



NEW JERSEY AUTISM REGISTRY

In 2009, New Jersey created the Autism Registry to better understand the prevalence of autism or Autism Spectrum Disorders (ASD)¹ and the needs of children and their families. The Registry came about in part due to the Centers for Disease Control and Prevention's (CDC) 2002 Autism and Developmental Disabilities Monitoring (ADDM) study which showed that New Jersey had a higher than expected prevalence rate of autism. Prior to the ADDM study, the rate of autism was thought to be approximately 1 in 150 children; however, the 2002 rate for the four counties included in the New Jersey study showed a rate of 1 in 94 children born in 1994 had autism. The rate climbed to 1 in 57 in 2006, 1 in 49 in 2008, 1 in 46 in 2010, and 1 in 41 in 2012. The latest CDC's New Jersey ADDM report for 2014 shows the prevalence of autism is now 1 in 34 and continues to be higher than other states' study sites (Baio, 2018).

To understand the increasing rate of autism in New Jersey, this brief will provide:

- An overview of the New Jersey Autism Registry,
- Key findings from the Registry data,
- A comparison of the Registry's prevalence rates to the New Jersey ADDM study, and
- Risk factors that might be influencing New Jersey's autism rate.

Overview of the New Jersey Autism Registry

Registrations are submitted by licensed health care providers who either diagnose or follow² children with autism, and are required for all children who are:

- 0 to 21 years of age,
- Residents of New Jersey, and
- Diagnosed with an Autism Spectrum Disorder.

As a public health surveillance state law:

- Every child must be represented in the Registry,
- Parental consent is not required; however, parents can request that their children are registered anonymously, and

¹ The diagnosis of Autism Spectrum Disorder (ASD) was defined by the Diagnostic and Statistical Manual Version 5 in 2013. (American Psychiatric Association, 2013). The terms "autism" and "ASD" are used interchangeably to refer to the spectrum of autistic disorders which includes ASD and the previously used diagnostic terms: Autistic Disorder; Asperger's Syndrome; Pervasive Developmental Disorder-Not Otherwise Specified; Rett Disorder; and Childhood Disintegrative Disorder.

² Follow means to provide a medical home such as general pediatric services. This ensures that children diagnosed before the law was enacted or out-of-state are registered.

- The information is confidential and highly protected.

Once registered, all families are linked to Case Management Services in their respective county of residence except those registered anonymously. Case Managers provide referrals to important resources and help in locating programs. Children under three years of age are also linked to Early Intervention Services.

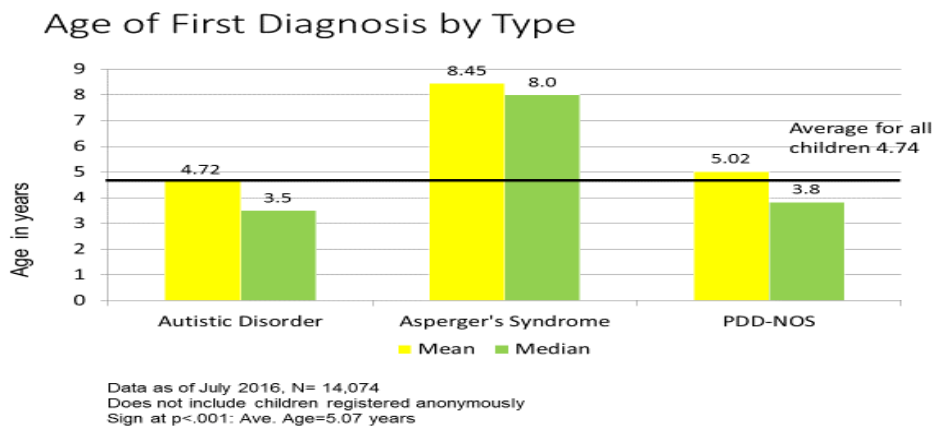
Registry data are also used to assist policy-makers such as program staff and legislators plan for services. The aggregate data provide policy-makers with a deeper understanding regarding the needs of the population as well as factors that may be associated with the prevalence of autism such as geographic factors, birth characteristics, and other known and potential risk factors.

