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# Prevalence and Utilization of Medical Care Services in Persons with Autism Spectrum Disorder using Medicare Claims

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## OBJECTIVE

To characterize the prevalence of autism spectrum disorder (ASD) among persons in Medicare claims and contrast with prevalence documented during disability determination in Social Security Administration (SSA) Supplemental Security Income (SSI) files.

## BACKGROUND

- Current CDC<sup>1</sup> prevalence of ASD suggest 1 of 68 children (1.47%) who are aged 8y have an ASD.
- Little is known regarding healthcare use or costs of services as children with ASD transition to adulthood<sup>2</sup>. Describing utilization of health services and costs associated with care as youth age with ASD will inform future interventions and policies aimed at improving the care and service needs of persons with ASD.
- Medicare is a potential source of data on adults with ASD, however, little is known regarding this sample of adults. CMS reports that the prevalence in the 2010 Medicare only file (no Medicaid coverage) is 0.01% for all ages<sup>3</sup>.
- **Medicare provides coverage to persons who meet certain criteria:**
  - ≥ 65 years
  - living children with disabilities of existing Medicare beneficiaries
  - persons who have worked for a period of time and have achieved sufficient working time before declaring a disability and receiving Social Security Disability Insurance (SSDI)
  - Disabled SSI recipients <65 are automatically enrolled in Medicare Part A (hospital) insurance after 24 months. Part B insurance requires premiums but most states automatically enroll SSI recipients into premium support programs (e.g., QMB's).

## METHODOLOGY

We used Centers for Medicare and Medicaid Services (CMS) national Limited Data Files (LDS) to:

- Identify persons with ASD in the 5% physician visit (Carrier) claims files for 2010.
- Link ASD Carrier claims records to the other five claims types: inpatient hospitalization, home health, hospice, outpatient facility claims, and skilled nursing facility claims.
- Compare the nationally weighted estimate of persons with ASD in 2010 Medicare physician visit files with 2010 SSA/SSI data<sup>4</sup> for beneficiaries eligible due to autistic disorder to determine the utility of using Medicare claims to understand utilization and costs of services among adults with ASD

## CONCLUSIONS

### Limitations of using Medicare data to describe utilization and costs include:

- The definition & diagnosis of ASD has changed over time, as well as the classification of disability, thus affecting identification
- Lack of concurrent Medicaid claims means some utilization is not observed (e.g. dual eligibles or in long-term-care facilities)

### Findings & Future Steps:

- Among individuals <18 years receiving SSI, 1 of 14 individuals have an ASD. No individuals with ASD <18 years were captured in our Medicare claims.
- The prevalence of ASD within SSI recipients 18-64 years is consistent with existing CDC estimates (Table 1), however among the same age group within Medicare claims, the prevalence was much lower (1 of 310 individuals). However, the frequency of unique individuals in Medicare 5% Carrier file with ASD increased by 61% from 2008 to 2010 (Table 3).
- Lower prevalence rates of individuals 18-64y with ASD in Medicare might be explained by comprehensive state Medicaid coverage, low realized access to care, poor documentation of diagnosis in claims, or consequences of disability program rules. Additionally, these individuals may use Outpatient services as opposed to the Carrier type service, which therefore would decrease the ability to identify claims in the Carrier file associated with ASD.
- The use of the 5% Carrier Medicare file likely underestimates the true prevalence of individuals with ASD receiving Medicare. Estimates of utilization and costs are likely lower than actual utilization and costs, although they provide preliminary information to guide future understanding of adult ASD-related care.
- Additional work may include Medicare and Medicaid linked files to ensure that utilization and costs reflect individuals who are dual-eligible, or the use of Research Identifiable Files which do not rely on identification of ASD cases through use of Carrier file

