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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

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.
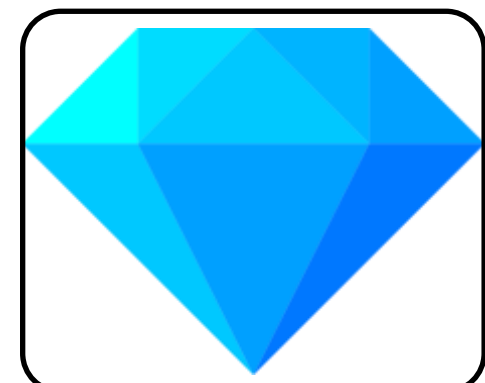
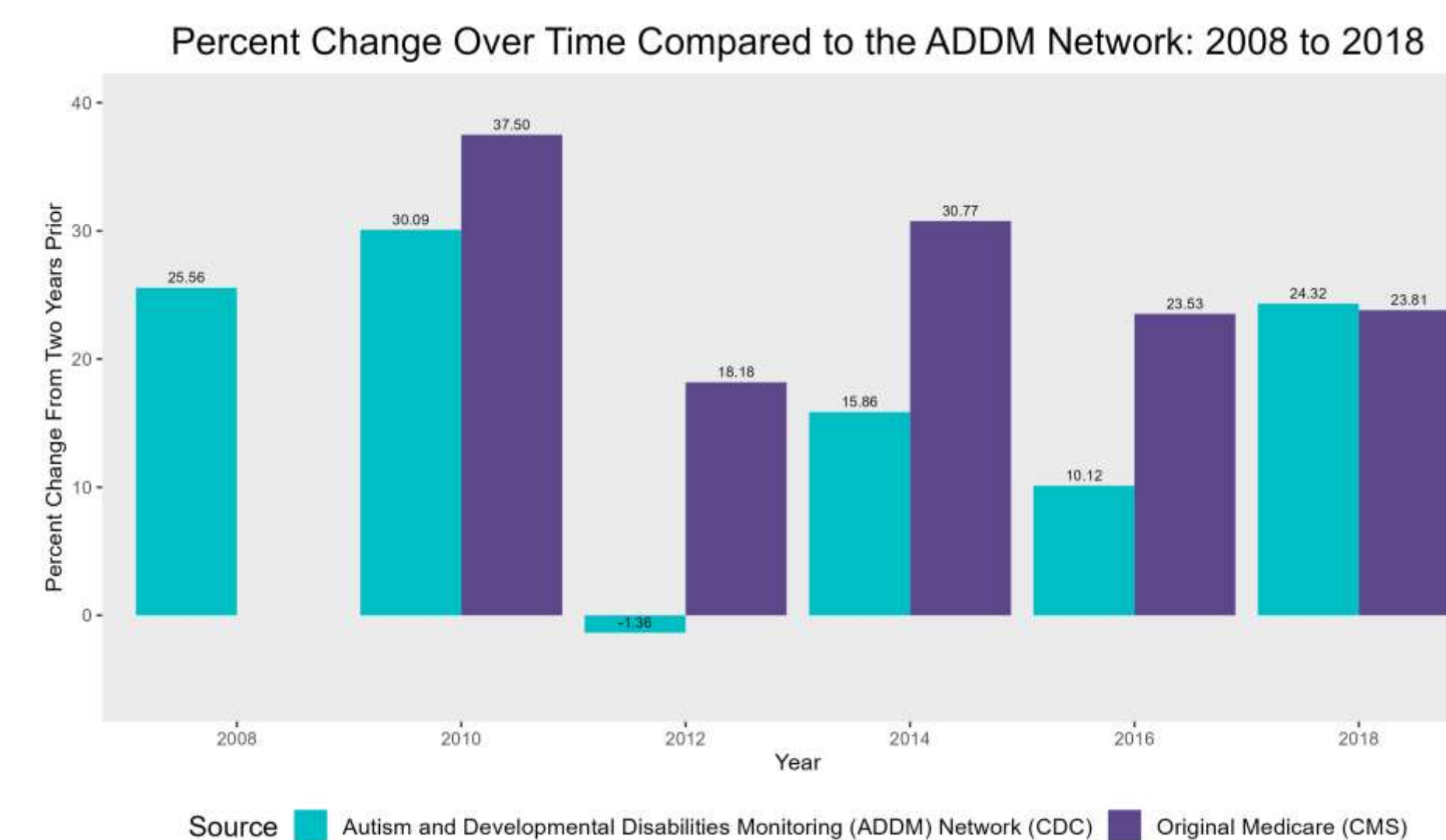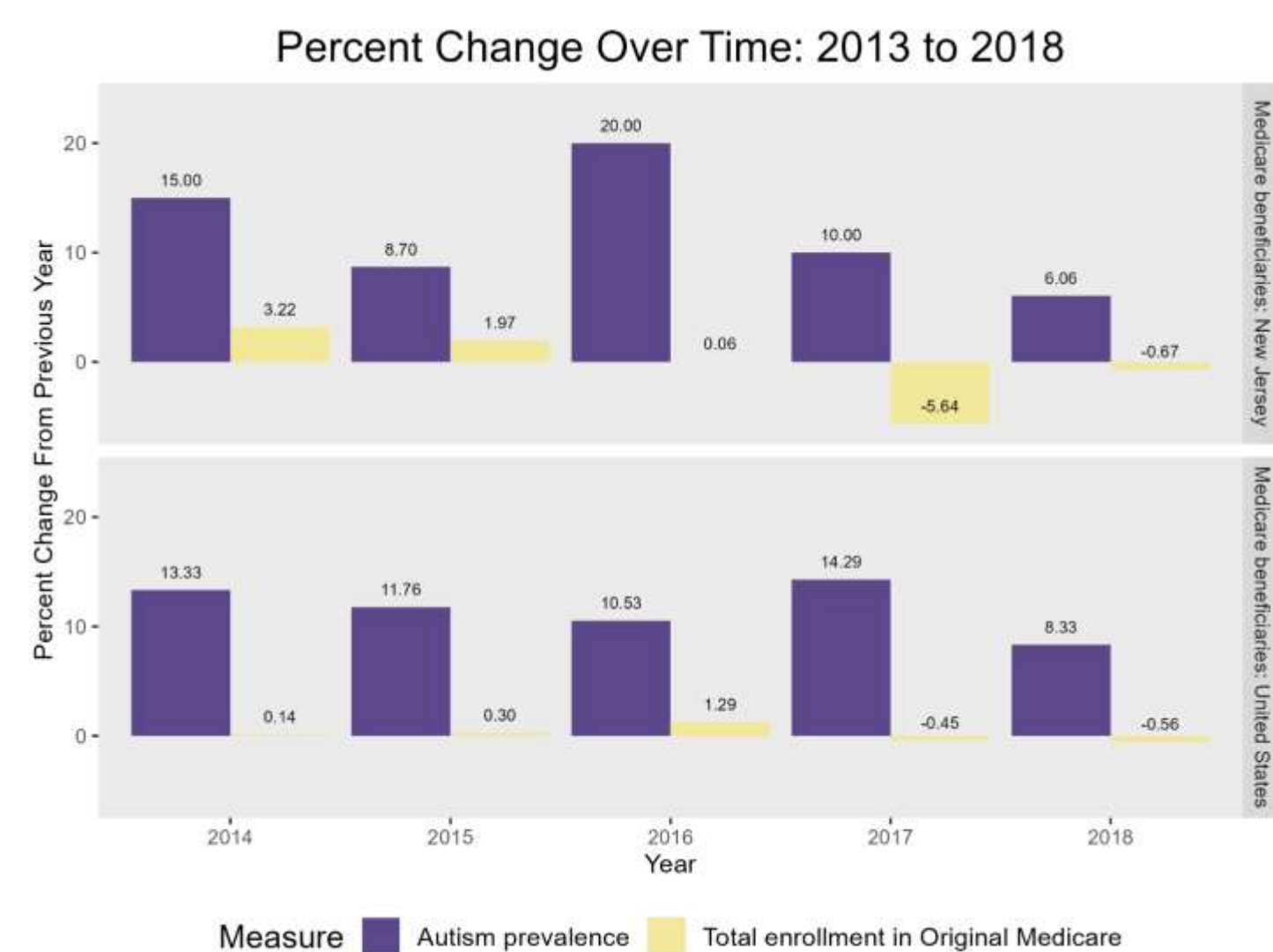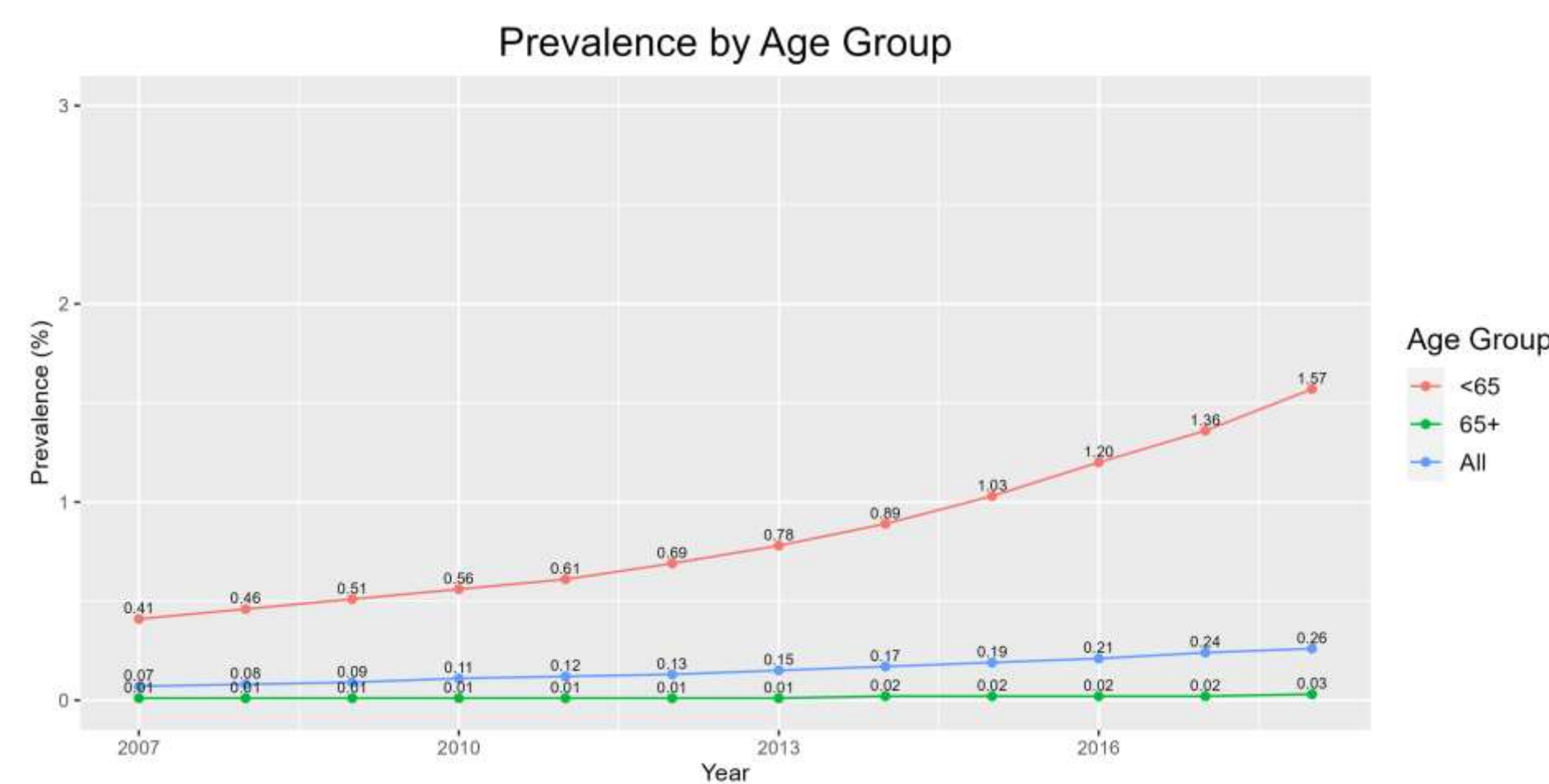