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Healthcare Costs of Pediatric Autism Spectrum Disorder in the United States, 2003–2015

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Abstract

Published healthcare cost estimates for children with autism spectrum disorder (ASD) vary widely. One possible contributor is different methods of case ascertainment. In this study, ASD case status was determined using two sources of parent reports among 45,944 children ages 3–17 years in the Medical Expenditure Panel Survey (MEPS) linked to the National Health Interview Survey (NHIS) Sample Child Core questionnaire. In a two-part regression model, the incremental annual per-child cost of ASD relative to no ASD diagnosis was $3930 (2018 US dollars) using ASD case status from the NHIS Child Core and $5621 using current-year ASD case status from MEPS. Both estimates are lower than some published estimates but still represent substantial costs to the US healthcare system.

Keywords

Autism spectrum disorder; Cost analysis; Health economics; Health services research

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Compliance with Ethical Standards

Autism spectrum disorder (ASD) is a neurodevelopmental disorder defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout life. The attributable cost associated with caring for someone with ASD is a question of growing concern as the proportion of children diagnosed with ASD has increased in recent years (Baio et al. 2018; Maenner et al. 2020). However, published cost estimates vary widely (Amendah et al. 2011; Buescher et al. 2014; Ganz 2007; Lavelle et al. 2014; Rogge and Janssen 2019). Two studies estimated direct and indirect economic costs of pediatric ASD in the United States as either $11.5 billion (Lavelle et al. 2014) or $61–66 billion annually in 2011 dollars (Buescher et al. 2014). Excess healthcare costs alone, not including costs for behavioral interventions delivered in schools, were estimated as either $2.0 billion (Lavelle et al. 2014) or $10–11 billion (Buescher et al. 2014).

One reason for variability in cost estimates is the use of different data sources. In particular, many US healthcare cost estimates have been based on analyses of insurance claims data limited to either public or private insurance (Leslie and Martin 2007; Peacock et al. 2012; Shimabukuro et al. 2008; Stuart et al. 2017; Wang and Leslie 2010; Wang et al. 2013). Such databases are not representative of the whole population of children, and expenditures differ between those with private and public insurance (Wang et al. 2013). Another limitation is that only children with a medical diagnosis of ASD who utilize healthcare services are included. Finally, few studies using claims data have estimated incremental expenditures relative to children without ASD (Peacock et al. 2012; Shimabukuro et al. 2008).

Three empirical studies have used Medical Expenditure Panel Survey (MEPS) data to directly calculate expenditures associated with ASD (Appendix Table 1) (Liptak et al. 2006; Thomas et al. 2014, 2016). The MEPS is a large, ongoing nationally representative survey of households conducted by the US government in which information on health services usage and expenditures, both reimbursements from private and public payers and out-of-pocket costs, is collected and verified; it is a highly-regarded data source for analyses of US healthcare costs associated with chronic conditions (Clabaugh and Ward 2008). Using 1999–2000 data, Liptak et al. reported $8670 mean and $5234 median annual spending per child ages 0–18 years with ASD and incremental mean spending of $7454 (2018 US dollars) (Liptak et al. 2006). Thomas et al. reported $7106 mean spending per child (0–17 years) using 2002–2011 data and median spending of $2789 per child (0–20 years) using 2000–2009 data (2018 US dollars), although they did not estimate incremental costs (Thomas et al. 2014, 2016). In addition, a modeling study reworked the Liptak et al. cost estimates (Buescher et al. 2014).

A fourth study by Lavelle et al. used 2003–2008 MEPS data linked to information from the National Health Interview Survey (NHIS) to assess costs for children aged 3–17 years with ASD case status based on a NHIS report that the child had ever been diagnosed with ASD (Lavelle et al. 2014). That study estimated an incremental per-child mean annual cost of $3398 (2018 US dollars) for ASD versus no ASD (Lavelle et al. 2014). The difference in cost estimates between the Liptak and Lavelle studies could reflect differences in data years, statistical adjustments for covariates, and method of ASD case ascertainment. In particular, it is likely that expenditures are lower for children whose parents report they were ever

diagnosed with ASD but who do not have current ASD-specific healthcare encounters. In addition, Lavelle et al. replaced the highest 1% of expenditure estimates with the value of the 99th percentile of expenditures for the pooled sample.

