

VIEWPOINT

## Autism Spectrum Disorder in Lower Socioeconomic Communities



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Given that reports place the costs of supporting individuals with autism spectrum disorder (ASD) throughout their lifetime at a staggering \$2.4 million, there is concerted interest in understanding the condition's epidemiological underpinnings.<sup>1</sup> The understanding of autism's epidemiology has morphed considerably over time, moving from a belief that ASD is a condition of the affluent towards an increasing recognition that ASD is equally common in individuals of low socioeconomic status (SES) and, in fact, often goes underdiagnosed in that population. Given the complex relationship between SES and a likelihood of an ASD diagnosis, a thorough review of studies concerning the epidemiology of ASD, particularly as it relates to socioeconomic status, is useful.

In the 1960s, two decades after Leo Kanner's seminal case series first introduced autism in the scientific literature, researchers considered autism a condition that disproportionately affected those from higher socioeconomic backgrounds. This perspective was fueled by the era's epidemiological studies, which consistently found higher rates of autism in higher socioeconomic areas. It was only decades later that researchers began to recognize bias implicit in such studies: carried out through surveys of families receiving services in treatment centers, the studies overlooked the significant population of individuals with ASD not presenting in the centers. The reports of the 1960s may have been a consequence of barriers hindering the identification of cases from lower socioeconomic communities rather than an actual socioeconomic association as this untreated population arose disproportionately from individuals of lower so-

cioeconomic status.<sup>2</sup> This trend is not unique to autism: similar biases have been found to underlie reported etiological differences among socioeconomic and racial groups in other conditions as well. Until a few decades ago, for instance, the prevailing view was that persons of lower socioeconomic status or of color were less susceptible to anorexia nervosa; this belief prevented physicians from considering the condition in the differential diagnosis of these patients and thus led to inaccurate measures of disease prevalence.

It was not until 2005 that researchers showed that bias in the process of diagnosing ASD likely confounded previous inquiries on the socioeconomics of autism. Larsson et al carried out a prospective, population-based, case-control study of 698 individuals with autism in Denmark, which has a uniformly organized and comprehensive health care system, providing an ideal setting for such demographic research on the socioeconomics of autism. Low parental wealth was actually associated with an increased risk of autism, but there was no statistically significant association between maternal education and likelihood of autism diagnosis.<sup>3</sup> Despite this finding, recent studies in the United States showed that earlier age of ASD diagnosis is significantly predicted by higher maternal education,<sup>4,5</sup> and even mean education level of the child's neighborhood.<sup>4</sup> Interestingly, a 2006 case-control study of 601 individuals with autism in the Metropolitan Atlanta Developmental Disabilities Surveillance Program found that when those with autism were divided into groups with and without mental retardation, only the autism group without mental

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retardation showed a significant association between higher socioeconomic status (quantified by higher median family income and higher maternal education) and likelihood of an ASD diagnosis. These findings may demonstrate the presence of ongoing barriers to patient identification in lower socioeconomic groups. It may be that while more severe autism presentations are broadly detected, “milder” cases—those unaccompanied by mental retardation—are more likely to go undiagnosed in patients from lower socioeconomic communities than in patients of higher SES, given differential access to health services and differing levels of awareness.<sup>2</sup> Such a trend would explain why the association between socioeconomic status and autism prevalence was found only in individuals with ASD without mental retardation. Indeed, research shows that barriers to diagnosis are especially intensified in non-English speaking families. In a California study of 267 primary care physicians, 81% offered some form of developmental screening in Spanish, but that number dropped to 29% when screening for ASD was measured, and only 10% offered both general developmental and ASD screening in Spanish. As such, underdiagnosis of exclusively Spanish-speaking patients seems highly likely.<sup>6</sup>

In sum, it appears that the historic correlation between autism rates and socioeconomic status is more the product of differing access to treatment and diagnosis than that of any true etiological roots. Larsson *et al.*'s findings suggest that when differential access to treatment is controlled for, ASD does not discriminate across varying socioeconomic groups, although our diagnoses of ASD and distribution of appropriate therapies certainly may, with barriers in evaluation leading to delays in diagnoses and receipt of appropriate therapeutic resources.<sup>7</sup>

Despite increasing recognition of the prevalence of ASD in disenfranchised communities, the danger that socioeconomic bias will interfere with diagnosis remains high, particularly given differences in treatment accessibility. It is imperative that community pediatricians, who stand at the front lines of caring for socioeconomically disenfranchised children, watch closely for the potential emergence of ASD. Earlier identification of these patients, which allows for commencement of early intervention behavioral therapies, leads to better outcomes.<sup>8</sup> Without appropriate diagnosis, parents of these children may well think that their child with ASD is merely mis-

behaving and become increasingly frustrated with their failing to meet developmental milestones. In practical terms, nuanced diagnosis can be incredibly difficult due to the competing pressure of high patient volume, but it is crucial, given that timely diagnosis by a thorough pediatrician in these cases may make the difference between parents helping and hindering their child's development.

In addition to taking special care not to overlook ASD in patients with low SES, pediatricians should also carefully attend to their families, as additional education and support might be required to ensure understanding of the diagnosis, particularly in non-English speakers. Antiquated notions of autism may be culturally bound; parents may believe the diagnosis is a result of their parenting and may also view the diagnosis as completely negative, without appreciating the potential for strengths in addition to limitations in those with ASD. Even once these families better understand the medical diagnosis, the pediatrician needs to shepherd them to appropriate resources and referrals because major barriers often stand between individuals of low socioeconomic status and such services. Referrals may be made to the Autism Response Team, a recently developed bilingual resource program that supports both English- and Spanish-speaking families through obtaining an appropriate diagnosis and subsequent services.<sup>9</sup> It may also be useful to work with colleagues in child and adolescent psychiatry for specialized treatment and to help integrate the medical care of these children with the development of their individualized educational plans through the school system.

When it comes to families potentially impacted by ASD, the advocacy component of our role as physicians cannot be overstated. Recent research has shown that autism is just as prevalent in low SES communities but is more vulnerable to being overlooked and untreated. In order to effect the early intervention and structured care necessary for a positive outcome, we must remain vigilant to the danger of bias in diagnosis. Further, as the trend of underdiagnosis of patients of lower socioeconomic status is far from unique to autism, we should keep in mind how our clinical work with patients with ASD has the potential to shape broader systems of bias: ASD treatment may perpetuate socioeconomic inequalities, or it may serve as a model for more equitable medical care.

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