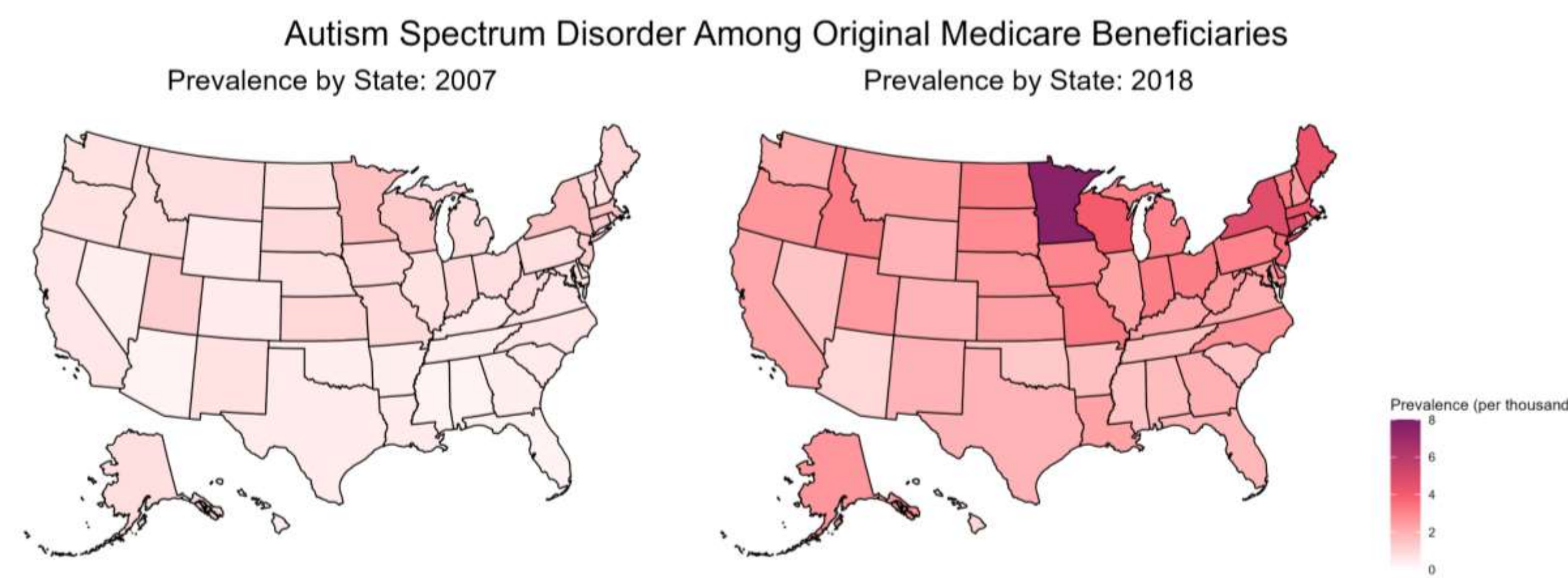| R and RStudio	OpenRefine	R packages	Git
• To merge and analyze data sets	• To clean data sets (e.g., missing values)	• To create graphics using *ggplot2*	• To track changes and publish code

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.

