

REPORTING OF AUTISM IN THE NEW JERSEY SPECIAL CHILD HEALTH REGISTRY PRIOR TO THE IMPLEMENTATION OF THE 2007 MANDATORY REPORTING LAW



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Overview

This brief provides an overview of Autism¹ in New Jersey by examining data from the Department of Health and Senior Services' Special Child Health Registry (SCHR) and the Department of Education (DOE). We also estimate the number of children that could potentially be registered to the Autism Registry.

Prior to the 2007 mandatory reporting law, Autism in New Jersey was a condition that did not require reporting to the SCHR. To date 2,360 children have been registered with the SCHR; however, we expect more children to be registered once the law's administrative rules become effective in July of 2009. The reporting of Autism has increased over time and the current SCHR data gives us some information about those who are currently registered:

- The rate of reported cases has fluctuated over the past 15 years but has sharply increased from 2002 to 2006, probably due to increased awareness of Autism.
- Children with Autism who were born between 1992 and 2006 were mostly male, white, and of normal birth weight.
- Between January 1985 and May 2009, most of the cases reported to the Registry came from Bergen, Camden, Essex, Gloucester, Hudson, Mercer, Middlesex, Monmouth, Ocean, and Passaic counties.

Considering only children enrolled in public schools in 2007, the New Jersey DOE data shows an overall rate of 2.29 per 1,000 children classified under the special needs category of Autism. Counties with the highest rates are Bergen, Burlington, Hudson, Mercer, Middlesex, Ocean, and Union. We believe this rate is low because many studies have shown that some children with Autism are classified under other categories of special needs.

Based on rates derived from a number of Autism studies, we estimate the number of children with Autism per age group will range from 438 to 1,195, with about 750 new cases per year estimated using the national rate of 1 in 150 children.

¹In this report, Autism is defined in accordance with the New Jersey administrative rules for the Autism Registry which defines Autism to include Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder -Not Otherwise Specified, Rett's Disorder, and Child Disintegrative Disorder. However, the Department of Education defines Autism administratively and not diagnostically and may or may not include the above-mentioned conditions.

Trends of Reported Autism in the Special Child Health Registry

Although not currently mandated, hospitals, case management units, and other facilities have voluntarily and with parental permission registered some children having Autism with the New Jersey Special Child Health Registry (SCHR). We examined this group of children using the following methodology:

- Diagnoses of Autism include Autistic Disorder (ICD-9: 299.00), Asperger's Syndrome (ICD-9: 299.80), Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (ICD-9: 299.90), and other Autism diagnoses which include ICD-9 codes 299.60, 299.10, 299.81, and 330.80.
- The years varied depending on the analysis. We noted the years used in each table and figure. When "all years" was used, it included those cases that were reported from January 1985 to May 2009.

