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Healthcare Service Use and Costs for Autism Spectrum Disorder: A Comparison Between Medicaid and Private Insurance

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Abstract

Healthcare costs and service use for autism spectrum disorder (ASD) were compared between Medicaid and private insurance, using 2003 insurance claims data in 24 states. In terms of costs and service use per child with ASD, Medicaid had higher total healthcare costs (\$22,653 vs. \$5,254), higher ASD-specific costs (\$7,438 vs. \$928), higher psychotropic medication costs (\$1,468 vs. \$875), more speech therapy visits (13.0 vs. 3.6 visits), more occupational/physical therapy visits (6.4 vs. 0.9 visits), and more behavior modification/social skills visits (3.8 vs. 1.1 visits) than private insurance (all $p < 0.0001$). In multivariate analysis, being enrolled in Medicaid had the largest effect on costs, after controlling for other variables. The findings emphasize the need for continued efforts to improve private insurance coverage of autism.

Keywords

Autism spectrum disorder; children; healthcare costs; service use; Medicaid; private insurance

Introduction

Autism Spectrum Disorders (ASD) are a set of neurodevelopmental disorders with defining features of impairment in social interaction and communication, stereotypic and/or repetitive behavior, and onset early in life (Miles JH). The prevalence of ASD has risen rapidly in recent years (Fombonne 2003; Waterhouse 2008). According to an estimate by the Centers for Disease Control and Prevention, ASD prevalence increased by 57% annually from 2002 to 2006, reaching one in every 88 children in 2008 (CDC 2012).

ASD requires intensive long-term treatment and the associated costs are usually higher than costs of care for other disorders (Wang and Leslie ; Leslie, Rosenheck et al. 2001; Liptak, Stuart et al. 2006; Mandell, Cao et al. 2006; Ganz 2007). Behavioral interventions have been proven effective and are recommended in treating ASD (McPheeters, Warren et al. ; Vismara and Rogers ; Case-Smith and Arbesman 2008). Traditionally, private insurance

plans in the United States have excluded the coverage of most ASD-specific treatment. As a result, privately insured children with ASD may not have adequate insurance coverage for needed ASD services. Perhaps as a result, out-of-pocket healthcare costs are higher for families of children with ASD than for families of children with other disorders (Jarbrink, Fombonne et al. 2003; Ganz 2007; Montes and Halterman 2008).

On the other hand, most state Medicaid programs provide health care services to eligible children with ASD through the Medicaid Home and Community-Based Services (HCBS) waiver program for mental retardation/intellectual disability/development disabilities, or through autism-specific Medicaid waivers (Wang and Leslie ; Shattuck and Grosse 2007; Shattuck, Grosse et al. 2009). Under these HCBS waiver programs, children with ASD may be eligible for Medicaid coverage irrespective of their family income. With the rising prevalence of ASD and its high medical costs, however, state Medicaid programs face the financial challenges of providing services to more and more children with ASD (Semansky, Xie et al. ; Waterhouse 2008).

How the costs of ASD care should be shared among public and private health insurers has been a long-debated topic. To address this issue, comparing the financial burden and types of services provided in both the private and public health insurance sectors can be informative. This comparison can inform policies aimed at improving the financing and coordination of care for ASD. Insurance type has been shown to be an important factor in determining the utilization and costs of general medical services, though there is a lack of formal study regarding ASD care and insurance type. Many studies have examined the associations between insurance type and service utilization and costs among children with special health care needs (SHCN). Findings from these studies have been inconsistent; some suggest that private insurance plans are superior to public plans in providing access to services and ensuring greater variety of services (Newacheck, Pearl et al. 1998; Newacheck, McManus et al. 2000); whereas others indicate that Medicaid is superior (Krauss, Gulley et al. 2003; Weller, Minkovitz et al. 2003; Witt, Kasper et al. 2003; Liptak, Benzoni et al. 2008), and still others report no differences (Newacheck, McManus et al. 2000; Kuhlthau, Nyman et al. 2004; Honberg, McPherson et al. 2005; Smaldone, Honig et al. 2005; Liptak, Benzoni et al. 2008). Findings related to children with SHCN may not be directly applicable to children with ASD, however. The only published study that has addressed ASD as a subgroup of children with SHCN is Young et. al. (Young, Ruble et al. 2009), in which a community based survey was used to examine the associations between insurance type and out-of-pocket expenditures, variety of services used, and access to services. Contrary to previous findings, no statistically significant differences were found based on insurance type. The small sample size (n=107) may have limited the power to detect such differences, if they existed.

There is no head-to-head comparison in the literature of public and private systems regarding the health service use and costs of children with ASD using nationwide insurance claims data. Previous studies have focused on only the public or private insurance system separately (Wang and Leslie ; Croen, Najjar et al. 2006; Mandell, Cao et al. 2006; Leslie and Martin 2007). Since the analytical methods and data sources differ from one study to another, cross-comparisons among independent studies may yield distorted information. Additionally, different studies have examined different aspects of care, making comparisons across systems difficult.