In this paper, we report new estimates of the annual incremental cost for pediatric ASD in an original analysis of MEPS data from 2003 through 2015 linked to NHIS data. In particular, we compare estimated annual incremental costs for children reported in NHIS as ever diagnosed with ASD and for those with current-year diagnoses of ASD in MEPS. The study is primarily intended to help account for methodological differences in published estimates of ASD healthcare costs or expenditures derived from national-level survey data. In addition, we compare our cost estimates with ASD cost estimates from previous US studies using various national-level data sources, including administrative claims data as well as survey data, to help triangulate among published estimates of healthcare costs for US children with ASD.

Methods

Data Sources

The data are drawn from the 2003 to 2015 waves of the MEPS. The MEPS is a nationally representative household survey of US healthcare use and costs, conducted by the Agency for Healthcare Research and Quality, in conjunction with the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention. A new panel of households, sampled from households included in the NHIS conducted by NCHS in the prior year, is selected each year. Each household is interviewed five times over a 2-year period with information collected on every household member. The data from two overlapping panels are combined to produce estimates for each calendar year. Additional information is also available from the linked NHIS data. The NHIS Sample Child Core questionnaire collects detailed health information for one randomly selected child aged 0–17 years in each household, including parent-reported health conditions. The Sample Child Core questionnaire indicates whether a parent had ever been told by a doctor or other health professional their child had autism (1997–2010), autism or ASD (2011–2013), or autism, Asperger's disorder, pervasive developmental disorder, or ASD (2014–2016) (Xu et al. 2018; Zablotsky et al. 2015).

A single respondent in each household in the MEPS Household Component is asked to report all healthcare encounters (hospitalizations, emergency department visits, outpatient medical visits, prescription medications, home healthcare visits, and other healthcare providers) and, if known, associated expenditures for each member of the household. Follow-back surveys of healthcare providers and pharmacies reported by MEPS household respondents are the primary source of healthcare expenditures in the MEPS. For each encounter reported, the MEPS household respondent is asked what conditions were responsible for the encounter. Prior to 2018, household respondents were also asked whether each household member was bothered by any other health conditions. Professional coders convert all conditions into International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) (through 2015)/ICD-10-CM (2016 and beyond) diagnostic codes.

ASD-Case Identification

We constructed two measures of ASD case status in our MEPS-NHIS linked sample: NHIS ASD and MEPS ASD case status. NHIS ASD case status was taken directly from the NHIS Sample Child Core question about whether a doctor or other professional had ever told a knowledgeable adult (usually a parent) that the child had ASD. MEPS ASD case status was identified from household reported health conditions in two ways. First, any person with at least one encounter in MEPS with an ICD-9-CM code of 299 (pervasive developmental disorders) for the calendar year was classified as having ASD—75% of MEPS ASD cases were identified this way. The remaining MEPS ASD cases were identified based on the household respondent reporting that the family member was bothered by ASD during at least one of the MEPS rounds covering the calendar year. The decision to use a single calendar year of MEPS data to ascertain ASD cases was made to ensure that ASD case status was consistently measured across both MEPS panels comprising a given year's expenditures.

We created four ASD case indicators from the two case status measures: ASD in NHIS with or without MEPS, in MEPS with or without NHIS, in MEPS or NHIS, and in NHIS and MEPS.

Data Analysis

We analyzed pooled data from the 2003–2008, 2009–2012, and 2013–2015 waves of the MEPS. We pooled data across multiple waves in order to attain adequate samples of children identified with ASD and facilitate comparisons with earlier MEPS ASD studies. Prevalence and all other estimates were calculated using population weighted estimates.

