

Income-related Disparity in Diagnosis and Service Utilization of Autism Spectrum Disorder

Introduction

Autism Spectrum Disorder (ASD) is a class of neurodevelopmental disorders that manifests during the onset of life and leads to impaired behaviors and interactions.^{1, 2} There has been a tremendous increase in the prevalence of ASD over the past 3 decades, from approximately 7% in 2000 to the current 19%.³ The rising prevalence is largely attributed to the increasing awareness of ASD, improvements in screening processes, and changes in policies related to ASD.⁴ Although there is no cure for children diagnosed with ASD, ASD treatment, especially at an early age, can significantly improve the functionality, general health, and quality of life of diagnosed children.⁵ Treating ASD through behavioral treatment is expensive and time-intensive.⁶ However, behavioral treatment is arguably the most effective approach and has high rates of success.⁷ Medicaid and private insurance have made great progress in providing care access to ASD patients via Medicaid ASD coverage and autism private insurance mandates.⁸

Race-related disparity in ASD diagnosis and/or access to care is well documented. In a 2000-2010 study, researchers found that the ASD prevalence ratios in 2002 for Non-Hispanic Whites, Non-Hispanic Blacks, and Hispanics were 6.7, 5.9, and 3.9 per 1000 respectively.⁹ Moreover, in a composite analysis of 2006, 2008, and 2010 survey data, the ASD prevalence ratios for Non-Hispanic Whites, Non-Hispanic Blacks, and Hispanics were 13.2, 11.1, and 8.0 per 1000 respectively.⁹ As follows, not only is there disparity in ASD prevalence between races, but disparity between the prevalence ratios between different years. Such differences may be influenced by a multitude of factors, including income and care access. However, little is known about income-related disparity in ASD diagnosis and access to care. Though some studies have included income as a factor in explaining the ASD diagnosis, the income variable is not a focal variable. No in-depth information nor specific patterns surrounding the income effect can be revealed or discovered when it is not a central variable.⁹

It is important to examine the income-related disparity in ASD diagnosis and service utilization for several reasons. First, it helps resource allocation and contributes to timely diagnosis of children with ASD. If low income is associated with a lower likelihood of diagnosis, then more resources should be allocated to low-income areas to ensure early diagnosis. Second, service utilization to ASD care may be income-dependent. Though the hard-fought insurance coverage has guaranteed most children the right to ASD care, the actual service utilization of ASD care can be a great challenge due to the difficulty of navigating the healthcare system and the scarcity of ASD care providers.¹⁰ In 2011-2014, 29% of children diagnosed with ASD faced one or more healthcare access problems, including failure to find an appointment, difficulty affording needed healthcare, and trouble finding a care.¹⁰ Knowledge of income-related disparity in service utilization of ASD care can inform the autism community on how to assist low income families in securing services for their children with ASD. Third, knowledge of this income-related disparity can help predict future ASD prevalence and future demand for ASD services. Moreover, overall changes in prevalence and service demand may be highly dependent on how fast low income families can receive diagnoses and services that match high income families in the future.

Race and income are highly related variables. In the United States, Non-Hispanic Whites tend to have higher income than Blacks or Hispanics. Of the children with ASD that are Non-Hispanic White, 17.3% live in an area of poverty. The same statistic has been derived for Blacks and Hispanics, with 57.2% and 48.8% living in areas of poverty, respectively.⁹ However, it is important to draw the distinction between the income factor and the race factor. Sometimes, it can be that both racial and economic factors are key factors, such as in the case of lower dietary quality in American Americans compared to Asian Americans. This disparity can be due to both racial/cultural differences in the ingredients of cuisine as

well as income differences that determine the access to better quality food (could not find a reference). Other times, it is the economic factor rather than the seemingly racial or genetic factor that is at play. For example, the high blood lead levels in Blacks are not derived from a higher genetic susceptibility to lead exposure but from the lower income level posing a higher risk of lead exposure (could not find a reference).

In this study, we will use the National Survey of Children's Health data to study how income related disparities affect the diagnosis and service utilization of ASD patients.

References

1. Sanchack KE, Thomas CA. Autism Spectrum Disorder: Primary Care Principles. *Am Fam Physician*. Dec 15 2016;94(12):972-979.
2. Lord C, Elsabbagh M, Baird G, Veenstra-Vanderweele J. Autism spectrum disorder. *Lancet*. Aug 11 2018;392(10146):508-520. doi:10.1016/s0140-6736(18)31129-2
3. CDC. Data & Statistics on Autism Spectrum Disorder. Accessed 09/25 2020.
4. Levy SE, Mandell DS, Schultz RT. Autism. *Lancet*. Nov 7 2009;374(9701):1627-38. doi:10.1016/s0140-6736(09)61376-3
5. Johnson CP, Myers SM. Identification and Evaluation of Children With Autism Spectrum Disorders. *Pediatrics*. 2007;120(5):1183-1215. doi:10.1542/peds.2007-2361
6. Elder JH. Behavioral Treatment of Children With Autism, Mental Retardation, and Related Disabilities: Ethics and Efficacy. *Journal of Child and Adolescent Psychiatric Nursing*. 1996;9(3):28-36. doi:https://doi.org/10.1111/j.1744-6171.1996.tb00263.x
7. Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *J Consult Clin Psychol*. Feb 1987;55(1):3-9. doi:10.1037//0022-006x.55.1.3
8. Stein BD, Sorbero MJ, Goswami U, Schuster J, Leslie DL. Impact of a Private Health Insurance Mandate on Public Sector Autism Service Use in Pennsylvania. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2012;51(8):771-779. doi:10.1016/j.jaac.2012.06.006
9. Durkin MS, Maenner MJ, Baio J, et al. Autism Spectrum Disorder Among US Children (2002–2010): Socioeconomic, Racial, and Ethnic Disparities. *American Journal of Public Health*. 2017;107(11):1818-1826. doi:10.2105/ajph.2017.304032
10. Lindly OJ, Zuckerman KE, Kuhlthau KA. Healthcare access and services use among US children with autism spectrum disorder. *Autism*. 2019;23(6):1419-1430. doi:10.1177/1362361318815237