NEW JERSEY AUTISM REGISTRY SHOWS INCREASING PREVALENCE AMONG HISPANIC CHILDREN

Introduction

While national autism rates are valuable for guiding policy on a national level, they may not be as meaningful as state-level data (Brodert-Fingert, et.al. 2018.) Even within the <u>CDC's Autism and</u> <u>Development Disability Monitoring Network (ADDM) study</u>, there are wide differences in prevalence between the states. Methodology and documentation vary from state to state, and specific prevalence trends in one state may not appear in other states.

New Jersey's autism prevalence rates are monitored in two ways. First, New Jersey has participated in the <u>ADDM</u> studies since its inception in 2006. The <u>New Jersey ADDM study</u> examines medical and school records for children in four counties (Essex, Hudson, Ocean and Union). Secondly, the <u>New Jersey</u> <u>Autism Registry which</u> began in 2007 in response to the original ADDM rates requires that all New Jersey resident children with Autism Spectrum Disorder (ASD) be registered. Today, more than 32,000 children have been registered.

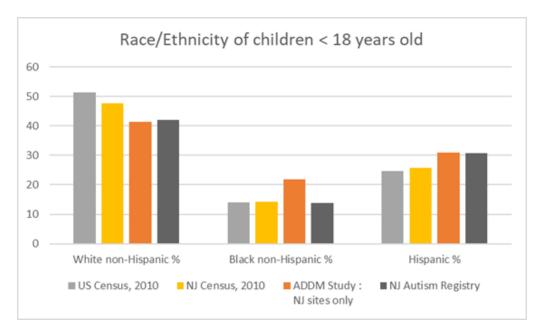
New research using recent the <u>ADDM</u> data and U.S. Department of Education under the Individuals with Disabilities Education Act (IDEA) data suggest that in a third of states (including New Jersey) autism rates among Hispanic and black children are now exceeding the rates for their white counterparts (Nevison and Zahorodny, 2019.)

Since the Autism Registry is statewide, it provides an important resource for estimating county and local rates, comparing autism rates across several demographic indicators, and provides a deeper examination as to why New Jersey has exhibited such high rates. Therefore, the New Jersey Autism registry data were examined to better understand the changes in autism rates by race and ethnicity for children born between 2000 and 2010.

Trends in New Jersey Autism Population Trends by Race

Comparing the percentage of children under age 18 by race in the general population of the United States, New Jersey, and the NJ ADDM study sites, the chart below shows that:

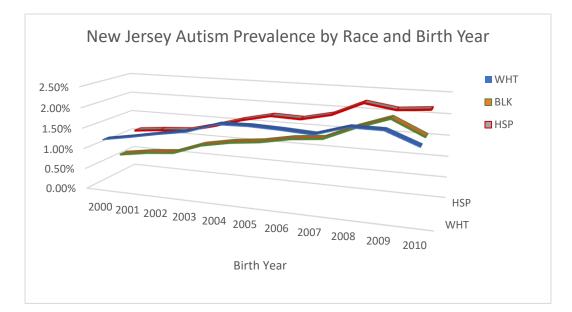
- Compared to the national and state populations, fewer white children are represented in the NJ ADDM study
- The number of black children was similar in the US and New Jersey but was higher in the NJ ADDM sites.
- The percentage of Hispanic children is higher in the NJ ADDM study and the New Jersey Autism Registry than in the NJ and US general populations



Trends in Autism Prevalence Over Time

An examination of the Autism Registry data shows significant differences by race over time. The rates of autism increase over time for all race/ethnic groups increases. These rates mirror the increases found in the CDC ADDM study. In the ADDM study, the Autism Rates as seen in the figure below examines 8-year olds born between 2000 and 2010 regardless of their age at diagnosis. In general, Autism Registry data show:

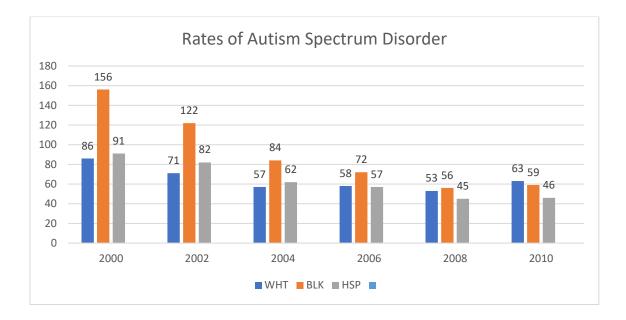
- Total ASD prevalence climbed from 1.1% in 2000 to nearly 2.0% in 2009
- Total prevalence leveled off slightly to 1.9% in 2010
- For rate for white children born between 2000-2004 climbed steeply, plateaued for those born between 2004 and 2007, then increased again for children born after 2007
- The rate for Black, Hispanic, and Asian children started lower and did not appear to plateau.