We restricted analyses to calendar year expenditures for children aged 3–17 years at the end of the calendar year and who were linked to the NHIS Sample Child Core, as in a previous analysis (Lavelle et al. 2014). All expenditure estimates were adjusted to 2018 US dollars in two steps. First, expenditures within pooled samples were adjusted for medical inflation to the last year using the Personal Consumption Expenditures health-by-function price index, e.g., 2008 prices for 2003–2008 pooled years (Dunn et al. 2018). Second, expenditures from each period were adjusted to 2018 values using the gross domestic product (GDP) deflator for general price inflation. All expenditure estimates reported for comparison purposes have been adjusted to 2018 US dollars using the GDP deflator.

We assessed both mean total expenditures and ASD-specific expenditures for encounters with ASD listed as an associated condition; most encounters have just one condition listed. (Median total expenditures are reported in Appendix Table 2). We calculated mean incremental expenditures as the difference in spending between children with and without ASD, both unadjusted and adjusted using regression models.

We estimated regression models of total expenditures by ASD case status with (adjusted) and without (unadjusted) the following covariates: sex and age of child (3–7, 8–12, 13–17 years), highest parental education, family income relative to the federal poverty line, race-ethnicity, and census region. To increase precision of the expenditure estimates, we pooled data across the entire 2003–2015 study period. To control for general increases in health

spending over time, we included a categorical time-period variable (2009–2012 and 2013–2015 vs. 2003–2008). Because the results for the two younger age groups were essentially identical, we collapsed those two categories and used 3–12 years as the reference age category. We found similar results using ordinary least squares, generalized linear model (GLM), or two-part models with various functional forms. Based on the results of recommended specification tests (Manning and Mullahy 2001), we selected a two-part model with a first-part logistic regression on the dichotomous variable of zero expenditures and a second-part GLM model with a log link and gamma distribution (which assumes the variance is proportional to the square of the mean) for observations with positive expenditures to report (full results in Appendix Table 3).

In sensitivity analyses, we calculated regression results after replacing reported expenditures in the top 1% of values for the entire sample with the 99th percentile value in order to match a previous analysis (Lavelle et al. 2014). We also calculated regression results using an alternative measure of MEPS case status based on any report of ASD in both years a child appeared in MEPS rather than a single year.

All statistical analyses use MEPS person-level weights adjusted for non-response to the NHIS Sample Child Core questionnaire using propensity-scoring methods (Austin 2011). All analyses also adjust for the stratified and clustered design of the MEPS.

Results

The reported prevalence of ASD in the linked NHIS-MEPS sample increased over time using both sources of case ascertainment (Table 1). Using MEPS ASD case status, weighted prevalence increased from 0.6% in 2003–2008 to 1.5% in 2013–2015. The weighted percentage of children with NHIS parent reported ASD diagnoses also more than doubled during the same period, from 0.7 to 1.5%, a 0.8 percentage point increase (95% confidence interval [CI] 0.4% to 1.2%; $P \leq 0.001$; not shown in Table 1).

The distributions of most covariates were similar by ASD case definition (Table 2). Males accounted for 82% of children with ASD in both data sources. Non-Whites, those living in households in poverty or with low educational attainment, and children living in the south Census region were all underrepresented among those with reported ASD. Finally, a smaller fraction of those with the NHIS case definition were in the youngest age group.

Mean unadjusted annual gross, ASD-specific, and incremental expenditures for children with ASD case status indicators along with gross expenditures for non-ASD children for each study period are shown in Table 3. Roughly one-half of the children in the linked NHIS-MEPS sample who had ASD reported in NHIS also had ASD reported in MEPS, and roughly two-thirds of those with ASD reported in MEPS also had ASD reported in the linked NCHS data (Table 3). However, just 40% of those classified as ASD in either NHIS or MEPS were classified as ASD in both.

During 2003–2008, the gross weighted mean annual expenditure for all children with ASD identified in MEPS was 44% higher than for those with ASD reported in NHIS ($7700 vs. $5364). The relative difference decreased to 30% in 2009–2012 and 16% in 2013–2015.

