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ORIGINAL PAPER

Medical Expenditures for Children with an Autism Spectrum Disorder in a Privately Insured Population

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Abstract This study provides estimates of medical expenditures for a subset of children and adolescents who receive employer-based health insurance and have a medical diagnosis of an autism spectrum disorder (ASD). Data analyzed were from the 2003 MarketScan® research databases. Individuals with an ASD had average medical expenditures that exceeded those without an ASD by $4,110–$6,200 per year. On average, medical expenditures for individuals with an ASD were 4.1–6.2 times greater than for those without an ASD. Differences in median expenditures ranged from $2,240 to $3,360 per year with median expenditures 8.4–9.5 times greater. These findings add to a growing body of evidence that children and adolescents with medical diagnoses of an ASD incur elevated medical utilization and costs.

Keywords Autism · Autism spectrum disorders · Medical expenditures · Incremental cost · Cost ratio

The increase in numbers of children with a diagnosis of an autism spectrum disorder (ASD) has been accompanied by a growing demand for current estimates of the economic costs associated with the ASDs (Newschaffer and Curran 2003). An often-cited cost study from the United Kingdom did not have access to comprehensive health care utilization and cost data for children with ASDs (Jarbrink and Knapp 2001). The purpose of this analysis is to provide estimates of medical expenditures for a large, national sample of children and adolescents with a medical diagnosis of an ASD who receive medical services paid for by private, self-insured corporate employers in the United States. The findings are compared with estimates from other U.S. studies of medical expenditures for children with ASDs to provide a range of the likely magnitude of medical costs associated with a diagnosis of an ASD.

Three recently published studies have reported medical expenditure estimates for children with an ASD in the U.S. An analysis of Medicaid fee-for-service claims data from a large, metropolitan county in Pennsylvania during 1994–1999 reported that children aged 0–21 years old with an ASD had mean medical expenditures 9 times higher than non-ASD children (Mandell et al. 2006). An analysis of 1999–2000 data from the nationally representative Medical Expenditure Panel Survey (MEPS) reported that a small sample of 31 children with an ASD had mean medical expenditures 7 times higher than non-ASD children (Liptak et al. 2006). Finally, an analysis of 2003–2004 administrative data on 3,053 privately insured children with an ASD enrolled in the Kaiser Permanente Medical Care Program in northern California reported that mean medical costs were 3 times higher than for non-ASD children (Croen et al. 2006). Our study is similar to the latter study in having a large sample of over 3,000 children and adolescents with an ASD but has the advantage of being a nationwide sample encompassing a variety of health care plans.

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Methods

Data Source and Study Population

Data used were drawn from the MarketScan® research databases maintained by Thompson Medstat, a healthcare information company serving large, self-insured employers; government health programs; health plans; providers; and pharmaceutical companies. The MarketScan® databases cover active employees, early retirees, Consolidated Omnibus Budget Reconciliation Act (COBRA) continues, and their dependents, insured by large, corporate employer-sponsored plans, although the different classes of primary beneficiaries cannot be distinguished. The proprietary MarketScan® databases, to which access can be obtained by paying a license fee, contain information on utilization and insurance reimbursement payments for inpatient and outpatient services, and prescription drugs covered by health plans. Person-level demographic, clinical, administrative, and service utilization information is also available (Thompson Medstat 2003). The MarketScan® Commercial Claims and Encounters database was used to access information on medical encounters and costs. The Centers for Disease Control and Prevention (CDC) at the time of this study had access to the Commercial Claims and Encounters databases for the years 1993–2003.

The study population was limited to active enrollees in 2003 with valid unique identification numbers, aged 1–21 years old at the beginning of the year, who were continuously enrolled for the entire calendar year in a fee-for-service insurance plan with pharmaceutical reimbursement data available. Children younger than 1 year of age were excluded because the ASDs are not reliably diagnosed in infants and fewer than 10 children younger than 1 year of age had an ASD diagnosis recorded. The other exclusion criteria were necessary because enrollees in capitated plans do not always have reimbursements or accurate fee-for-service equivalents recorded. This approach ensured that individuals included in the final analysis would have valid cost data for covered services and medications. The study population included both utilizers and non-utilizers of the healthcare system (enrollees with claims and enrollees without claims for 2003). The study population was stratified into four age groups: 1–4-year-olds (early childhood), 5–10-year-olds (middle childhood), 11–17-year-olds (early to mid adolescence), and 18–21-year-olds (late adolescence to early adulthood).

