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Use of Medicare Claims As a Source for Research Prevalence and Utilization of Medical Care Services in Persons with Autism Spectrum Disorder Over and Under Age 65

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OBJECTIVE

1. To evaluate the feasibility of using Medicare claims by determining the number of identifiable persons with autism spectrum disorder (ASD) in a three year limited data set (2008-2010)
2. To describe the structure, types, and limitations of Medicare claims files for ASD research

BACKGROUND

- Increased use of restrictive medical care has been documented among adolescent cohorts of persons with ASD (Cidav et al., 2013)

- Little is known about the patterns of health care utilization and expenditures for persons with ASD who are older than 21 years

- Medicare may be a potential source of healthcare claims data for examining service utilization and expenditures for adults with ASD
  - Most studies using Medicaid claims among children require identification of ASD with a minimum of two ICD9 claims of 299.xx (ASD, specified and unspecified pervasive developmental disorder, child disintegrative disorder)
  - It was unclear if a large enough sample of individuals would be identifiable using 2 or more claims in Medicare
  - We wanted to identify those with ASD (299.00 and 299.80) and those with ASD-related conditions (all 299.xx)

- **Medicare provides coverage to adults who meet certain criteria**:
  - ≥ 65 years or;
  - living children with disabilities of existing Medicare beneficiaries or;
  - 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

METHODOLOGY

The Centers for Medicare and Medicaid Services (CMS) national Limited Data Files (LDS) were used to:
- Link ASD patient records to the other four claims types: inpatient hospitalization (INP), home health (HHA), outpatient facility claims, and skilled nursing facility (SNF) to identify frequency of claim occurrence
- Identify the frequency of individuals with at least one ASD ICD-9 claim (299.00 & 299.80) in the 5% Carrier claims or 100% files
- Identify the frequency of individuals with ASD-related diagnoses (299.xx) who had a claim in both the 5% Carrier claim file and a minimum of one 100% file
- Summarize the age, race and ethnicity and gender of individuals with ASD

RESULTS

Table 1. Number of persons with ASD with at least 1 ICD9 claim of 299.00 or 299.80 in each file by year

File Name	Year	Unique IDs with any ASD (*f*)	Unique IDs with any ASD <65y (*f*)	Unique IDs with any ASD ≥65y (*f*)
Carrier 5%	2008	422	391	31
INP 100%	2008	808	736	72
Outpatient 100%	2008	2067	1899	168
SNF 100%	2008	43	19	24
HHA 100%	2008	62	46	16
Hospice 100%	2008	5	1	4
Carrier 5%	2009	457	429	28
INP 100%	2009	947	879	68
Outpatient 100%	2009	2472	2288	184
SNF 100%	2009	48	16	32
HHA 100%	2009	77	46	31
Hospice 100%	2009	2	1	1
Carrier 5%	2010	551	514	36
INP 100%	2010	217	193	24
Outpatient 100%	2010	3124	2896	206
SNF 100%	2010	67	26	41
HHA 100%	2010	47	32	15
Hospice 100%	2010	3	1	2

Figure 1. Age distribution of individuals 18-64 years with two or more 299.xx claims in 2010 files