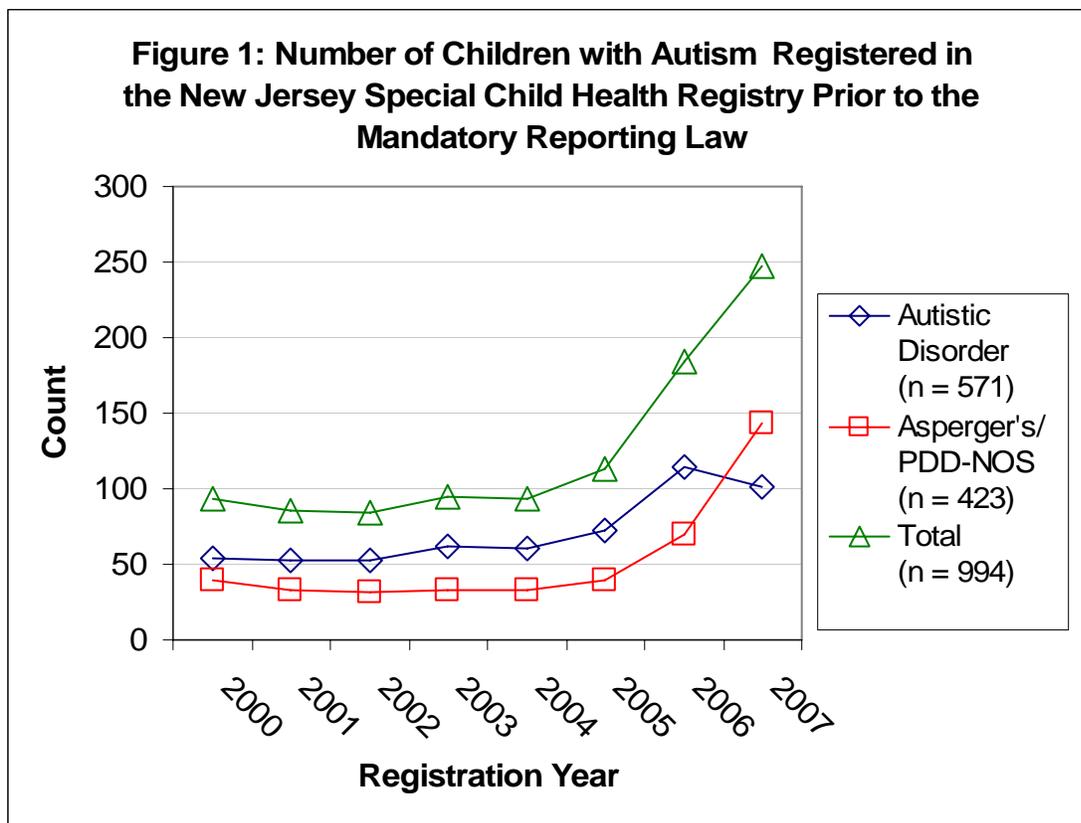
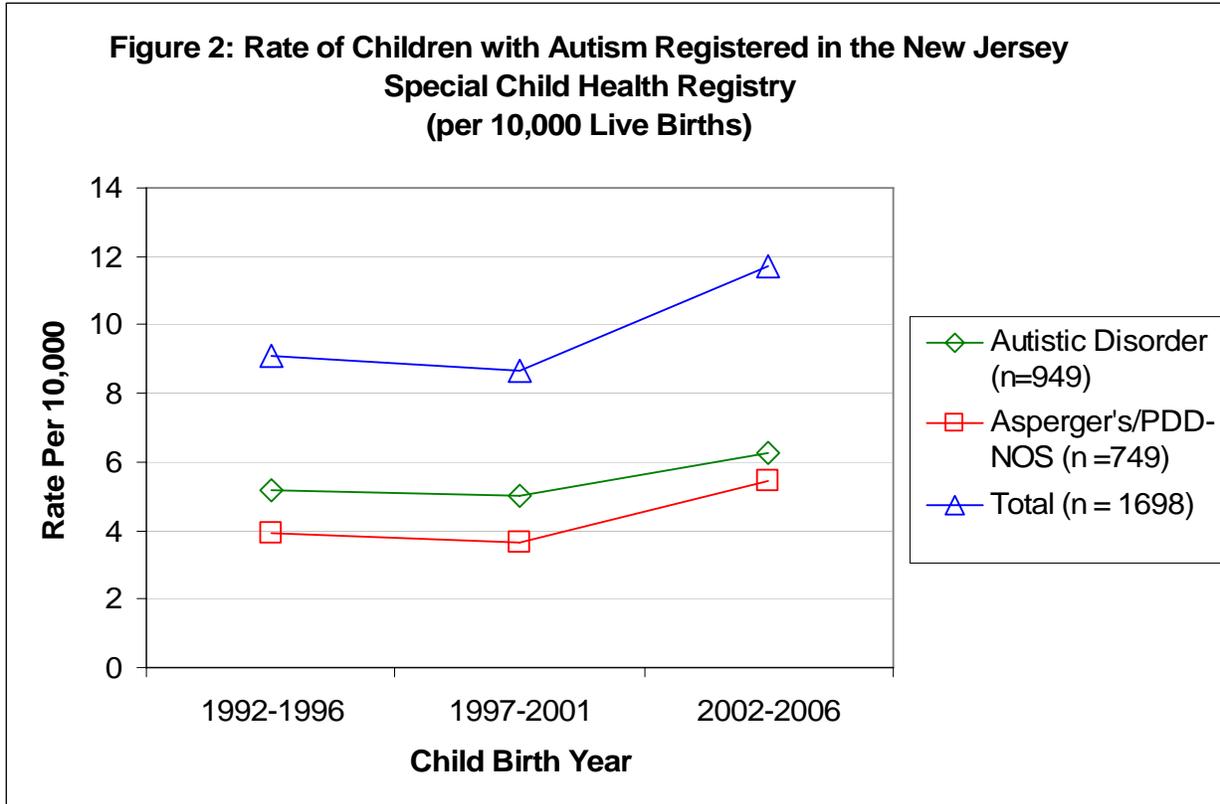