Key Findings from the Registry data

As of January 2018, over 28,000 children in New Jersey have been registered with an ASD. This makes the New Jersey Autism Registry the largest mandated registry in the country.

So, what has been learned?

The average age of being diagnosed with an ASD is approximately four years and nine months old. The age of diagnosis is important because receiving a diagnosis is often a first step in treatment. As it may take time to schedule an evaluation by a specialist, many children may already be receiving Early Intervention Services for developmental delays before being formally diagnosed.³ Additionally, there are many differences in the presentation of symptoms that affect when children receive an ASD diagnosis. For instance, children who are diagnosed with Asperger’s Syndrome are often diagnosed much later than children diagnosed with Autistic Disorder.

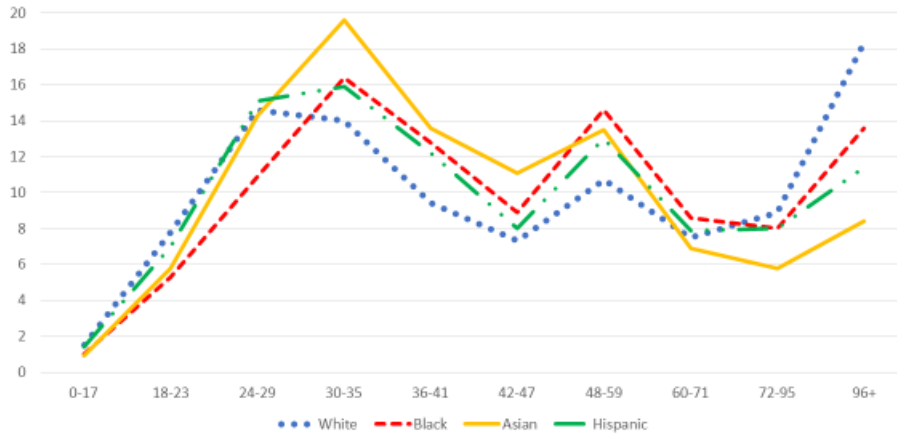


³ http://nj.gov/health/fhs/autism/documents/autism_registry_early_intervention_analysis.pdf

While there are no significant racial or ethnic differences in the likelihood of being registered by their health care provider, there are significant differences between all racial and ethnic groups in terms of when children are first diagnosed with autism. Age of diagnosis is considered in two ways: average age of diagnosis and looking at the distribution of age of diagnosis. Since Asperger’s Syndrome is typically diagnosed later as discussed above, only data for children with Autistic Disorder and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) are included in the analysis.

Looking at the averages, White non-Hispanics (NH) children are older (5.4 years) than all other groups at age of first diagnosis. Black NH children (4.9 years) were more likely to be older than Hispanic children (4.6 years), and Asian children (4.1 years) at the time of first diagnosis. As seen in the figure below, however, there are three age periods when children are mostly likely to be diagnosed. The first is between two and three years of age. During this time Black NH and Asian children seem to be diagnosed later than White NH and Hispanic children. The second peak is between four and six years of age. White NH children have a lower peak probably because they were already diagnosed between 24 and 29 months or are more likely to be diagnosed at the later peak of age of eight.

