



Medical School

Analyzing Autism Prevalence Among Original Medicare Beneficiaries

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Background

Prevalence estimates and reported increases in the rate of autism spectrum disorder (ASD) are typically based on childhood identification (e.g., the Autism and Developmental Disabilities Monitoring [ADDM] Network). Few studies have estimated the prevalence of ASD among adults in the United States; none existed until May 2020, when it was estimated that 2.21% of adults aged 18 and older in 2017 had ASD.¹

Autistic individuals have been found to have high rates of co-occurring health conditions and early mortality. For example, the average age of death among 406 community-based Americans with ASD (a cohort followed from 1998 to 2018) was 39 years old.²

Methods

The Centers for Medicare and Medicaid Services (CMS) publishes data related to 21 chronic conditions, including ASD, among fee-for-service Medicare beneficiaries (i.e., individuals enrolled in both Part A and Part B but not Medicare Advantage). For context, by excluding Medicare beneficiaries with any Medicare Advantage enrollment or beneficiaries who were enrolled only in Part A or Part B, approximately 44.9% of the total Medicare population was excluded from the 2018 data.³

Using the R programming language and OpenRefine, I downloaded and analyzed data sets for the years 2007 to 2018. Please click on or scan the QR code to access processed data and interactive Jupyter notebooks.



The Boggs Center on Developmental Disabilities

New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service New Jersey's Leadership Education in Neurodevelopmental and Related Disabilities Program

Results

The prevalence of autism as a chronic condition among Original Medicare beneficiaries has increased every year since 2007. Even while total enrollment in Original Medicare (Part A and Part B) declined from 2016 to 2017 and 2017 to 2018, the reported prevalence of ASD increased. The prevalence of ASD among Medicare beneficiaries also increased by 18% between 2010 and 2012, a period in which the estimated prevalence of ASD among 8-year old children decreased.



Percent Change Over Time: 2013 to 2018



Percent Change Over Time Compared to the ADDM Network: 2008 to 2018



Discussion

- Only 46.2% of counties had valid data in 2007. 1625 of 3250 counties (50%) had valid data in 2018, including 384 counties (11.8% of all counties) with zero prevalence for ASD among Original Medicare beneficiaries.
- While only 10 states had a prevalence at or above 1 in 1000 beneficiaries in 2007, every state and the District of Columbia had a prevalence above that value in 2018. In fact, 36 states had a prevalence at least twice that and six states had a prevalence at or above 4 in 1000.
- The 2018 prevalence was highest among individuals who were both under the age of 65 and dually eligible for Medicaid and Medicare (2.46%). Beneficiaries under 65 years old have had the highest prevalence by age group every year since 2007.
- Other questions to consider: Will the prevalence of ASD continue to grow among Medicare beneficiaries? How might older adults benefit from receiving a diagnosis? How can we ensure that more autistic adults are eligible for Medicare on the basis of age?

Autism Spectrum Disorder Among Original Medicare Beneficiaries: 2018 Prevalence by County



New Jersey's Medicare Beneficiaries: 2018 Prevalence by County





Prevalence (per thousand)

3 6 9













References and code