During 2013–2015, incremental costs for ASD versus no ASD averaged $4670 for children identified in MEPS as having ASD and $3740 for those identified as having ASD in NHIS (Table 3). The ratios of mean incremental expenditures between the two groups were 1.6 in 2003–2008, 1.43 in 2009–2012 and 1.25 in 2013–2015. Children with ASD reported in either NHIS or MEPS had mean incremental expenditures of $3628 in 2013–2015, compared with $5462 for those reported in both NHIS and MEPS (Table 3).

The results of regression analyses using the pooled sample are reported in Table 4. The regression-adjusted incremental cost estimate for ASD relative to no ASD was $3930 using NHIS parent-reported ASD case status and $5621 using MEPS case status. Both the unadjusted ($1659, 95% CI $676 to 2641; $P = 0.001$) and adjusted differences ($1691, 95% CI $648 to 2734; $P = 0.001$) in annual costs by source of case status (MEPS vs. NHIS) were roughly $1700.

In sensitivity analyses, the adjusted estimate using MEPS case status would be $4948 if 2 years of MEPS data were used to identify ASD cases (Table 4). In other sensitivity analyses, truncating expenditures at the 99th percentile reduced MEPS and NHIS ASD case incremental cost estimates by roughly one-third.

Discussion

Published estimates of the average healthcare cost per child with ASD vary widely (Amendah et al. 2011; Rogge and Janssen 2019). This study was designed to identify one source of variability in cost estimates based on analyses of survey data, namely source of ASD case ascertainment. The study reports incremental healthcare costs for a national sample of US children with ASD using two different approaches to identify ASD cases in NHIS-MEPS linked survey data. From 2003 to 2015 we found that mean adjusted annual incremental expenditures associated with ASD were almost 50% higher when calculated using the MEPS current-year ASD case status compared to the NHIS Core indicator of ever diagnosed ASD, $5621 vs. $3930. Those estimates reflect differences in case ascertainment; many children reported in the NHIS as having ever been diagnosed with ASD did not meet the MEPS case definition that was based on encounters or ongoing problems within the same year. When 2 years of MEPS data were used in a sensitivity analysis to identify ASD cases, the incremental expenditure was 12% lower, $4948, and the gap in incremental expenditures between the MEPS-based and NHIS-based case status was reduced by 40%. Analyses of claims data have likewise found that using multiple years of data to identify cases results in lower mean expenditure estimates, since individuals with lower healthcare requirements are less likely to have condition-related encounters in a given year (Shimabukuro et al. 2008).

Both survey-based cost estimates in this study appear low relative to estimates from analyses of healthcare administrative data that only include children with healthcare encounters associated with a medical diagnosis of ASD reported for billing purposes (Appendix Table 1). For example, analyses of nationwide private insurance claims data reported gross mean expenditures for children with ASD of between roughly $7000 and $12,000 per year in 2018 US dollars (Leslie and Martin 2007; Shimabukuro et al. 2008; Stuart et al. 2017; Wang et al.

2013). Analyses of nationwide Medicaid claims data reported mean expenditures of roughly $11,000 to $30,000 for children with ASD in 2018 (Cidav et al. 2013; Peacock et al. 2012; Wang and Leslie 2010; Wang et al. 2013). Medicaid programs have historically provided greater access to behavioral health services, including through state waiver programs (Cidav et al. 2014; LaClair et al. 2019; Liptak et al. 2008; Shattuck et al. 2009; Yingling et al. 2019).

Our incremental cost estimate of $3930 per year for children with parent-reported ASD diagnoses in NHIS is higher than the corresponding inflation-adjusted Lavelle et al. estimate of roughly $3400 using the same ASD case definition (Appendix Table 1) (Lavelle et al. 2014). Mean expenditure estimates can be sensitive to the upper tail of the expenditure distribution, which typically has a heavy right-hand tail. Our sensitivity analysis that replaced the top 1% of expenditures reduced the mean expenditure estimate using the NHIS case definition to $2696 (Table 3), because almost half of all spending for children with ASD in the pooled 2003–2015 MEPS sample is accounted for by children whose expenditures exceeded the 99th percentile for the entire sample. Other econometric methods for use with expenditure distributions with heavy tails are commonly recommended (Mullahy 2009).

