



Examining Autism Prevalence: What Factors Play a Role in its Increase?

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Since the original formal diagnostic classification of autism spectrum disorder (ASD) in the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III; American Psychiatric Association, 1980), its prevalence has increased dramatically. A study published several years prior to publication of the DSM-III estimated that approximately 1 in 2,500 individuals had ASD (Wing, Yeates, Brierley, & Gould, 1979), while the most recent estimate posits 1 in 59 individuals with ASD in the United States (Baio et al., 2018). While a true increase in the incidence of ASD over this time period cannot be ruled out, several other factors have played a role in the observed increase in its prevalence.

First, with the exception of the DSM-IV-R (American Psychiatric Association, 2000), changes in the diagnostic criteria for ASD since its formal introduction in 1980 have been made in each revision of the DSM (DSM-III-R, DSM-IV, DSM-5). These changes have led to an increase in the number of individuals who meet criteria for ASD. In a study re-examining epidemiological data from the DSM-III era, Miller et al. (2013) found that 59 percent of individuals from the sample who originally did not meet criteria for ASD based on the DSM-III now met the criteria for ASD based on the DSM-IV.

Developmental screening recommendations by the American Association of Pediatrics (AAP) have also likely played a role in increasing rates of ASD diagnosis (Centers for Disease Control and Prevention, 2019). As early as 2004, the

AAP's Autism Expert Panel proposed a tool called A.L.A.R.M. (Autism is prevalent; Listen to the parents; Act early; Refer; Monitor), which served to establish the first standard early screening practices (Johnson, 2004). Based on evidence that ASD could reasonably be diagnosed between 12-18 months, the AAP released a policy statement in 2006 establishing developmental surveillance at every preventive care visit as best practice. A year later, this policy was revised to include a provision for routine ASD screening at 18 and 24 months (Earls & Curry, 2011). Implementing these policy changes served not only to identify those at risk for ASD among the general population, but also to help inform the trajectory of treatment planning for the child and family.

Finally, changes in criteria for qualification for special education related to ASD also occurred since its inclusion in the DSM-III. In 1991, ASD became a distinct categorical educational disability, with criteria for qualification similar to but separate from the applicable DSM diagnostic criteria. In addition to changes in medical diagnostic criteria and special educational qualification, increased knowledge and awareness of ASD has almost certainly affected the prevalence rates of ASD due to diagnostic substitution and accretion, increased availability of services, and changes in public perception and community inclusion.

If, as the evidence suggests, prevalence rates of ASD seem to be rising more due to these extrinsic factors, rather than reflect a significant increase in actual incidence, why should these numbers matter? Unfortunately, as the number of individuals formally diagnosed with ASD has increased, the cumulative costs associated with ASD have also risen. It is estimated that the societal cost for a typical individual with ASD totals \$3.2 million over the lifespan, including service costs and lost wages (Ganz, 2007). Further, it has been demonstrated that costs increase as an individual gets older, often with greater reliance on more restrictive and expensive services, and decreased use of lower cost and less restrictive services (Cidav, Lawer, Marcus, & Mandell, 2013). More importantly, the support needs of these individuals are commonly not being met, restricting their access to community participation and diminishing their quality of life (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013; Shattuck, Orsmond, Wagner, & Cooper, 2011).

About the Authors

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