Prevalence and Disparities in the Detection of Autism Without Intellectual Disability

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Bottom line up front:

The expression of autism may have changed over time. Past studies have shown that many children identified with autism also have intellectual disability. Our findings show that 2 in 3 children identified with autism do not have intellectual disability. Autism rates have increased from 2000-2016 in the Metropolitan New York-New Jersey region; however, the increase was not equally distributed. While we observed a 2-fold increase in prevalence estimates for autism with co-occurring intellectual disability, estimates increased 5-fold for autism without co-occurring intellectual disability. Our findings also reveal disparities in identification of autism without co-occurring intellectual disability among underserved populations. Non-Hispanic Black children and children residing in socially disadvantaged regions were less likely to be identified with autism without co-occurring intellectual disability compared to Non-Hispanic White children and children residing in economically affluent regions, respectively.



Key Findings:

 From 2000-2016, autism prevalence estimates increased 3-fold from approximately 1% in 2000 to 3% in 2016 in the New York-New Jersey Metropolitan Area.

• Children identified with autism without intellectual disability grew at a faster rate (5-fold increase) compared to children identified with autism and intellectual disability (2-fold increase).

Approximately 2-in-3 children identified with autism do not have intellectual disability.



• Non-Hispanic Black children were 30% less likely to be identified with autism without intellectual disability compared to Non-Hispanic White children.

- Children residing in affluent areas were 80% more likely to be identified with autism without intellectual disability compared to children residing in underserved regions.
- Male to female ratio among children with autism and intellectual disability was *slightly lower* than among children with autism and no intellectual disability.



Key Messages:

Even in a metropolitan area with abundant resources and services, disparities in autism identification among historically disadvantaged populations remain. Innovative strategies are needed to improve identification of autism without intellectual disability among these populations.

Autism rates in the New York-New Jersey Metropolitan area likely reflect rates in other metro areas. While the study shows a 3-fold increase overall in autism rates, we expect autism estimates to continue to rise as disparities in identification are addressed.

Universal autism screening before 36-months with improved linkage to care is needed to identify children with autism early, and also likely to have the greatest effect on children from underserved communities.

Study Data:

This study used cross-sectional data from an active surveillance system developed by the CDC called Autism and Developmental Disabilities Monitoring (ADDM) Network. New Jersey has been part of the ADDM Network since its inception back in 2000 and has completed 7 cycles of surveillance tracking autism prevalence among 8-year-olds in the same region, using the same case definition and methodology.