Our adjusted incremental cost estimate of $5621 using the MEPS ASD case indicator was lower than a previous incremental cost estimate of $7454 in 2018 dollars in an analysis of 1999–2000 MEPS data (Appendix Table 1) (Liptak et al. 2006). One possible explanation for the difference in cost estimates is temporal changes in the characteristics of children with ASD diagnoses. For example, autism surveillance data indicate that 45% of 8-year old children with ASD assessed in 2002 had intellectual disability, compared with 31% of those assessed with ASD in 2010 (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators; Centers for Disease Control and Prevention 2007; Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators; Centers for Disease Control and Prevention 2014). Children with ASD in the 1999–2000 MEPS data may have been more severely affected than those with ASD in later waves. The mean number of home healthcare visits per child with ASD in the 1999–2000 MEPS data was almost three times higher than in the 2003–2008 MEPS data (Lavelle et al. 2014; Liptak et al. 2006). However, the sample size (n = 31) used in Liptak et al. falls below MEPS guidelines for statistical reliability (Agency for Healthcare Research and Quality).

Our upper-bound $5621 estimate of healthcare costs associated with current ASD case status from MEPS is a fraction of the incremental healthcare cost assumed in a widely cited analysis of the economic impact of ASD in the United States (Buescher et al. 2014). This difference could be explained by two reasons. First, Buescher et al. cited the Liptak study as the source of their US pediatric medical cost estimate, but they summed mean costs for cost categories reported in Table 3 of Liptak et al. (personal communication, D.S. Mandell, December 14, 2014). Their sum of total costs per child with ASD in 2000 dollars was $9800, which compares with a total of $6132 per child reported in the first row of Table 3 (Liptak et al. 2006). One of the cost categories, outpatient total, included several specific outpatient cost categories; including both resulted in double-counting of outpatient costs.

Self-pay (out-of-pocket) expenditures were similarly double counted. Second, Buescher et al. estimated average costs for children with and without co-occurring intellectual disability by age group, assuming that average costs per child with ASD with intellectual disability are twice those of children without intellectual disability and a 40:60 split. In 2011 dollars, mean annual costs in the 6–17 age group were assumed to be $18,106 and $9053, respectively, and the weighted cost was $12,674. The weighted average incremental cost of $14,242 in 2018 dollars was almost twice the inflation-adjusted total reported by Liptak et al., $7454, for a sample of children with ASD, with or without co-occurring diagnoses, of whom 92% were ages 5–17 years.

Our per-child cost of $3930 multiplied by the weighted average of 1.0 million children with NHIS parent-reported ASD in the linked NHIS-MEPS 2013–2015 sample yields estimated annual spending during 2013–2015 of $3.9 billion in 2018 dollars attributable to ASD. In comparison, researchers at the Institute for Health Metrics and Evaluation (IHME) at the University of Washington estimated aggregate healthcare spending on ASD of $3 billion dollars in 2013 (Dieleman et al. 2016).

The MEPS data used in this study have limitations. First, while reports of ASD in both MEPS and NHIS are growing over time, MEPS sample sizes are small. Even pooling across multiple years, statistical precision is limited. Second, the limited number of ASD cases do not permit stratification by co-occurring conditions, such as intellectual disability, which is associated with substantially higher expenditures among children with ASD (Peacock et al. 2012). Third, use of healthcare services is based on household reports, which may underreport outpatient services, misreport clinical diagnoses (Bhandari and Wagner 2006; Zuvekas and Olin 2009b), and exclude use of school-based services. Underreporting of outpatient services may result in an underestimation of ASD costs. Fourth, some children with ASD may be institutionalized or in foster care and are out-of-scope in MEPS; such children are likely to incur higher costs. Analyses of private health insurance data likewise exclude individuals in foster care or residential care. In contrast, Medicaid claims data include substantial spending on intermediate care facilities for children with ASD and intellectual disability (Wang et al. 2013), an area that merits further investigation.