Autism Spectrum Disorder Among Original Medicare Beneficiaries
Prevalence by State: 2007   Prevalence by State: 2018

Prevalence by Age Group

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
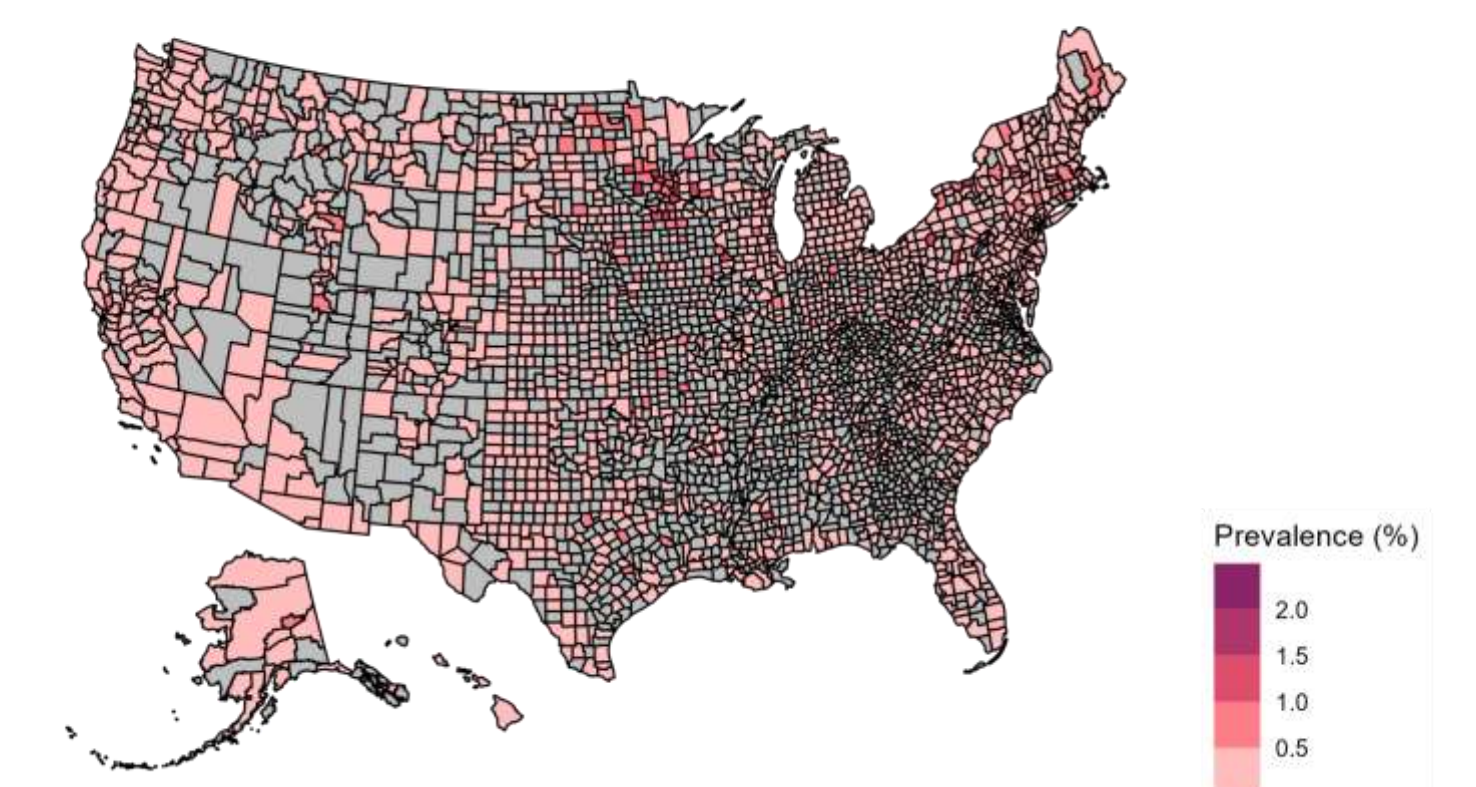
New Jersey's Medicare Beneficiaries:
2018 Prevalence by County