Enrollees in the 2003 database were identified as having an ASD if International Classification of Diseases, Ninth Revision (ICD-9-CM) codes 299.00, 299.01, 299.80, or 299.81 were documented as a primary, secondary, or tertiary diagnosis in the inpatient or outpatient databases. These four ICD-9-CM codes encompass autistic disorder (299.0X), and Asperger's disorder and pervasive developmental disorder—not otherwise specified (299.8X), in both active and residual states. These are the diagnostic subtypes conventionally referred to as the ASDs (Yeargin-Allsopp et al. 2003). These diagnoses could not be confirmed by medical chart reviews and were not necessarily validated by structured observational assessments. This disadvantage common to all administrative datasets was offset by the advantage of a very large sample size.

The presence of one or more ICD-9-CM codes for an ASD recorded during any of the years 1993–2003 was considered sufficient to identify an individual as having a medically diagnosed ASD. This method allowed us to identify patients with an ASD in 2003 that might not have had any ASD-coded hospitalizations or outpatient visits during 2003, but had received an ASD diagnosis sometime in the previous 11 years. In addition, we repeated the analysis using 1 year of diagnostic data (2003) to examine how estimates of medical costs differ when only a single year of diagnostic history is used to identify individuals with an ASD. This should make more of a difference in prevalence and cost estimates for older children, because they would have more previous years of exposure in which to have been diagnosed with an ASD.

Cost Variables

Reimbursement payments for 2003 were used to define medical expenditures. The monetary amounts recorded in the MarketScan® databases represent actual payments by payers (insurers and out-of-pocket expenditures by enrollees or their families, or both) to healthcare providers and facilities. Medical expenditures are not necessarily equivalent to costs as defined by economists in terms of resource consumption; we use expenditure data as a proxy for costs, while recognizing that reimbursements for medical services do not necessarily provide accurate estimates of the societal costs of medical care.

Financial variables were either abstracted directly from the Commercial Claims and Encounters database or calculated from the abstracted variables. Three cost components were used in the analysis: (1) inpatient costs—the costs for services incurred during inpatient hospitalizations, including medications; (2) outpatient costs—the costs for services incurred during outpatient visits; and (3) drug costs—the costs for prescriptions drugs used on an outpatient basis. Total costs are the sum of inpatient, outpatient, and drug costs. Total expenditures are also broken down into its two components, health plan reimbursements and out-of-pocket expenses of families.

Non-utilization by enrollees was set to zero costs. Inpatient and outpatient services included physician services, facility fees, diagnostic services, laboratory services, non-physician provider services, medications, medical equipment, and any other services or products associated with a hospitalization or clinic visit. If health plans covered services such as speech and occupational therapy, claims for those services would also have been included under outpatient visits.

Analysis

Descriptive statistics, including mean and median per capita costs, were calculated for enrollees with and for those without an ASD. The incremental mean costs associated with having a diagnosis of an ASD were calculated by subtracting the mean costs of enrollees without an ASD from the mean costs of enrollees with an ASD. Similarly, the incremental median costs were calculated by subtracting the median costs of enrollees without an ASD from the median costs of enrollees with an ASD. Because the distribution of healthcare costs is highly skewed, with a relatively small number of individuals incurring a disproportionate share of total costs, the mean and the median costs provide distinct types of information. The mean cost is the average cost to payers, whereas the median cost is the cost incurred by the average child. Studies that report mean costs as representing average costs for children without also reporting median costs are subject to misinterpretation. Among recent autism cost studies, two have reported both mean and median costs (Liptak et al. 2006; Croen et al. 2006).

All costs were rounded to the nearest $10 for presentation in the results. We used the 2-tailed t-test to determine whether differences in mean expenditures were statistically significant. Data were extracted from the MarketScan® databases using DataProbe® software (Thompson Medstat 2004) and statistical analysis was conducted using SAS version 9.1 (SAS Institute 2004).

Results

Administrative Prevalence of ASD

A total of 1,202,861 individuals aged 1–21 years old enrolled in a fee-for-service plan for 12 months during 2003 were included in the analysis. Of these, 3,481 had received an ICD-9-CM coded diagnosis of an ASD during any of the years 1993–2003 (Table 1). Accordingly, the administrative prevalence of the ASDs in 1–4-year-olds was 3.2 per 1,000; in 5–10-year-olds it was 4.4 per 1,000; in 11–17-year-olds it was 2.5 per 1,000; and in 18–21-year-olds it was 1.2 per 1,000. Overall, there were 3.9 males with an ASD for each female with an ASD. When the analysis was restricted to 1 year of diagnostic data (2003) to identify individuals with an ASD, the average administrative prevalence was calculated to be 34% lower, 1.9 per 1,000 rather than 2.9 per 1,000 (Table 1). The two sets of prevalence rates were similar in the youngest age group, but the difference increased with age, and in the 18–21-year-old age group, half of all individuals with a recorded ASD diagnosis in the database did not have an ASD billing code recorded in 2003.