Fifth, MEPS understates personal healthcare spending by household members by roughly one-fifth relative to the National Health Expenditure Accounts, with the biggest relative discrepancies in physician services, home healthcare, and medical equipment (Bernard et al. 2012). Those differences may reflect both underreporting by households and underrepresentation of high-spending individuals relative to claims data for the same payer types (Sing et al. 2006; Zuvekas and Olin 2009a).

The linked NHIS-MEPS data also have limitations. The definition of ASD has changed in the NHIS survey over time (Zablotsky et al. 2015). Moreover, children with ASD may be diagnosed after their NHIS interview, but before their MEPS interview, and be incorrectly classified as not ASD using the NHIS case definition.

In conclusion, regardless of specific estimates, individuals identified with ASD incur substantially greater healthcare costs than neurotypical children. Other societal costs

associated with ASD include outlays by school systems and families and lost productivity associated with unpaid family care and the employment limitations experienced by adults with ASD, all of which are important areas for research. Appropriate treatment for ASD is an important policy concern, particularly given that healthcare expenses are only a small part of the societal costs associated with ASD (Amendah et al. 2011; Buescher et al. 2014; Lavelle et al. 2014; Rogge and Janssen 2019).

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability

This paper has not been previously presented in any form.

Abbreviations

ASD	Autism spectrum disorder
GDP	Gross domestic product
GLM	Generalized linear model
ICD-9-CM	Ninth Revision: Clinical Modification
MAX	Medicaid Analytic eXtract
MEPS	Medical Expenditure Panel Survey
NHIS	National Health Interview Survey

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Table 1

Reported prevalence of ASD in MEPS by source of case ascertainment, U.S. children ages 3–17 Years

Calendar Years			NHIS Sample Child Core Indicator			MEPS Condition Indicator			NHIS Sample Child Core Indicator or MEPS Condition Indicator		
	All children (N)	Weighted Population in millions[a]	Children with ASD (N)	Weighted Population in millions[a]	Weighted Prevalence[a] (95% CI)	Children with ASD (N)	Weighted Population in millions[a]	Weighted Prevalence[a] (95% CI)	Children with ASD (N)	Weighted Population in millions[b]	Weighted Prevalence[b] (95% CI)
2003–2008	20,795	61.9 (59.4–64.4)	119	0.4 (0.3–0.6)	0.7% (0.5–0.9)	95	0.3 (0.3–0.5)	0.6% (0.4–0.7)	151	0.6 (0.4–0.7)	0.9% (0.7–1.1)
2009–2012	14,242	62.0 (59.0–64.9)	146	0.8 (0.6–0.9)	1.2% (0.9–1.5)	127	0.7 (0.5–0.9)	1.1% (0.8–1.4)	196	1.1 (0.8–1.3)	1.7% (1.4–2.0)
2013–2015	10,907	62.4 (58.9–65.9)	170	1.0 (0.7–1.2)	1.5% (1.2–1.9)	138	0.9 (0.7–1.1)	1.5% (1.1–1.8)	221	1.3 (1.0–1.6)	2.1% (1.6–2.5)

Source: Authors' estimates from MEPS 2003–2015 linked to NHIS Sample Child Core 2001–2014

ASD autism spectrum disorder; *CI* confidence interval; *MEPS* Medical Expenditure Panel Survey; *NHIS* National Health Interview Survey

[a]MEPS person-level weights adjusted for non-response to the NHIS Sample Child Core questionnaire applied and then averaged over the pooled time period

Table 2

Distribution of sociodemographic and socioeconomic characteristics in MEPS by source of case ascertainment, U.S. children ages 3–17 years

