# New Jersey Autism Registry Shows Increase in Autism Prevalence Among Hispanic Children

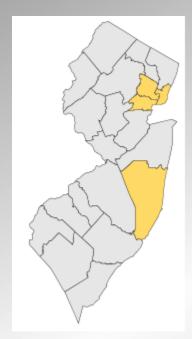Data from the New Jersey Autism Registry By Race, Birth Years 2000 to 2010

# Introduction

- National autism rates are valuable for guiding policy on a national level, but may not be as meaningful as state-level data (Brodert-Fingert, et. al. 2018)

- Studies show wide differences in prevalence between states, even within the CDC's Autism and Development Disability Monitoring Network (ADDM) study

- Methodology and documentation vary from state to state, and specific prevalence trends in one state may not appear in other states

# How New Jersey Monitors Autism Prevalence Rates

ADDM: Essex
Hudson
Ocean and
Union
Counties

NJ Autism
Registry: All
Counties

New Jersey monitors autism prevalence in two ways:

The New Jersey ADDM Study
- Examines medical and school records for children in four counties (Essex, Hudson, Ocean and Union)
- New Jersey has participated in the ADDM study since its inception in 2006

The New Jersey Autism Registry
- 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 statewide have been registered

NJ Health
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# Autism Prevalence by Race

- New research using the ADDM data and the 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.)

# Monitoring Autism Prevalence by Race in New Jersey

- 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.

- 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.
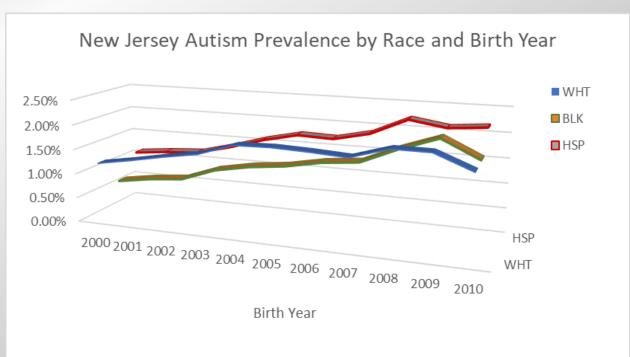
# NJ Autism Prevalence Rates Over Time
# Birth Years 2000-2010

An examination of the Autism Registry data show significant differences by race over time. The rates of autism increase over time for all race/ethnic groups.

These rates mirror the increases found in the CDC ADDM study. In keeping with the ADDM study, the autism rates as seen in the figure examines 8-year-olds born between 2000 and 2010 regardless of their age at diagnosis.

- Compared to white children, ASD prevalence in children of other races increased more quickly

- Whereas black 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 children are not significantly different.

- Autism prevalence for Hispanic children born in 2000 was close to their white counterparts. Over time, prevalence rates for both groups have increased but 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 compared to white non-Hispanic children



New Jersey Autism Prevalence by Race and Birth Year

# NJ Autism Prevalence Rates Over Time
# Birth Years 2000-2010

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

- The 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 and Hispanic children started lower and did not appear to plateau

# Changes in New Jersey Autism Prevalence by Race
Birth years 2000 and 2010 (per 1,000 Children)

Birth Year 2000

White: 12 children per 1,000

Black: 6 children per 1,000

Hispanic: 11 children per 1,000

Birth Year 2010

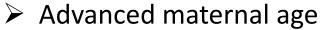White: 19 children per 1,000

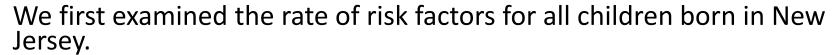Black: 17 children per 1,000

Hispanic: 22 children per 1,000

Source: New Jersey Autism Registry, 2019

# Examining the Rise of Autism Among Hispanic Children

To better understand the rise of autism rates, we studied four known risk factors.  Children with autism do have significantly higher rates of these risk factors compared to the total New Jersey population:

- ➢ Advanced maternal age
- ➢ Low birth weight
- ➢ Plurality/multiple birth
- ➢ Gestational age (i.e. prematurity)

We first examined the rate of risk factors for all children born in New Jersey.

In particular, we wanted to test if these risk factors rose faster for the Hispanic population than other groups.
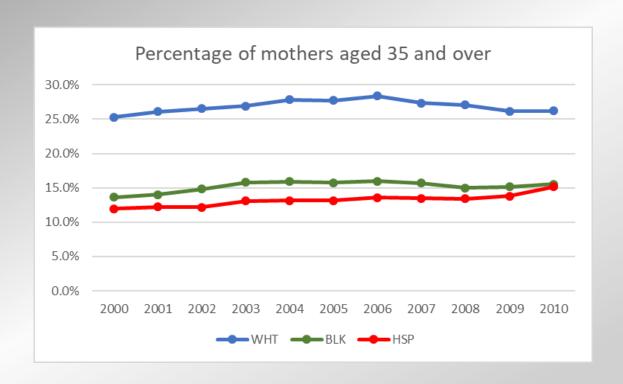
If the percent of Hispanic children with these risk factors increased, and the percent of children with these risk factors remained stable over time, then this could explain the rise of autism among Hispanic children.
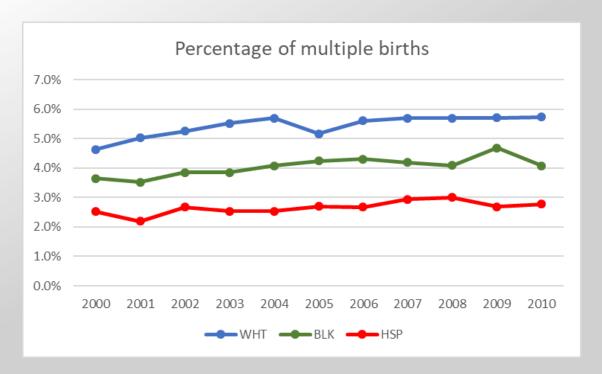
# Two Known Risk Factors Excluded as Potential Causes

A look at two known risk factors – mothers over age 35 and multiple births showed that the percentages for both groups were steady over the years across racial groups. It seems that those risk factors could not explain the different growth rates of autism.

# Understanding New Jersey's Prevalence Trends

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

- Poor access to health care

It is unclear why the rate of autism among the Hispanic population in New Jersey is increasing faster than other groups.

# Understanding New Jersey's Prevalence Trends

- When studies showed a rise in Hispanic and Black autism rates, the increase was credited to a "catch-up" 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 all children are screened early for developmental concerns and evaluated without delay if autism is suspected.

- Known perinatal risk factors did not explain the different growth rates of autism among racial groups. Further research is needed to pinpoint what may be causing the difference.

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# Monitoring Prevalence in New Jersey

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 potential explanations for the change.

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

In addition, the New Jersey Early Intervention System provides timely evaluations and offers a robust array of services for any child experiencing developmental delays.

# References

[1] Nevison, 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,* https://doi.org/10.1007/s10803-019-04188-6

[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*, https://doi.org/10.1542/peds. 2018-295