Figure 1 presents the rising numbers of reported cases of Autism in the SCHR. Reporting of Asperger's Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) increases much more dramatically than Autistic Disorder and by 2007 surpasses the reporting of Autistic Disorder. Reasons for this are unknown; however, it can be speculated that new cases of Asperger's Syndrome are more likely to be recognized later in a child's life (Barnard, Harvey, Prior, & Potter, 2001)¹ and therefore more likely to be reported by such agencies as county-based case management units who serve older children with special health

care needs and frequently report to the SCHR. The number of registrations may also have increased because of more awareness of Autism, and the introduction of a law to create an Autism Registry in New Jersey. The law was passed by the New Jersey Legislature and signed by Governor Corzine in 2007. These increases in reporting are seen in other states and the nation as well.

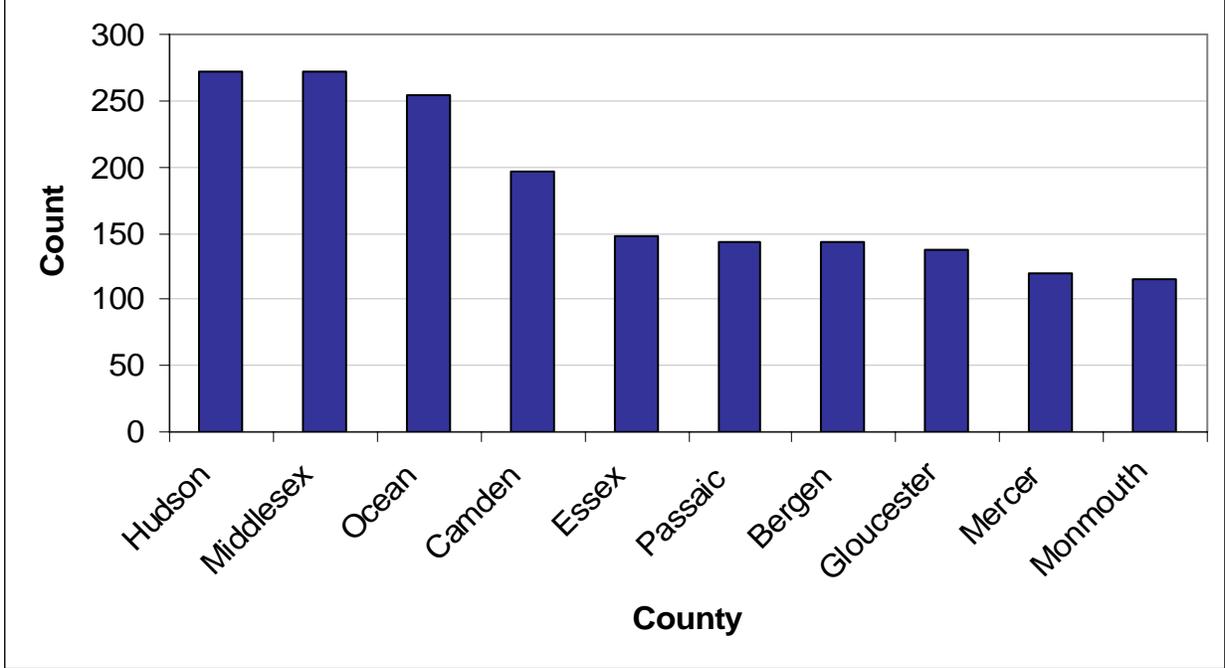


Examining the reporting trends of Autism by live births, we found that rates fluctuated over the 15 year span. Nevertheless, as noted in Figure 2, rates of Autism increased in the later years from 2002 and 2006, especially for Asperger’s Syndrome/PDD-NOS. It is interesting to note that trends rise even though reporting in the SCHR was voluntary prior to 2006 and not a complete representation of actual rates of Autism in New Jersey.

Reporting of Autism by County

Most counties have reported cases of Autism to the Special Child Health Registry; however, more cases were reported in some counties than in others. Figure 3 presents the 10 counties that had the highest number of reported Autism cases in the Registry between January 1985 and May 2009. Interestingly and probably not coincidental, three counties (Hudson, Ocean, and Essex) in this group were three of the four counties (excludes Union) that participated in the CDC Autism Developmental Disabilities Monitoring (ADDM) Network Project.ⁱⁱ This CDC study concluded that the rate of Autism in New Jersey is 10.6 per 1,000 children or 1 out of 94 children.