Race/Ethnicity by Age at First ASD Diagnosis

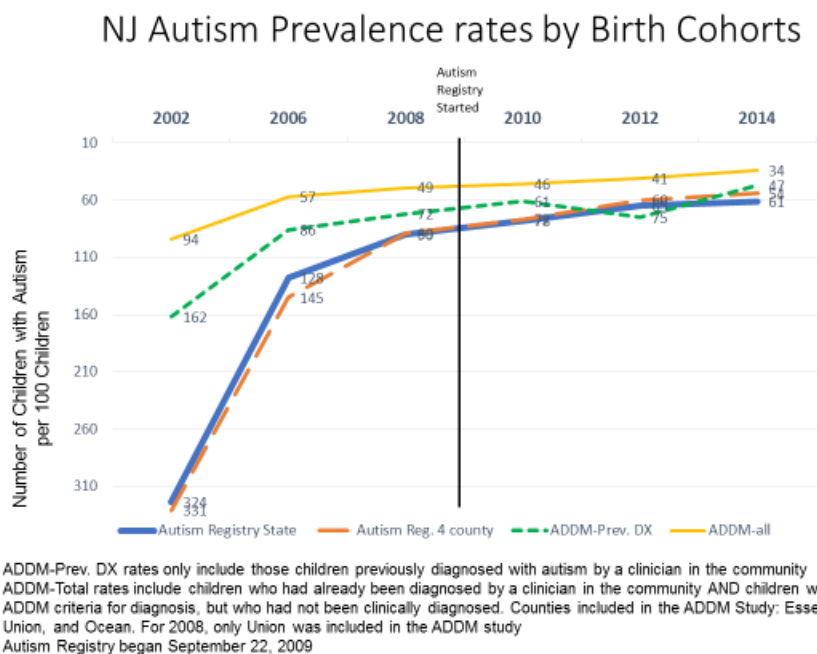


- Only Autistic Disorder and PDD-NOS
- Data as of July 2016, N=16921
- Sign. at p<.001

A comparison of the Registry to the New Jersey ADDM study

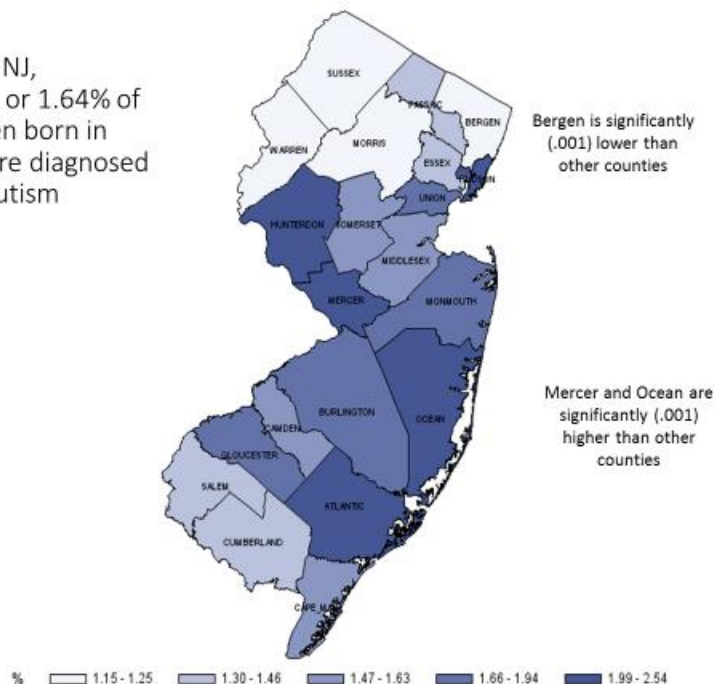
While the New Jersey Autism Registry relies on health care providers to register children whom they diagnose or treat, the CDC’s ADDM study uses a combination of children’s school records (i.e., Special Education evaluations) and health care records. Four counties--Essex, Hudson, Ocean, and Union Counties--are included in the NJ ADDM study. Each study period follows a

birth cohort of eight-year-olds. For instance, the 2014 study period included only children born in 2006. The following figure compares the Registry's rates for the entire state and the four counties that are included in the CDC's NJ ADDM study. Additionally, the ADDM rates for the 2006 birth cohort are presented in two ways. The "ADDM-All" rates include children who have been formally diagnosed with an autism as well as those who DO NOT have a previous autism diagnosis, but who meet the study criteria of autism. Since the rate of having a previous diagnosis varies by year from 58% to 81%, the figure also shows the "ADDM- Prev. DX" rates which are based only on previously diagnosed children. As the Registry is based on diagnosed children submitted by health care providers, the Registry rate should be compared to the ADDM- Prev. DX rate. Since the Registry began in September 2009, the prevalence rates for those four counties is comparable to the rates of previously diagnosed children in the NJ ADDM study. Children diagnosed prior to 2009 are being registered since they fall within the age range; however, they are typically registered by primary care providers rather than their diagnosticians.