Cost Analysis

Mean medical expenditures for individuals with and for those without an ASD diagnosis recorded during any of the years 1993–2003 are displayed in Fig. 1 and Table 2. In both groups, average costs decrease going from ages 1–4 years old to ages 5–10 years old, are roughly stable through ages 11–17 years old, then rise again at ages 18–21 years old. Across age groups, average total expenditures for individuals with an ASD were 4.1–6.2 times greater than for individuals without an ASD. Average incremental expenditures associated with an ASD ranged from a low of $4,110 in 11–17-year-olds to a high of $6,200 in 1–4-year-olds. Median incremental expenditures associated with an ASD ranged from a low of $2,240 in 5–10-year-olds to a high of $3,360 in 1–4-year-olds (Table 2). Across age groups, median expenditures for individuals with an ASD were on the order of 8.4–9.5 times greater than for individuals without an ASD.

In both ASD and non-ASD groups, reimbursements by health plans comprised the bulk of total expenditures for medical care claims (Fig. 1). Specifically, reimbursements covered between 89% and 93% of total expenditures for the ASD group and between 84% and 89% for the non-ASD group. Because total expenditures were much higher, average out-of-pocket expenses for families in the ASD group, including copays and deductibles, amounted to approximately $500–600 per year across all age groups compared with $150–200 per year for the non-ASD group.

Individuals with an ASD diagnosis recorded during a 2003 encounter had high average costs relative to individuals with an ASD diagnosis recorded during the period 1993–2002 but not during 2003 (Fig. 2). The ratio of mean costs relative to non-ASD children was 5.5 times higher for those with a 2003 diagnosis (Table 2) versus 4.8 times higher for the whole ASD sample (Table 2). Mean expenditures during 2003 among children under age 18 years old who had an ASD diagnosis in a previous year but not during 2003 with those who had a diagnosis recorded during 2003, were 51–64% as high as among those with an ASD diagnosis recorded during 2003 (Fig. 2). Inpatient expenditures were 18–39% as high, and outpatient expenditures were 53–63% as high (data not shown). Inpatient admissions

Table 1 Administrative prevalence (per 1,000 individuals) and male to female ratio of autism spectrum disorders (ASD)

Age group	ASD total (diagnosis recorded anytime 1993–2003)	ASD in 2003 (diagnosis recorded in 2003)	Total number in age group in 2003	Prevalence (per 1,000): ASD total (diagnosis recorded anytime 1993–2003)	Prevalence (per 1,000): ASD in 2003 (diagnosis recorded in 2003)	Male/Female ratio for ASD (diagnosis recorded anytime 1993–2003)
1–4 years old	597	504	184,423	3.2	2.7	3.8
5–10 years old	1,427	966	322,266	4.4	3.0	4.5
11–17 years old	1,182	699	471,242	2.5	1.5	3.7
18–21 years old	275	132	224,930	1.2	0.6	2.8
Total 1–21 years old	3,481	2,301	1,202,861	2.9	1.9	3.9

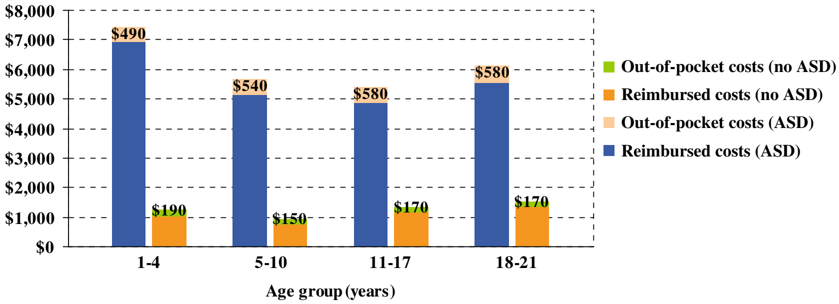

Fig. 1 Age-specific average expenditures during 2003 for individuals with and without an autism spectrum disorder (ASD) diagnosis recorded anytime 1993–2003, comparing health plan reimbursements and family out-of-pocket expenses