	Total population age 3–17			NHIS Any ASD			MEPS Any ASD		
	N	Weighted %[a]	95% CI	N	Weighted %	95% CI	N	Weighted %	95% CI
Gender									
Male	23,596	51.0	(50.2–51.8)	356	81.9	(76.2–87.6)	293	82.2	(76.4–87.9)
Female	22,348	49.0	(48.2–49.8)	79	18.1	(12.4–23.8)	67	17.8	(12.1–23.6)
Age									
Age 3–7	16,210	32.8	(32.2–33.5)	111	20.5	(15.5–25.4)	137	32.6	(25.7–39.5)
Age 8–12	14,345	33.1	(32.3–33.8)	179	43.2	(36.5–49.9)	120	34.1	(27.0–41.2)
Age 13–17	15,389	34.1	(33.4–34.8)	145	36.3	(29.0–43.7)	103	33.3	(25.8–40.8)
Race/Ethnicity									
Hispanic	15,970	21.8	(20.2–23.4)	106	15.0	(10.5–19.5)	87	15.3	(10.5–20.1)
Non-Hispanic White	16,682	55.2	(53.6–56.9)	202	63.9	(57.0–70.8)	176	66.2	(59.0–73.4)
Non-Hispanic Black	9011	14.4	(13.3–15.4)	78	12.8	(8.5–17.2)	61	11.5	(7.4–15.6)
Non-Hispanic Asian	2272	4.2	(3.8–4.7)	17	3.2	(0.9–5.5)	13	2.2	(0.6–3.9)
Non-Hispanic Other	2009	4.3	(3.8–4.9)	32	5.0	(2.0–7.9)	23	4.8	(1.8–7.7)
Poverty Status									
Poor	12,417	19.1	(18.2–20.0)	102	17.8	(13.0–22.5)	83	16.4	(11.8–20.9)
Near poor	3414	5.6	(5.3–5.8)	42	7.2	(4.2–10.3)	35	7.4	(4.7–10.1)
Low income	8485	16.0	(15.5–16.5)	73	14.3	(9.8–18.8)	58	15.6	(10.0–21.1)
Middle income	12,415	31.8	(30.9–32.6)	123	31.2	(24.9–37.6)	107	33.1	(26.0–40.3)
High income	9213	27.6	(26.5–28.7)	95	29.4	(22.3–36.5)	77	27.6	(20.4–34.7)
Highest Education in Family									
Less than high school	7409	10.1	(9.5–10.7)	48	8.0	(4.2–11.7)	37	6.8	(3.3–10.3)
High school graduate	13,542	26.3	(25.5–27.2)	103	21.6	(15.6–27.5)	82	21.7	(15.4–28.0)
Some college	12,559	28.7	(27.9–29.5)	122	25.0	(18.6–31.5)	117	31.6	(24.4–38.8)
Bachelors	7536	20.6	(19.8–21.3)	87	24.8	(17.7–32.0)	69	23.9	(16.5–31.2)
Post-graduate	4898	14.4	(13.6–15.2)	75	20.5	(13.7–27.4)	55	15.9	(10.3–21.6)
Census Region									
North	6979	17.0	(15.9–18.1)	77	18.1	(12.2–24.0)	65	19.7	(13.3–26.2)

	Total population age 3–17			NHIS Any ASD			MEPS Any ASD		
	N	Weighted %[a]	95% CI	N	Weighted %	95% CI	N	Weighted %	95% CI
Midwest	8814	21.5	(20.4–22.7)	96	26.3	(18.8–33.9)	84	27.2	(19.1–35.2)
South	17,477	37.2	(35.7–38.7)	133	27.9	(21.2–34.7)	118	31.0	(23.9–38.1)
West	12,674	24.2	(22.9–25.6)	129	27.6	(19.4–35.9)	93	22.1	(15.7–28.5)
Metropolitan Statistical Area (MSA)									
MSA	39,337	84.7	(82.9–86.4)	386	85.9	(80.3–91.5)	316	86.4	(80.6–92.3)
Non-MSA	6607	15.3	(13.6–17.1)	49	14.1	(8.5–19.7)	44	13.6	(7.7–19.4)
Total	45,944	100.0		435	100.0		365	100.0	

Source: Authors' estimates from MEPS 2003–2015 linked to NHIS Sample Child Core 2001–2014.