Looking more closely at the entire state, the autism prevalence rate for children born in 2006 appears to be significantly lower in Bergen County (1 in 87), but significantly higher in Mercer (1 in 41) and Ocean (1 in 39) Counties. While the remaining 18 counties have varying rates, these rates are not statistically different from one another. The low rate in Bergen county may be attributable to children being diagnosed in neighboring New York than to a true lower rate; however, when looking across multiple birth cohorts (1996, 1998, 2000, 2002, and 2004), Bergen county appears to consistently demonstrate lower rates. Hunterdon, Mercer, and Ocean counties appear to be significantly higher in multiple birth years.

Across NJ,
1 in 61 or 1.64% of
Children born in
2006 are diagnosed
with Autism



Risk factors that might be impacting New Jersey's autism rate

So, why does New Jersey seem to have higher autism rates than other states participating in the CDC's ADDM studies? One reason is that New Jersey has very good diagnostic services, and therefore, more children are getting evaluated and referred for services than in areas where diagnostic services are scarce. Another reason is that New Jersey's population may have higher rates of some of the known risk factors of autism such as prematurity, low birth weight, being a twin or triplet, and advanced maternal age. Of course, these risk factors are not independent of each other. For instance, pre-term babies typically have lower birth weights. Multiples tend to be born early, at lower birth weights, and to older mothers.

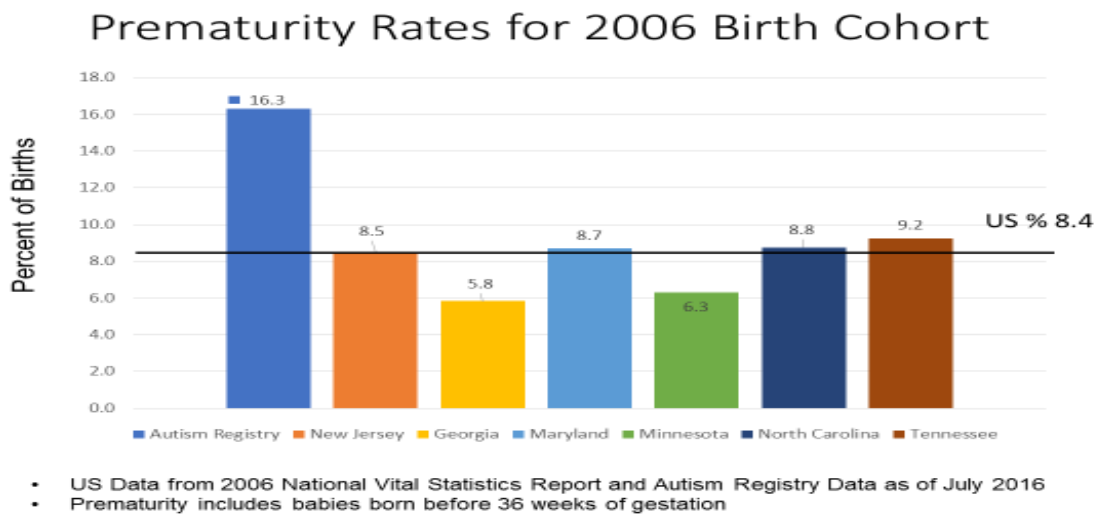
To see the potential impact of these risk factors, the following figures show how New Jersey's 2006 birth cohort compares to five states that also participated in the 2014 ADDM study (based on children born in 2006). Additionally, the Registry data are included to show the prevalence of these risk factors within the children registered for autism, while the United States (US) rates are also included as a comparison point.