This study compares health care costs and types of services provided for ASD treatment between Medicaid and private insurance. We use nationwide data, and conduct comparisons at both the national level and individual state level.

Methods

Data

The data for individuals covered by private health insurers were obtained from the 2003 Thomson Reuters MarketScan® Commercial Claims and Encounters Database, which contains information from about 100 private health insurers across all 50 states and the District of Columbia. The MarketScan database includes a patient-level enrollment file and insurance claims data for inpatient and outpatient care as well as prescription drug use.

Medicaid data were obtained from the 2003 Medicaid Analytic eXtract (MAX) files. Data were available for 42 states and the District of Columbia. The following states were excluded: Colorado, Delaware, Michigan, Montana, North Dakota, South Dakota, Tennessee, Utah and Washington. Medicaid data include a patient-level enrollment file and four claims data files: inpatient, long-term care, outpatient, and drug use. Long-term care claims were grouped into the outpatient care category for analysis. Long-term care rarely exists in MarketScan data, for private insurance seldom covers long-term care. For the rare long-term care identified in MarketScan data, it was also analyzed as outpatient care.

To examine how county-level income, racial composition and urbanicity affected health care costs, data from the 2003 Area Resource File were merged with the patient-level data by the patient's county of residence (Stambler 1988). The patient's county of residence was not available in MarketScan, so the employer's county was used as a proxy. A county's urban/rural status was collected from the Area Resource File using the Rural/Urban Continuum Codes, based on a county's metro/non-metro status as determined by the US Office of Management and Budget (Stambler 1988).

The Institutional Review Board of the Pennsylvania State University College of Medicine approved this study.

Inclusion Criteria

Children who were 17 years or younger in 2003 and continuously enrolled for the entire calendar year in a Medicaid fee-for-service plan or a MarketScan private insurance plan were included in the study. Medicaid managed care plans were not included because claims and expenditure data may not be as accurate as in fee-for-service plans (DHHS 2009). For the MarketScan sample, only children for whom the information on prescription drug use was also available were included. About one fourth of children with ASD in MarketScan did not have accompanying prescription drug information and were excluded from our study, whereas all Medicaid-enrolled children had data on medication use.

Children with ASD were identified from claims data files using International Classification of Diseases, Ninth Edition (ICD-9) codes 299.0 and 299.8. Children having either two or more outpatient claims on two different days or at least one inpatient claim with an ASD diagnosis were considered to have ASD. This method of case ascertainment has been widely used in the literature (Wang and Leslie ; Mandell, Cao et al. 2006). Although Medicaid data were available for 42 states, only the 24 states that had at least 20 children with ASD in both the Medicaid and the MarketScan system who met inclusion criteria were included (see Table 3 for a list of these states).

Data Analysis

The patient characteristics were compared between all enrolled children and children with ASD in each system respectively. The same states and the same inclusion criteria mentioned above were applied to all enrolled children and children with ASD.

For children with ASD, health care utilization and associated costs were categorized to study specific types of services or procedures. Psychiatric care and ASD care were defined as care with a primary diagnosis code of a mental disorder (ICD-9 code of 290-319) and of ASD (ICD-9 code of 299.0 or 299.8), respectively. We examined the use of occupational therapy/physical therapy (OT/PT), behavior modification and speech therapy, which were identified from a collection of procedural codes used in the literature (CMHPSR 2012). Psychotropic medication use included prescriptions for antidepressants, stimulants, tranquilizers, antipsychotics, and anxiolytics/sedative/hypnotics (Mandell, Morales et al. 2008; Rubin, Feudtner et al. 2009), which were identified using the corresponding National Drug Codes. Healthcare costs were measured by the amount of the reimbursement made by the insurance system to providers, and were categorized into inpatient, outpatient and medication costs. The costs considered in the study were from the payer's perspective, i.e., what the insurance system paid for health services. Out-of-pocket costs were not considered because, although they are likely minimal for Medicaid, data on out-of-pocket spending in Medicaid were not available.

Statistical Methods

Group means were compared using t-tests in univariate analysis. Although the raw data were not normally distributed, t-tests provide robust results when the sample size is large (Lumley, Diehr et al. 2002). Chi-square tests were used to compare proportions. A Pearson correlation coefficient was derived to test the correlation of Medicaid costs and MarketScan costs within a given state. The Pearson correlation coefficient is a standardized coefficient with possible values in $[-1, 1]$. The closer the coefficient is to zero, the less the correlation. In multivariate analysis, costs were modeled using generalized linear models with a log link function and Gamma error distribution. The interaction terms of the insurance type (Medicaid vs. private insurance) and all other covariates were included to test whether the effects of the covariates differed by insurance type, and only the significant interaction term was included in the final model. SAS software (Cary, NC) was used for data analysis.