Figure 3: Counties With the Highest Number of Reported Cases of Autism in the New Jersey Special Child Health Registry: All Registration Years (January 1985 - May 2009) (Total for all Counties = 2360)



Characteristics of Children with Autism in the Special Child Health Registry

Children reported to SCHR as having Autism who were born between 1992 and 2006 were mostly male, white, and of normal birth weight (see Table 1). Black children were proportionately less represented in the Registry for all categories of Autism. Black children are 17.5% of all children born in New Jersey, but account for only 11.7% of the Autism cases reported to the Registry.

Table 1: Characteristics of Children and Youth with Autism in the New Jersey Special Child Health Registry: Birth Years 1992 to 2006 (n = 1732)

| | Autistic Disorder | | Asperger's / PDD-NOS | | Other | | Total | | New Jersey Live Births |
|---------------------------------|-------------------|------|----------------------|------|-------|------|-------|------|------------------------|
| | N | % | N | % | N | % | N | % | % |
| Race^a | | | | | | | | | |
| White | 664 | 70.0 | 566 | 75.6 | 3 | 79.4 | 1257 | 72.6 | 70.7 |
| Black | 116 | 12.2 | 88 | 11.7 | 4 | 11.8 | 208 | 12.0 | 17.5 |
| Other ^b | 169 | 17.8 | 95 | 12.7 | 3 | 8.8 | 267 | 15.4 | 11.8 |
| Hispanic | | | | | | | | | |
| Any Race | 229 | 24.1 | 143 | 19.1 | 3 | 8.8 | 375 | 21.7 | 19.6 |
| Sex | | | | | | | | | |
| Male | 753 | 79.4 | 623 | 83.2 | 7 | 20.6 | 1383 | 79.9 | NR |
| Female | 196 | 20.7 | 126 | 16.8 | 27 | 79.4 | 349 | 20.1 | NR |
| Birth weight (in grams) | | | | | | | | | |
| 300 to 1,000 | 12 | 1.3 | 7 | .9 | 0 | 0.0 | 19 | 1.1 | NR |
| 1,001 to 1,500 | 13 | 1.4 | 35 | .7 | 1 | 2.9 | 19 | 1.1 | NR |
| 1,501 to 2,500 | 56 | 5.9 | 47 | 6.3 | 4 | 11.8 | 107 | 6.2 | NR |
| 2,501 to 4,500 | 540 | 56.9 | 471 | 62.8 | 22 | 64.7 | 1033 | 59.6 | NR |
| 4,501 & over | 15 | 1.6 | 9 | 1.2 | 0 | 0 | 24 | 1.4 | NR |
| Unknown | 313 | 33.0 | 210 | 28.0 | 7 | 20.6 | 530 | 30.6 | NR |