Table 2 Average and median costs, incremental costs associated with an autism spectrum disorder (ASD), and age-specific average and median cost ratios

Age group	ASD diagnosis recorded anytime during:				No ASD diagnosis		Incremental cost (may contain rounding errors)				Cost ratio (ASD ÷ No ASD)			
	1993–2003		2003		1993–2003		1993–2003		2003		1993–2003		2003	
	Mean	Median	Mean	Median	Mean	Median	Mean	Median	Mean	Median	Mean	Median	Mean	Median
1–4 years old	$7,430	3,820	$8,040	4,460	$1,230	460	$6,200*	3,360	$7,810*	4,000	6.1	8.4	6.5	9.8
5–10 years old	5,670	2,500	6,420	3,020	920	260	4,750*	2,240	5,500*	2,760	6.2	9.5	7.0	11.5
11–17 years old	5,430	2,900	6,550	3,670	1,330	310	4,110*	2,590	5,220*	3,360	4.1	9.4	4.9	11.8
18–21 years old	6,130	2,870	6,630	4,240	1,500	310	4,630*	2,560	5,130*	3,930	4.1	9.3	4.4	13.7
Total 1–21 years old	5,930	2,870	6,830	3,600	1,230	320	4,690*	2,550	5,590*	3,280	4.8	9.0	5.5	11.2

* *P*-value < .001

accounted for 16–34% of the total difference in expenditures between the two diagnostic groups.

Average inpatient, outpatient, and drug costs for individuals with and for those without an ASD are shown graphically in Fig. 3. The mean cost ratio was highest for prescription medications, 6.2, and lowest for inpatient care, 3.8. Although relative inpatient costs are stable across age groups, the cost ratio for outpatient care decreased with age from 7.2 at 1–4 years old to 2.2 at 18–21 years old. Conversely, the cost ratio for medications increased from 2.4 at 1–4 years old to 9.6 at 18–21 years old. As children with an ASD age, prescription medications represent an increasing share of total costs.

Our findings indicate that for privately insured children with a medical diagnosis of an ASD, the distribution of costs is concentrated in outpatient services in younger age groups and shifts more to pharmaceuticals in older age groups. Previous work confirms that psychoactive medication use in individuals with an ASD is positively associated with increasing age (Aman et al. 2003; Langworthy-Lam et al. 2002; Martin et al. 1999).

Discussion

When using diagnostic data from 1993 to 2003 to identify current year (2003) ASD cases, age-specific mean medical expenditures were 4–6 times higher for privately insured children with a medical diagnosis of an ASD than for those without such a diagnosis. Median medical expenditures

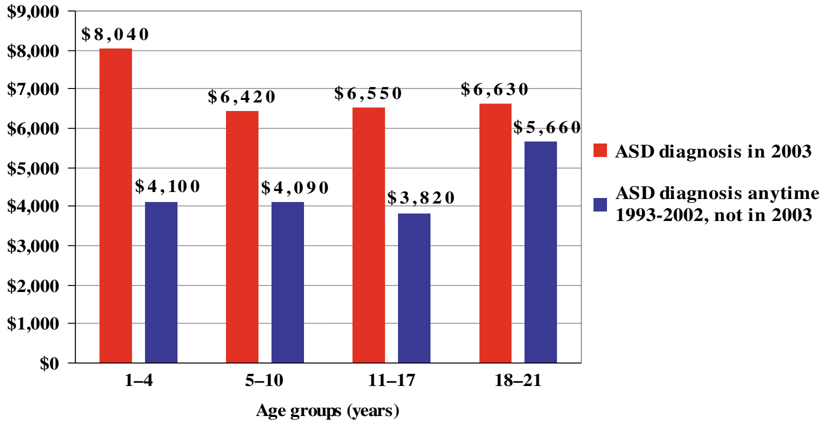

Fig. 2 Age-specific average expenditures during 2003 for individuals with an autism spectrum disorder (ASD) diagnosis recorded in 2003, comparing those with a diagnosis recorded anytime from 1993 to 2002, but not in 2003