Since approximately 80% of the autism cases were found in school records, it is critical to compare states that had complete access to school records. New Jersey (1 in 34), Georgia (1 in 59), North Carolina (1 in 57), and Tennessee (1 in 64) had access to both health and education records. Tennessee is the only state in the comparison whose rate was below the mean autism rate of (1 in 59) across the 2006 ADDM network.⁴ Although Maryland (1 in 50) and Minnesota

⁴ US Department of Health and Human Services/Centers for Disease Control and Prevention, MMWR/April 27, 2018 / Vol. 67 / No. 6

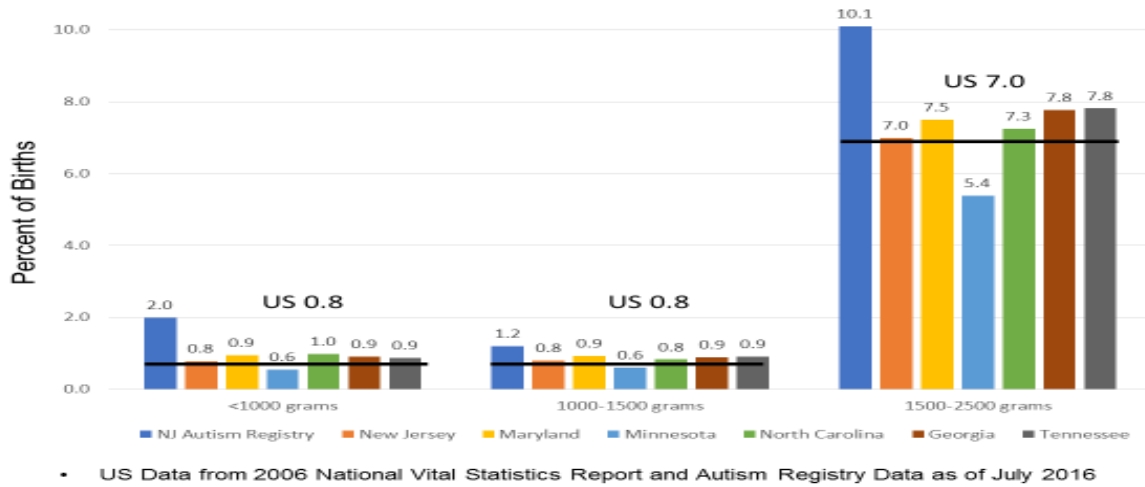
(1 in 42) had incomplete school access and a smaller study population, they also had relatively high rates of autism and are, therefore, included in the comparison.

Across the US, 8.4 percent of babies are born before 36 weeks of gestation. In the figure below, 16.3% of children in the Autism Registry were born before 36 weeks. Comparing New Jersey to other ADDM states, most states are close to the national average; however, Georgia and Minnesota seem to have much lower rates of prematurity, while Tennessee has higher rates of prematurity.



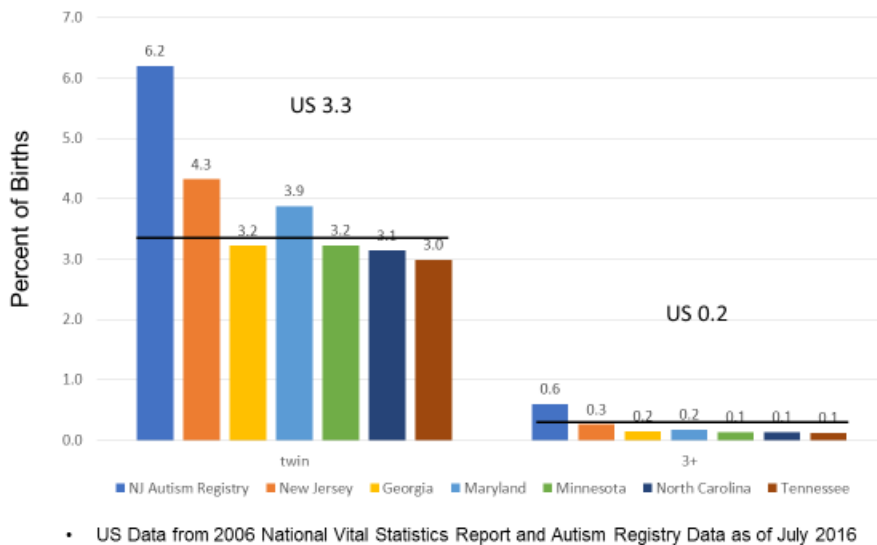
Another risk factor to be considered is birth weight. Birth weight is divided into three categories: less than 1000 grams; 1000 to 1500 grams; and 1500 to 2500 grams. Again, children in the Registry were more likely to have lower birth weights compared to the total population in New Jersey and across the US. Comparing the ADDM states, there appears to be little difference between the states including Tennessee which has lower autism rates.