ASD autism spectrum disorder; *CI* confidence interval; *MEPS* Medical Expenditure Panel Survey; *NHIS* National Health Interview Survey

[a]MEPS person-level weights adjusted for non-response to the NHIS Sample Child Core questionnaire applied and then averaged over the pooled time period

Table 3

Estimated mean total, ASD-specific, and incremental expenditures for ASD by study period and case source, 2018 dollars

		ASD case status				
MEPS Survey Years	**Expenditures (2016 USD)**	**No ASD**	**NHIS**	**MEPS**	**NHIS orMEPS**	**NHIS & MEPS**
2003–2008	N	20,644	119	95	151	63
	Total (95% CI)	1553 (1457–1649)	5364[b] (1785–8943)	7700 (3159–12,241)	5999 (2949–9049)	7357[b] (1007–13,706)
	ASD-specific (95% CI)		_[a]	4340[b] (460–8220)	2745 (240–5250)	_[a]
	Incremental (95% CI)		3811 (266–7356)	6147 (1645–10,649)	4446 (1424–7469)	_[a]
2009–2012	N	14,046	146	127	196	77
	Total (95% CI)	1869 (1611–2128)	6031 (3360–8701)	7835 (4995–10,674)	6137 (4027–8247)	8899 (4498–13,279)
	ASD-specific (95% CI)		3713[b] (1292–6261)	5509 (2805–8212)	3682 (1715–5650)	6913[b] (2655–11,171)
	Incremental (95% CI)		4161 (1497–6826)	5965 (3138–8792)	4268 (2165–6371)	7019 (2653–11,385)
2013–2015	N	10,686	170	138	221	87
	Total (95% CI)	2000 (1588–2412)	5740 (3892–7588)	6669 (4825–8514)	5628 (4039–7217)	7462 (5176–9748)
	ASD-specific (95% CI)		2356 (1288–3424)	3343 (2011–4676)	2343 (1359–3328)	3944 (2314–5574)
	Incremental (95% CI)		3740 (1915–5565)	4670 (2834–6505)	3628 (2044–5212)	5462 (3211–7713)

Source: Authors' estimates from the MEPS 2003–2015 linked to the NHIS Sample Child Core 2001–2014. All estimates (except Ns) weighted using MEPS person-level weights adjusted for non-response to the NHIS Sample Child Core questionnaire

ASD autism spectrum disorder; *CI* confidence interval; *MEPS* Medical Expenditure Panel Survey; *NHIS* National Health Interview Survey; *USD* United States Dollars

[a] Estimate suppressed because it does not meet MEPS guidelines for minimum cell size and/or statistical precision (relative standard error > 0.50)

[b] Relative standard error > 0.30

Table 4

Incremental annual cost estimates for ASD among US children aged 3–17 years, by case source, 2003–2015 pooled, 2018 dollars

	NHIS Any ASD	MEPS Any ASD	MEPS-NHIS Difference	MEPS-NHIS *P*-value
Total N	45,944	45,944		
ASD case N	435	360		
Incremental (unadjusted)(95% CI)	3893 (2305–5480)	5552 (3745–7358)	1659 (676–2641)	0.001
Incremental (adjusted)[a](95% CI)	3930 (2282–5578)	5621 (3671–7570)	1691 (648–2734)	0.001
Sensitivity analyses				
Incremental (adjusted and using 2-year MEPS autism indicator)[a](95% CI)	3930 (2282–5578)	4948 (3279–6618)	1019 (61–1977)	0.037
Incremental (adjusted & trimmed)[b]	2696 (1849–3543)	3966 (3050–4883)	1259 (760–1757)	<0.001

Source: Authors' estimates from the MEPS 2003–2015 linked to the NHIS Sample Child Core 2001–2014. All estimates (except Ns) weighted using MEPS person-level weights adjusted for non-response to the NHIS Sample Child Core questionnaire

ASD autism spectrum disorder; *CI* confidence interval; *MEPS* Medical Expenditure Panel Survey; *NHIS* National Health Interview Survey

[a]Two-part GLM Model (logit predicting any expenditure, GLM model in 2nd part with log-link, gamma distribution). In regression models, we adjusted for a robust set of covariates, including sex, age, poverty status, race/ethnicity, highest education in family, region, and pool year

[b]Two-part GLM Model (logit predicting any expenditure, GLM model in 2nd part with log-link, gamma distribution). Total expenditures above 99th percentile trimmed to 99th percentile