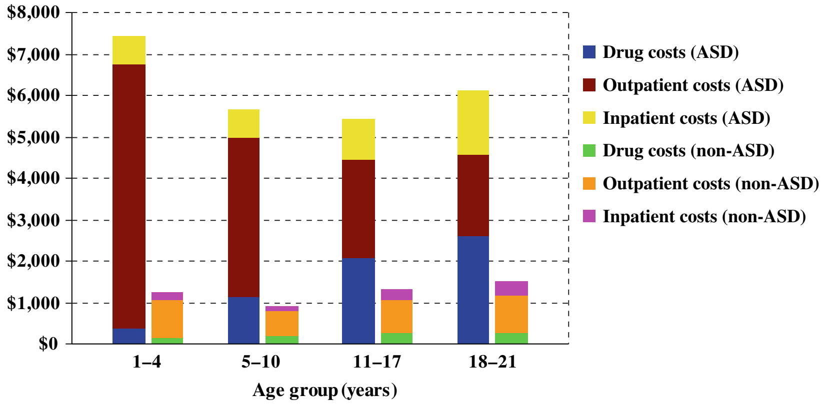

Fig. 3 Age-specific average component costs for individuals with and those without an autism spectrum disorder (ASD); diagnosis recorded anytime 1993–2003

were 8–9 times higher. When restricted to those with a current year ASD diagnosis, mean expenditures were 4–7 times higher and median expenditures were 10–14 times higher than for those without a current ASD diagnosis.

Those individuals who had an ASD diagnosis recorded in the current year constitute a subset of individuals for whom an ASD diagnosis was regarded as relevant for current billing purposes. It is reasonable that they would be more likely to be high users of services because they were presumably more likely to require medical services related to an ASD in the past year. An important implication is that analyses that define ASD cases based on an ASD diagnosis recorded in health insurance claims data during a single year are likely to yield upwardly biased estimates of average healthcare utilization and costs for children with an ASD. This varies with age. As expected, among the youngest children the estimated administrative prevalence of ASDs does not depend much on use of multiple years of data but it does for older age groups. This has implications for the use of administrative data to identify expenditures for older children and adolescents with an ASD.

Our finding of the ratio of mean medical expenditures for all children 1–21 years old with an ASD relative to those without an ASD in a privately-insured population was 4.8 to 1, which compares with a ratio of 9.0 to 1 reported by Mandell et al. (2006) for a Medicaid sample. The latter analysis used ICD-9-CM codes of 299.xx to define cases of ASDs. However, 299.1 codes for childhood disintegrative disorders and 299.9 includes atypical and unspecified child psychosis and schizophrenia. Our ratios are intermediate between those of two other recent cost analyses that used the same 299.0 and 299.8 ICD-9-CM codes as this study, 3.0 (Croen et al. 2006) and 7.1 (Liptak et al. 2006).

An important finding is that the distribution of medical care utilization shifts as children with ASDs age, including an increasing use of prescription medications and inpatient care. These results suggest that individuals with an ASD are utilizing increasingly intense pharmacotherapy to control behavioral symptoms as they grow older. A separately published drug class-specific analysis of MarketScan® prescription drug claims for children over 8 years of age with an ASD medical diagnosis, conducted in parallel with the present analysis, found that the highest rates of utilization were for antidepressants (32%), stimulants (27%), and antipsychotics (24%) (Oswald and Sonenklar 2007). According to Mandell et al. (1999) the predominant type of inpatient admissions for adolescents with ASDs are for psychiatric care. An implication is that adolescents with ASDs require increasing levels of mental health services.

The distribution of payments between fee-for-service health plan reimbursements and family out-of-pocket costs reflected in the MarketScan® Commercial Claims and Encounters database indicates that families of children with ASDs pay a smaller share of total medical expenditures than families of unaffected children but several times more in absolute dollars. This finding applies only to out-of-pocket expenditures for allowable claims, however. Medical care services not covered by health plans are not included.

Limitations

This study is subject to several limitations. First, not all individuals classified as having an ASD were necessarily actual ASD cases, and valid case determination would require access to individual medical records. There are likely to be some instances of an ASD "rule-out" diagnosis where an autism diagnostic evaluation was performed for a child who was determined not to have autism and a claim was submitted under a 299 ICD-9-CM code. One approach that has been used before to eliminate rule-out diagnoses is to require the presence of two or more ASD diagnoses per individual, although it was not stated how many cases were thereby excluded (Mandell et al. 2006). In this study we required that a subtype classification be recorded (e.g., 299.0), which should eliminate many rule-out diagnoses. The finding in a previous study from Atlanta, Georgia that 98% of children with an administrative diagnosis of an ASD were subsequently confirmed as ASD cases when a structured approach was used (Yeargin-Allsopp et al. 2003) is also reassuring, although it applies to a different population.