Compared to white children, ASD prevalence in children of other races increased more quickly. Whereas black and Asian ASD prevalence estimates were previously significantly lower than the estimates for white children, the data now shows that among children born in 2009-2010, the prevalence rates for black and Asian children are not significantly different.

Autism prevalence for Hispanic children born in 2000 was close to their white counterparts at 1 in 91 and 1 in 86 respectively. Over time, the prevalence rates for both groups have increased; however, the rates for Hispanic children overtook the rates for White children beginning with children born in 2007. Similar to other studies, the rate for white children seemed to plateau for those born between 2004 and 2007. However, Hispanic children born in 2008 and 2010 had significantly higher autism rates (1 in 46) compared to white non-Hispanic children (1 in 63).

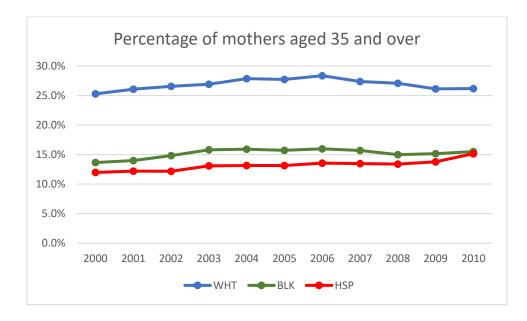
Below is another look at Autism Registry data showing prevalence by race between 2000-2010.

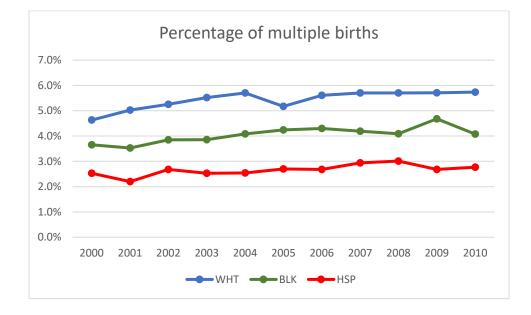


Examining the rise of autism among Hispanic Children

To better understand the rise of these rates, we reviewed four known risk factors of autism: advanced maternal age, low birth weight, plurality, and gestational age. Children with autism have significantly higher rates of these risk factors compared to the total NJ population. To address the rise of the Hispanic rates, and the rates in general, we examined the rate of these risk factors for all children born in NJ. For instance, if being born prematurely increases a child's likelihood of having autism, then if more children are born prematurely, then more children will be at risk for having autism. Therefore, such risk factors were examined by birth cohort and reviewed to determine whether these risk factors rose faster for the Hispanic population than other groups. If the percent of Hispanic children with these risk factors remained stable over time, then this could explain the raise of autism among Hispanic children.

The percentages of mothers over 35 years and multiple births were steady over the years across racial groups. It seems that those risk factors could not explain the different growth rates of Autism. Further research is needed to pinpoint the difference of Autism growth rates among racial groups.





Conclusion

What do prevalence trends tell us about the rates of autism among different racial and ethnic groups?

Research that has focused on lower-than-expected autism prevalence rates among non-white populations have attributed the difference to factors such as language barriers, negative cultural perceptions of autism and poor access to health care.

When studies showed a rise in Hispanic and Black autism rates, the increase was credited to a "catchup" due to elimination of barriers through better community outreach, increased access to healthcare and better availability of culturally appropriate diagnostics services. These efforts seem to explain increases in Hispanic prevalence in other states and might have initially explained the continued increase in New Jersey's black and Hispanic populations in the mid-2000s, even while white prevalence plateaued.

This may be due to New Jersey's early adoption of policies and practices to ensure children are screened early for developmental concerns and evaluated without delay if autism is suspected. In addition, the New Jersey Early Intervention System provides timely evaluations and offers a robust array of services for any child experiencing developmental delays.

However, it is unclear why the rate of autism among the Hispanic population in New Jersey is increasing at a faster than the other groups. Known perinatal risk factors did not explain the different growth rates of Autism. Further research is needed to pinpoint the difference of Autism growth rates among racial groups.

The Autism Registry continues to be an important resource to identify unique trends such as the increase in Hispanic ASD prevalence in New Jersey and will continue to report on trends and will continue to consider potential explanations for this change.

For more information about the Registry and publications on registry data, visit <u>https://www.nj.gov/health/fhs/autism/</u>.

References

¹Nevison, C. and Zahorodny, W. (2019) Race/ethnicity-resolved time trends in United States ASD prevalence estimates from IDEA and ADDM. *Journal of Autism and Developmental Disorders*, <u>https://doi.org/10.1007/s10803-019-04188-6</u>

² Brodert-Fingert, S. Sheldrick, C. and Silverstein, M. (2018) The value of state differences in autism when compared to a national prevalence estimate. *Pediatrics*, <u>https://doi.org/10.1542/peds. 2018-295</u>