^aIncludes both Hispanic and Non Hispanic Individuals

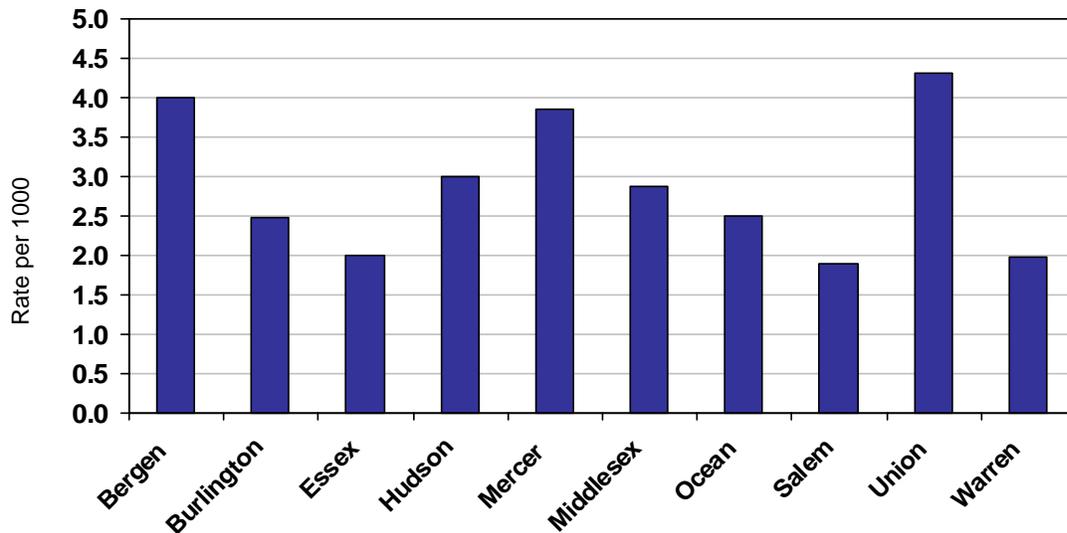
^bCategory includes all other races such as Native American, Pacific Islander, and Asians.

NR= Not Reported

New Jersey Department of Education Autism Classification Data

Data from the New Jersey Department of Education (DOE) is often used to describe Autism within and across states. These data, however, have reliability and validity issues that make them unsuitable to accurately estimate the true number of children with Autism, but are often used to describe “administrative prevalence” or the total number of children with Autism. Administrative prevalence means that children are grouped into the category that best fits their diagnosis or need for services. For example, not all children with Autism are classified under the Autism category; they may be classified under the speech or the developmental delay category depending on the services they receive. In previous Autism prevalence studies, about 90% of children diagnosed with Autism were classified as special needs, however, only about 50% were under the category of Autism (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2000 Principal Investigators, 2007; Bertrand, et.al., 2001; Bertrand Yeargin-Allsopp, et al., 2003; Van Naarden Braun, et al., 2007).ⁱⁱⁱ Being classified under different categories was especially true in the 1990’s when autism was first introduced as a category (Shattuck, 2005);^{iv} however, in later years, more children were classified under the Autism category. Autism may also be defined differently within each state so some states will include children that would not be classified in other states. The increase in administrative Autism prevalence was also significantly associated with corresponding decreases in the prevalence of mental retardation and learning disabilities. This “category shift” is commonly seen when a new category is added. This shift was also seen when the Traumatic Brain Injury and Developmental Delay categories were introduced (Newschaffer et al., 2005).^v

Figure 4: 2007 Rate of Children with Autism per 1000 Publically Enrolled School Children by County in New Jersey



Data source: NJ Dept of ED: Office of Special Education Programs; 2006/2007 Enrollment Data

State Rate= 2.29 per 1000

Recognizing the limitations of the New Jersey DOE public school enrollment data, we see the rates of children aged six to 21 classified with Autism within individual New Jersey counties for 2007 (Figure 4). While Autism is typically diagnosed by age three and schools provide services for children from three to five, the number of children is much smaller and does not include many children who are not enrolled in public school programs. Overall, the State rate is 2.29 per 1,000 children, and the counties with the highest rates are Bergen, Burlington, Hudson, Mercer, Middlesex, Ocean, and Union.