## RESULTS

Table 1: Comparison of ASD Medicare Beneficiaries with ASD SSI Recipients for 2010

|                         | Weighted Estimate of Medicare Beneficiaries* with ASD in 2010<br>f (%) | All Medicare Beneficiaries in 2010<br>f (%) | SSI Recipients** with ASD in 2010<br>f (%) | SSI Recipients** 2010<br>f (%) | Prevalence of ASD in Medicare 2010 files<br>% | Prevalence of ASD among SSI Recipients 2010<br>% |
|-------------------------|--|---|--|--------------------------------|---|--|
| <b>Total (all ages)</b> | 33,540<br>(100)  | 39,214,672<br>(100)                         | 151,377<br>(100)                           | 7,912,266<br>(100)             | 0.09  | 1.91   |
| <b>&lt; 18y</b>         | --<br>(0.0)  | 2,844<br>(0.01)                             | 94,626<br>(62.5)                           | 1,239,269<br>(15.7)            | --  | 7.64   |
| <b>18-64y</b>           | 29,940<br>(89.3)   | 9,500,021<br>(24.23)                        | 56,634<br>(37.4)                           | 4,631,507<br>(58.5)            | 0.32  | 1.22   |
| <b>&gt; 65y</b>         | 3,600<br>(10.7)  | 29,711,807<br>(75.77)                       | 117<br>(<1)                                | 2,041,490<br>(25.8)            | 0.01  | 0.01   |

\*Note: Beneficiaries with 1 or more 299.xx diagnosis code in 2010 Medicare 5% carrier file, upweighted by 20.

\*\*SSI Data Source: SSI files available at: <http://www.socialsecurity.gov/policy/docs/data/ssi-2010/index.html> for disability types including 'Autistic'

Table 2: Months of Medicaid State Buy-In Enrollment with Medicare for Individuals with ASD (unweighted)\*

|                    | Ages 18-64y<br>f (%) | Age > 65y<br>f (%) |
|--------------------|----------------------|--------------------|
| <b>0 Months</b>    | 4,420<br>(14.8)      | 2,080<br>(57.8)    |
| <b>1-11 Months</b> | 2,660<br>(8.9)       | 200<br>(5.5)       |
| <b>12 Months</b>   | 22,640<br>(75.6)     | 1,320<br>(36.7)    |
| <b>Missing</b>     | 220<br>(0.7)         | --<br>(0.0)        |
| <b>Total</b>       | 29,940<br>(100)      | 3,600<br>(100)     |

\*Data Source: 2010 Medicare 5% Carrier file

Table 3: Medical reimbursements in a 5% unweighted sample of Medicare beneficiaries with a diagnosis of ASD (299.xx), ages 18-64 in claim years 2008, 2009, 2010

|  | Claim Year    |               |               |
|--|---------------|---------------|---------------|
|  | 2008          | 2009          | 2010          |
| <b>Individuals with ASD in 5% Carrier file (f)</b>     | 929           | 1,321         | 1,497         |
| <b>Total annual claims for all ASD individuals (f)</b> | 24,378        | 35,062        | 41,262        |
| <b>Mean annual claims per person</b>                   | 26.2          | 26.5          | 27.6          |
| <b>Mean payment per claim (\$)</b>                     | 173.22        | 184.07        | 203.69        |
| <b>Mean annual payment per person (\$)</b>             | 4,546.00      | 4,886.00      | 5,614.00      |
| <b>Total payment for all ASD individuals (\$)</b>      | 4,222,783.00  | 6,453,862.00  | 8,404,627.00  |
| <b>Mean charged per claim (\$)</b>                     | 622.53        | 693.19        | 766.41        |
| <b>Mean charged per person (\$)</b>                    | 16,336.00     | 18,399.00     | 21,125.00     |
| <b>Total charged for all ASD individuals (\$)</b>      | 15,175,935.00 | 24,304,507.00 | 31,623,793.00 |

Note: The number of individuals refers to how many unique people had at least 1 ASD Dx in the 5% Carrier file per year. The claims and expenditures reflect all of these individual's claims for that year in the 6 file types, whether it was associated with ASD or not.

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