Another limitation is incomplete case ascertainment, which appears to be the case given the lower administrative prevalence found here than in other recent estimates (Centers for Disease Control and Prevention 2006). It is possible that not all individuals with an ASD that was clinically identified were identified as such in the MarketScan® data, in part because they might have had another diagnostic code recorded for billing purposes. Certain healthcare plans maintain a list of diagnoses for which healthcare services will not be covered, and childhood mental health and developmental disorders often figure prominently (Peele et al. 2002). Furthermore, because of the existence of such exclusions, some providers are hesitant to use ASD diagnoses even if they are not explicitly excluded in a given child's healthcare plan. In such cases, providers are likely to bill services under one of the child's comorbid conditions. In addition, records of an ASD diagnosis are likely to be restricted to those receiving medical treatment relevant to an ASD, which are not necessarily representative of all those having received an ASD diagnosis at some point. We attempted to mitigate these problems by identifying children with an ASD if they had an ICD-9-CM coded ASD diagnosis anytime during the period 1993–2003.

The most important limitation of this analysis is that it is restricted to children with physician-diagnosed ASD. A study from a large U.S. metropolitan area indicated that the majority of children with an ASD were diagnosed by psychologists, not physicians (Wiggins et al. 2006). Those with an ASD not known to the medical system and not receiving medical care for an ASD are presumably more likely to have utilization of medical care similar to the general population. Studies of children identified with an ASD through representative population surveys, the majority of whom are likely to not have a medical diagnosis of an ASD, report less elevated utilization of outpatient healthcare services compared with the general population, with utilization ratios less than 2 to 1 (Ganz 2006; Gurney et al. 2006).

Another critical issue in understanding healthcare costs for children with an ASD is the impact of multiple health insurance coverage. Some portion of the population is eligible for, and makes use of, Medicaid coverage through special waivers in addition to private insurance. In these cases, Medicaid might assume responsibility for certain charges related to treatment for developmental disabilities. Therefore, private insurance reimbursements could underestimate direct medical costs associated with an ASD.

The method of tabulation of average health expenditures for subgroups used in this analysis is simple in comparison with multivariate regression analysis methods that are often used in analyses of medical expenditures, although the same limitation applies to all other published analyses of medical expenditures for individuals with an ASD. A limitation of administrative datasets is that identifying information is generally limited to age and sex, and it is not clear that including those variables in a regression framework would provide an advantage relative to tabulation. We did not present results stratified by sex, because there were no significant differences in expenditures among males and females with an ASD diagnoses.

Further analyses of these data could address other comparisons, such as children with an ASD relative to children with other developmental or mental health disorders. A similar analysis of the 2003 MarketScan® Commercial Claims and Encounters database comparing medical expenditures for individuals with spina bifida and the general population has recently been published (Ouyang et al. 2007). That analysis reported mean medical expenditures of $15,242 for children 1–17 years of age, 13.0 times higher than children without spina bifida. In comparison, the mean medical expenditures in 2003 for children 1–17 years of age with ASD were $5,909, or 0.4 times as much as for those with spina bifida. It could also be helpful to examine how the presence of other comorbid conditions or diagnoses influences the utilization of healthcare services. That type of analysis could identify the level of expenditures associated with an ASD diagnosis both with and without another mental health or developmental condition.

Conclusions

This study adds to the growing body of estimates of the medical expenditures of children with an ASD. Specifically, it quantifies the medical expenditures associated with a medical diagnosis of the ASDs in a large, national sample of privately insured children. An important advantage of this analysis relative to other studies of medical expenditures for ASDs using administrative datasets is that it demonstrates the inherent limitation of ascertaining cases from a single year of medical claims. A large percentage of children and adolescents with a previously recorded diagnosis of an ASD do not have the diagnosis recorded in a given year, and this percentage rises as children age. Consequently, analyses of claims data that rely on a single year of data to ascertain medically diagnosed cases are based on biased samples that are skewed toward those with relatively greater utilization of healthcare services and hence, costs. Furthermore, all studies that rely on a medically diagnosed ASD are biased relative to cohorts of children with an ASD that include those who have not been diagnosed in the healthcare system.

Our analysis only covers mental health, behavioral, and other therapeutics that were covered by private health plans in which families were enrolled, and these costs are almost certainly understated. Alternative and complementary therapies commonly used by individuals with an ASD are rarely covered by insurance (Ganz 2006). More comprehensive information on the economic costs associated with the ASDs requires data on expenditures for non-medical or alternative medical therapies and behavioral therapies, as well as the lost earnings of parents who care for a child with an ASD. Such information can only be derived from a survey of a representative sample of families of children and adolescents with an ASD.

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