Estimating the Prevalence of Autism in New Jersey and the Potential Enrollment to the Autism Registry

While the data we have on Autism in the Special Child Health Registry and the New Jersey Department of Education provides some information about Autism in New Jersey, the creation of the Autism Registry (mandating the reporting of Autism for children through the age of 21) will yield better estimates of the true number of children with Autism in New Jersey and will provide important information that can be used to better plan for services for those children. Based on various Autism studies, we are able to estimate the number of children per age group that we expect to register. Table 2 presents three estimates for the cohort of eight year olds in 2006. The three rates include the commonly referenced rate of 1 in 150 children, CDC's ADDM estimate of 1 in 94, and the New Jersey DOE estimates for the age group six to 21.

Table 2: Estimates of Number (per birth cohort) and Rate of Children with Autism in New Jersey Based on Previously Established Prevalence Estimates and the 2006 total population of 8 year olds (n = 112,368)

| | 1 in 150 Commonly Accepted National Rate | 1 in 94 ADDM Study-New Jersey Rate | 1 in 256 DOE Classified under Autism* |
|-----------------------|---|---|--|
| Number | 749 | 1195 | 438 |
| Rate per 1,000 | 6.7 | 10.6 | 3.9 |

*Based on Department of Education (DOE) data for children in Public School Districts & Charter Schools classified under the special needs category of Autism.

Since the Registry will include newly diagnosed as well as previously diagnosed children, we expect to receive more registrations than we normally would during the initial years of the Registry. Once the Registry includes those previously diagnosed, we expect to register between 750 and 1,200 newly diagnosed children per year. The importance of the mandatory registry can be seen in the magnitude of the children with Autism in New Jersey. The Registry will provide much more accurate estimates of the true number of children with Autism in New Jersey. Given the difference in the number of children enrolled in public school under the Autism category and the estimated number based on the research, we can see how important it will be to get these children registered and properly referred to early intervention and case management services. Since the main purpose of the Registry will be to ensure that children with Autism are offered appropriate services as early as possible, it is important that children are registered as soon as they are diagnosed. In this way, the Registry will provide valuable information needed to plan and provide services to New Jersey children with Autism.

ⁱBarnard, J., Harvey, V., Prior, A., & Potter, D. (2001). *Ignored or ineligible? The reality for adults with autistic spectrum disorders*. London: National Autistic Society.

ⁱⁱAutism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators. (2007). Prevalence of Autism Spectrum Disorders- Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2000. *MMWR*. Vol 56 (SS-1) 12-28.

ⁱⁱⁱAutism and Developmental Disabilities Monitoring Network Surveillance Year 2000 Principal Investigators. (2007). Prevalence of Autism Spectrum Disorders- Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000. *MMWR*. Vol56 (SS-1) 1-11.

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators. (2007). Prevalence of Autism Spectrum Disorders- Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2000. *MMWR*. Vol 56 (SS-1) 12-28.

Bertrand, J., Mars, A., Boyle, C., Bove, F., Yeargin-Allsopp, M., & Decoufle, P. (2001). Prevalence of Autism in a United States Population: The Brick Township New Jersey, Investigation. *Pediatrics*. Vol 108 (5) 1155-1161.

Bertrand, J., Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of Autism in a US Metropolitan Area. *JAMA*. Vol 289 (1) 49-55.

Van Naarden Braun, K. et. al. (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators). (2007). Evaluation of a Methodology for a Collaborative Multiple Source Surveillance Network for Autism Spectrum Disorders-Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2000. *MMWR*. Vol 56 (SS-1) 29-39.

^{iv}Shattuck, P. (2005). The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education. *Pediatrics*. Vol 117 (4) 1028-1037.

^vNewschaffer, C., Falb, M., & Gurney, J. (2005). National Autism Prevalence Trends from United States Special Education Data. *Pediatrics*. Vol 115(03) e277-282.