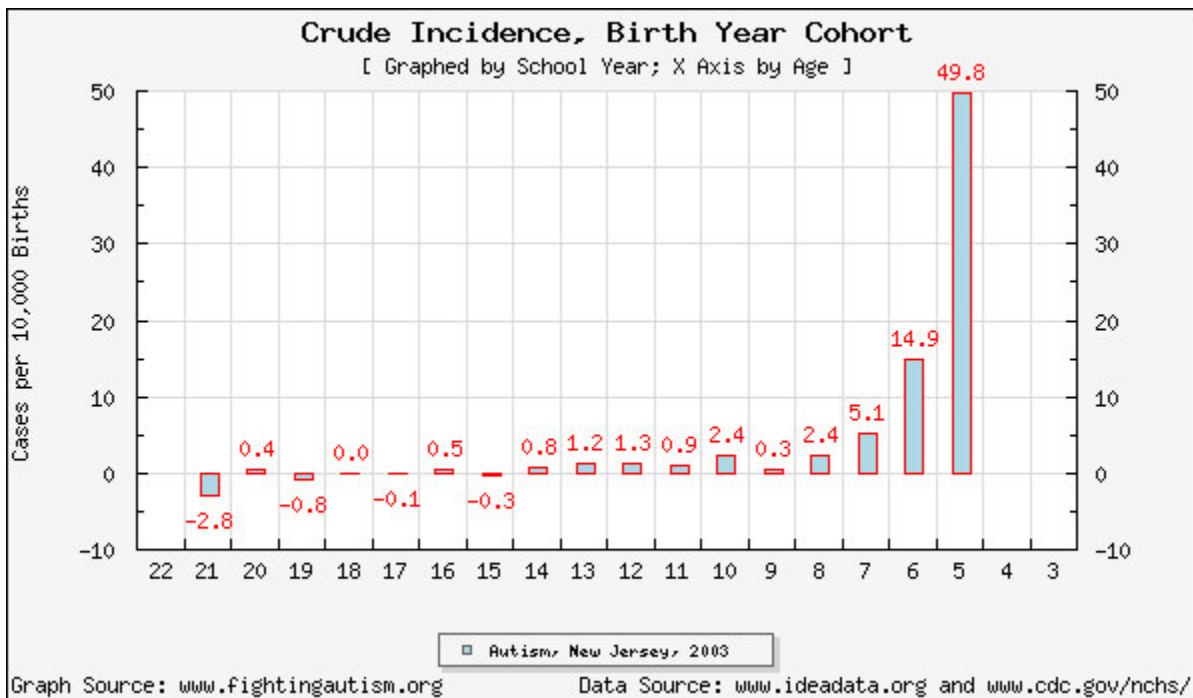


Figure 7 – Crude autism incidence rate age distribution in New Jersey. This figure is produced by taking two consecutive school year prevalence rates for all ages and subtracting them from one another, which produces the calculated incidence rate stratified by age for a specific school year. Notice that for most states the majority of the incidence rate is represented by the younger autistic children (ages 3-8).