% of Babies born with Low Birth Weight in 2006



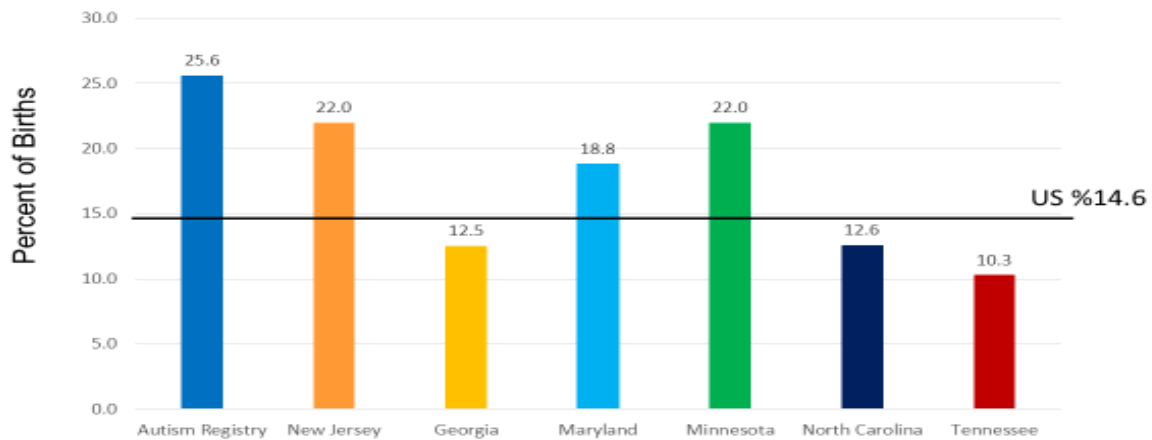
Being a multiple (twin or triplet) is also a risk factor for autism. The national rate of being a twin is 3.3% and being a triplet (or more) is only 0.2%. In the Registry, 6.2% of children are twins and 0.6% are triplets (or more). Overall, New Jersey and Maryland have higher percentages of twins than the US or other ADDM states.

Birth Plurality of Children born in 2006



While not independent of the other risk factors, children born to a mother of advanced maternal age (35 and over) is considered a risk factor. In the US, about 14.6% of mothers are aged 35 or over. In the Registry, 25.6% of children are born to mothers aged 35 or over. New Jersey, Maryland, and Minnesota all have higher percentages of older mothers. Interestingly, Tennessee which had a lower autism rate in the ADDM study, has only 10.3% of older mothers.

% of Births to Mothers aged 35 and over



- US Data from 2006 National Vital Statistics Report and Autism Registry Data as of July 2016

Understanding why New Jersey seems to continue to show high rates of autism is not clear cut. The New Jersey Autism Registry data indicate that New Jersey's population exhibits higher rates of all four risk factors. Specifically, New Jersey seems to have relatively higher rates of twins and triplets as well as mothers 35 and over than other states who participated in the CDC's ADDM study. These population characteristics, along with a vast network of diagnostic services, provide a clearer understanding of New Jersey's autism prevalence compared to other states that have been studied.

The New Jersey Autism Registry continues to examine other risk factors and provide more information for improved policy and planning of services such as the prevalence of comorbidities that may require intensive supports. As more is known about the prevalence of risk factors and ultimately potential causes of autism, the New Jersey Autism Registry will continue to provide a clearer understanding as to why New Jersey appears to have higher rates than other studied states.