Mean = 37.48
Std. Dev. = 12.202
N = 485
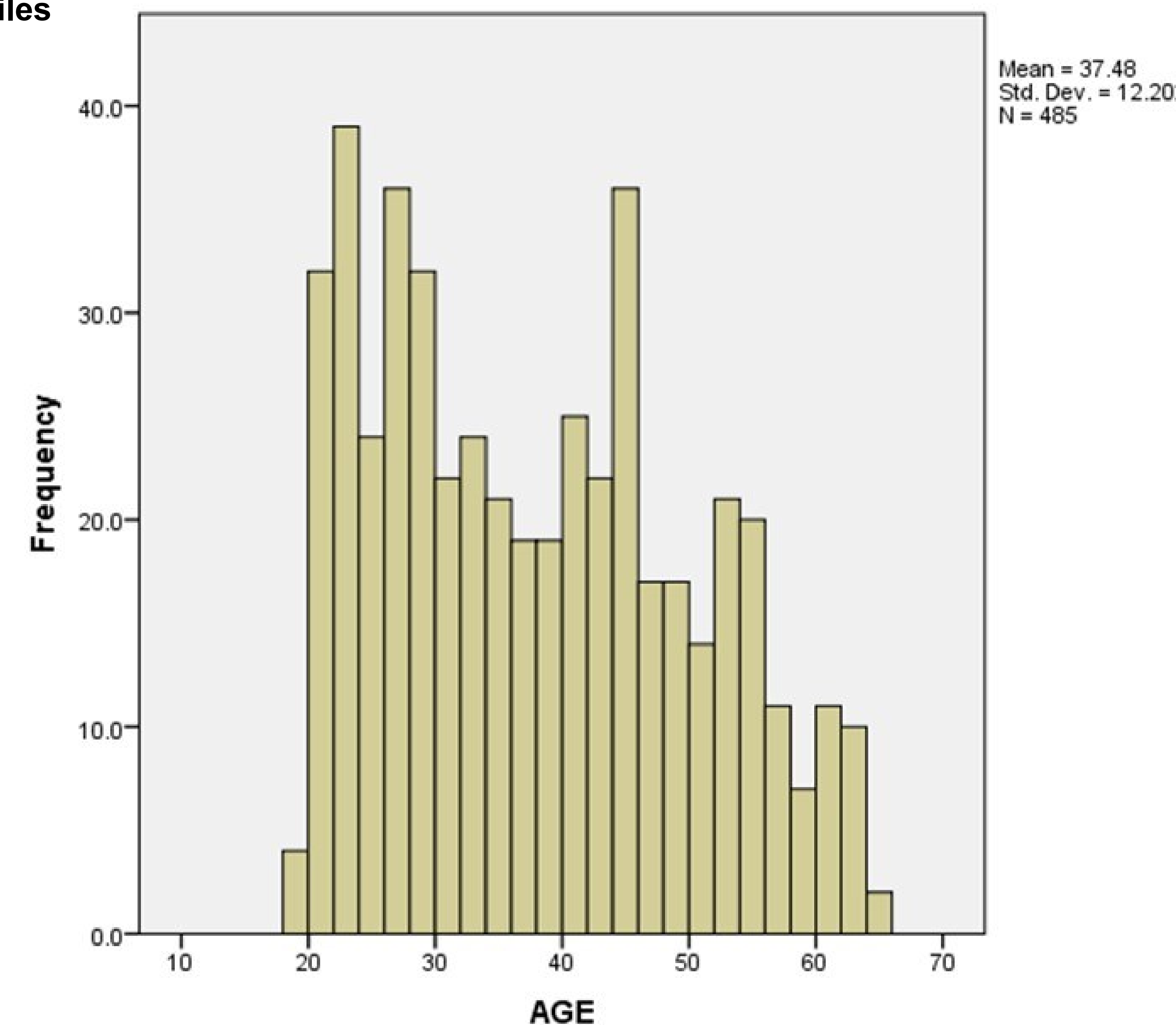
- Of individuals with at least one ICD9 claim of 299.00 or 299.80:
  - 869 individuals ages 18+ years in 2008-2010 Carrier (5% files)*
  - *n*= 422 (2008), *n*=457 (2009), *n*=551 (2010)
- Of individuals with at least two ICD9 claims of 299.xx, ages 18-64years:
  - 865 individuals 18-64 years in 2008-2010*
  - *n*=268 (2008), *n*=426 (2009), *n*=485 (2010)
- *Total n does not add up to the sum total of each year because some individuals are found in more than one claim year*

RESULTS

Table 2. Race and ethnicity of individuals 18-64 years with 2 or more claims (299.xx) by year

	2008			2009			2010		
	Males *f* (%)	Females *f* (%)	Total *f* (%)	Males *f* (%)	Females *f* (%)	Total *f* (%)	Males *f* (%)	Females *f* (%)	Total *f* (%)
White	159 (59.3)	67 (25.0)	226 (84.3)	240 (56.3)	94 (22.1)	334 (78.4)	283 (58.3)	94 (19.4)	377 (77.7)
Black	19 (7.1)	8 (3.0)	27 (10.1)	35 (8.2)	22 (5.2)	57 (13.4)	52 (10.7)	18 (3.7)	70 (14.4)
Asian	1 (0.4)	1 (0.4)	2 (0.8)	2 (0.5)	0 (0.0)	2 (0.5)	8 (1.6)	1 (0.2)	9 (1.8)
Hispanic	6 (2.2)	2 (0.8)	8 (3.0)	13 (3.1)	4 (0.9)	17 (4.0)	15 (3.1)	3 (0.6)	18 (3.7)
Native Am	3 (1.1)	0 (0.0)	3 (1.1)	6 (1.4)	0 (0.0)	6 (1.4)	1 (0.2)	0 (0.0)	1 (0.0)
Other	0 (0.0)	1 (0.4)	1 (0.4)	2 (0.5)	0 (0.0)	2 (0.5)	5 (1.0)	2 (0.4)	7 (1.4)
Unknown	1 (0.4)	0 (0.0)	1 (0.4)	2 (0.5)	0 (0.0)	2 (0.5)	2 (0.4)	1 (0.2)	3 (0.6)
Total	189 (70.5)	79 (29.5)	268 (100.0)	306 (71.8)	120 (28.2)	426 (100.0)	366 (75.5)	119 (24.5)	485 (100.0)

CONCLUSION

- The ≥65y+ sample size is very small, as would be expected by the historic identification of ASD by Kanner and others in the 1940s

- Use of two or more 299.xx claims to track individual outcomes is feasible by linking 5% sample carrier beneficiaries across other files for individuals < 65 years

- Sample sizes decrease when choosing to use samples with any 299.xx versus 299.00 and 299.80, as well as when using samples with a claim in both the 5% carrier file and at least one other 100% file

- Racial and ethnic composition of individuals with ASD in comparison to 2010 Census estimates suggest more than expected white adults, similar as expected black adults, and fewer than expected Hispanic adults

Limitations of using this data include:
- The definition and diagnosis of ASD has changed over time, as well as the classification of disability, thus affecting identification and eligibility within these claim files. Cohort effects must be considered.
- The covered population likely represents a severely disabled subset of the larger population of adults with ASD due to eligibility criteria
- Lack of Medicaid claims means some utilization is not observed, e.g. dual eligibles and persons in long-term-care facilities