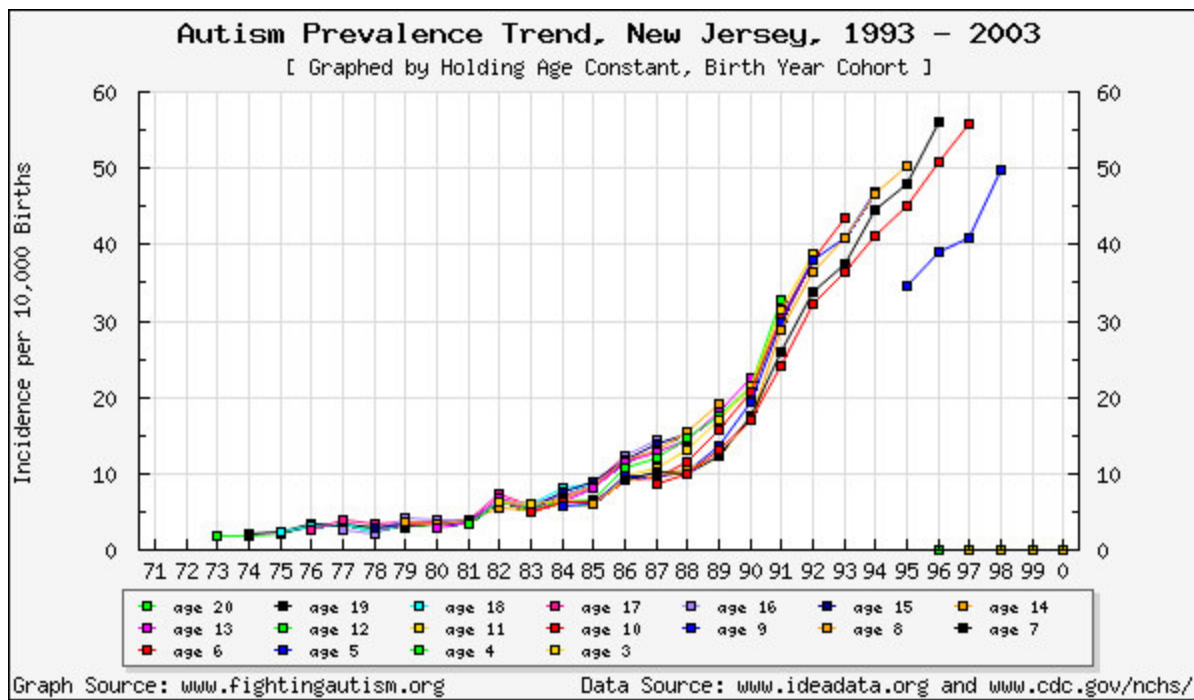


Figure 8 – Autism prevalence time trend by holding age constant in New Jersey. Each line represents a prevalence rate for a specific age group held constant over the past 11 years. By holding the age constant we can determine if the prevalence rate is changing over time for a specific age group. The left hand side of each line represents the prevalence rate in 1992. The right hand side of each line represents the prevalence rate in 2003. There are three short lines on the right side of the figure that represent ages 3-5. Data was first started to be recorded on ages 3-5 in 2000, therefore, these lines only represent the last 4 years. An upward slope of a line indicates that the prevalence rate is increasing. A downward slope of a line indicates that the prevalence rate is decreasing. The magnitude of the slope indicates the magnitude of the autism epidemic. Notice that the magnitude of the slope is greater for younger children (ages 3-10). If the cause of autism was identified and abated, you would expect to see lines for younger children to decrease in slope and slowly turn (hook) downward 4 to 7 years after abatement. Graph concept adapted from MF Blaxill. [9]

Limits on Interpretation of Results and Figures: States have different eligibility criteria for the autism disability category. As a result, the autism prevalence differs from State to State. The child count is a point-in-time count of students served. It is not a cumulative count of all students served throughout the school year. It is likely that States serve more students over the course of a school year than are served on a December 1 (or the last Friday in October). Variations in State data from year to year may be the result of policy changes such as revisions to the States' eligibility criteria for particular disabilities. States started to record the number of autistic students for ages 3-5 in 2000. In all trend calculations the 3-5 age group is excluded so as to not upwardly bias the trend results. Difficulty in recognizing autism in younger children (age < 5) can lead to ascertainment bias, which will lower the number of cases of autism, autism incidence and autism prevalence for specific birth years and ages < 5.

Methods: The IDEA child count data stratified by age, state and disability category was attained from the US dept of Education. The IDEA child count data set represents the six million children in the United States receiving public school special education services.[1] The birth year data was attained from the Vital Statistics of the United States 1970 through 2002, which is published by the U.S. Department of Health, Education, and Welfare.[2]The public school grade enrollment data was attained from the Common Core of Data of the National Center for Education Statistics.[3]

All three data sets combined to total a quarter million data points. The data was managed using MySQL [10], an open source database management system, running on a leased server located remotely in a data center on the internet. A special purpose graphing engine was developed to generate the figures using JpGraph [11], an open source software graphing library. All numerical results were calculated using PHP [12], an open source programming language. Development was done with MS Windows Notepad.

References:

1. Autism Disability Data Source: The Individuals with Disabilities Education Act (IDEA) requires each state and the U.S. Department of Education to record specific childhood disabilities including autism. This data can be requested from the U.S. Department of Education at the www.ideadata.org.
2. Birth Data (Nativity) Source: The birth year data was attained from the Vital Statistics of the United States 1966

through 2002, which published by the U.S. Department of Health, Education, and Welfare. It can be downloaded from the National Center for Health Statistics www.cdc.gov/nchs/.

3. Enrollment Data Source: The public school enrollment data was attained from the Common Core of Data of the National Center for Education Statistics. It can be downloaded from nces.ed.gov/ccd/bat/.
4. Blaxill MF. What's Going On? The Question of Time Trends in Autism. Public Health Reports, Nov-Dec 2004, Vol 119.
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About FightingAutism: To improve the quality of life for children with autism through research, education, advocacy and treatment. Research - Fostering scientific research to understand the underlying biological conditions of autism spectrum disorders. Education - Educating parents, scientists and healthcare professionals about autism treatment strategies through conferences, seminars and community fundraising events. Treatment - Creating a world-class autism treatment center in the greater Pittsburgh area encompassing biomedical treatments and opportunities to participate in clinical research studies.

Acknowledgement: *"For we are God's workmanship, created in Christ Jesus to do good works, which God prepared in advance for us to do."* Ephesians 2:10

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Hollenbeck, DF

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