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BRIEF REPORT



Community testing practices for autism within the autism and developmental disabilities monitoring network

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A commentary based on this manuscript appears on pages 432-434.

Abstract
Background: No data exist at the population level on what tests are used to aid in the diagnosis of autism spectrum disorder in community practice.
Objectives: To describe autism spectrum disorder testing practices to inform autism spectrum disorder identification efforts.
Methods: Data are from the Autism and Developmental Disabilities Monitoring Network, a multi-site surveillance system reporting prevalence estimates and characteristics of 8-year-old children with autism spectrum disorder. Percentages of children with autism spectrum disorder who received any autism spectrum disorder test or a ‘gold standard’ test were calculated by site, sex, race, median household income, and intellectual ability status. Risk ratios were calculated to compare group differences.
Results: Of 5058 8-year-old children with autism spectrum disorder across 11 sites, 3236 (64.0%) had a record of any autism spectrum disorder test and 2136 (42.2%) had a ‘gold standard’ ADOS or ADI-R test. Overall, 115 children (2.3%) had both the ADOS and ADI-R in their records. Differences persisted across race, median household income, and intellectual ability status. Asian/Pacific Islander children had the highest percent receiving any ASD test (71.8%; other groups range: 57.4–66.0%) and White children had the highest percent receiving ‘gold standard’ tests (46.4%; other groups range: 35.6–43.2%). Children in low-income neighbourhoods had a lower percent of any test (62.5%) and ‘gold standard’ tests (39.4%) compared to medium (70.2% and 47.5%, respectively) and high (69.6% and 46.8%, respectively) income neighbourhoods. Children with intellectual disability had a lower percent of any ASD test (81.7%) and ‘gold standard’ tests (52.6%) compared to children without intellectual disability (84.0% and 57.6%, respectively).
Conclusions: Autism spectrum disorder testing practices vary widely by site and differ by race and presence of co-occurring intellectual disability, suggesting opportunities to standardise and/or improve autism spectrum disorder identification practices.

KEYWORDS
ADI-R, ADOS, autism spectrum disorder, diagnosis, gold standard, public health surveillance



1 | BACKGROUND

Autism spectrum disorder (ASD) is characterised by impairments in social communication and restricted or repetitive behaviors.¹ Diagnosis is based on evaluating a child's behaviour and development. No definitive diagnostic test or biomarker exists, but the ‘gold standard’ in ASD diagnosis is considered to be an evaluation by a multidisciplinary clinical team and is often, but

Synopsis

Study question
How many children diagnosed with autism spectrum disorder have autism spectrum disorder tests in their health or education records?