Results

Table 1 describes the characteristics of all enrolled children and the study sample in Medicaid and MarketScan. In both Medicaid and private insurance, more than 2 million children served as the population from which the study sample was drawn. A total of 18,108 children with ASD from Medicaid and 2,366 children with ASD from MarketScan were included in our study, yielding a treated prevalence of ASD that was more than five times higher in Medicaid than in MarketScan. Though both genders were about equally represented for all children (about 51% of males), more than 78% of children with ASD were males in both datasets. Compared with all enrolled children, children with ASD were more likely to be from urban areas and from counties with higher median household income and higher percentage of white residents. Privately insured children were more likely to be from urban counties with a higher median household income.

Table 2 presents health care service use and costs per child with ASD in both Medicaid and MarketScan. Average total health care costs (regardless of whether the claim had a diagnosis of ASD) per child with ASD were more than four times higher in Medicaid than in MarketScan (\$22,653 vs. \$5,254, $p < 0.0001$). The biggest component of the cost difference across Medicaid and MarketScan was in outpatient services (\$19,948 vs. \$3,045, $p < 0.0001$). Psychiatric care costs as defined previously were over five times higher in Medicaid than in private insurance (\$12,851 vs. \$2,293, $p < 0.0001$) and were responsible for a larger fraction of total healthcare costs (57% vs. 44% per child with ASD, respectively). Most of this difference in psychiatric care costs was due to differences in outpatient costs. ASD-specific service costs were eight times higher in Medicaid than in the private sector (\$7,438 vs. \$928,

$p < 0.0001$). Medicaid patients also received significantly more visits for OT/PT, speech therapy and behavior modification treatment than patients enrolled in private insurance.

Table 3 indicates average total healthcare costs per child with ASD by state in both insurance systems. The average cost in Medicaid was higher than in private insurance in every state. There was no significant correlation between the Medicaid cost and private insurance cost (estimated correlation coefficient: 0.17; $p = 0.42$). Some states were heavy-spenders or low-spenders in both systems, while others had low spending in one system and high spending in the other. Some had a cost differential as large as more than \$30,000 between Medicaid and MarketScan, while others had a cost differential between Medicaid and MarketScan of no more than a few thousand dollars.

Health care costs were modeled using a generalized linear model, with covariates being gender, age, insurance type, logarithm of median household income, percentage of white residents and urbanicity by the child's county of residence. The only significant interaction term was that between insurance type and percentage of white residents. The model fits well by the goodness-of-fit statistics produced by SAS. In table 4, the unadjusted mean is the raw mean at a given level of a categorical variable; whereas the adjusted mean is the mean predicted by the estimated model, holding other factors at the sample mean level. Multivariate analysis showed that healthcare costs increased with age and income level, with male gender and urban county of residence also being associated with higher costs. Medicaid expenditures increased on average as the percentage of white residents increased, but private insurance expenditures did not. The covariate that attributed the biggest difference in costs was insurance type. At every category of the percentage of white residents, the cost difference between Medicaid and private insurance was at least \$15,000 in the unadjusted analysis, and at least \$13,000 in the adjusted analysis.

Discussion

This study is the first to directly compare healthcare utilization and costs for children with ASD enrolled in Medicaid versus private insurance using nationwide claims data. We found that average healthcare expenditures for Medicaid-enrolled children with ASD were four times higher than those of children enrolled in private insurance plans. ASD-specific healthcare costs alone in Medicaid were higher than the total healthcare costs in private insurance per child with ASD. Medicaid-enrolled children with ASD received many more services than those enrolled in private insurance. Each state in our study sample had greater expenditures per child with ASD in Medicaid than in private insurance.

To check whether the result of higher costs in Medicaid was robust to extreme cost outliers sometimes found in claims data, we performed a sensitivity analysis that minimized the influence of cost outliers. In the sensitivity analysis, we Winsorized the total cost data, where the actual cost for children in the upper 1% (or lowest 1%) in total health care costs were equated to that of the 99th (or 1st) percentile cost, thereby reducing the effect of extreme values (Tukey 1962). The Winsorized total costs were again about four times higher in Medicaid (\$22,014 vs. \$4,860, $p < 0.0001$) than in private insurance.

There are several potential explanations for the higher costs of care for children with ASD in Medicaid. It is possible that these differences are attributable to unmeasured differences in health status. Children in Medicaid may be more severely ill and hence need more care than children with private insurance. The eligibility criteria in Medicaid are quite different from private insurance, which may result in a more severely ill population.

Children in Medicaid received a lot more ASD-specific services like speech therapy, OT/PT, and behavior modification. There were few of these services in MarketScan, yet these are

the services that have been shown to be most effective in addressing core deficits in children with ASD. One reason for this may be that private insurance companies traditionally have severely limited coverage of treatments for individuals with autism or excluded coverage altogether (Peele, Lave et al. 2002; Boudier, Spielman et al. 2009). Many of the services recommended for children with ASD are often excluded under private plans on the grounds that they are unproven or experimental (Barry, Gabel et al. 2003; Rogers and Vismara 2008; Boudier, Spielman et al. 2009), or that they are the responsibility of the education system. Many states have now passed laws requiring that private health insurers cover the early testing, diagnosis and treatment of ASD, suggesting that private insurance has not independently covered these services without legislation requiring them to do so. Healthcare providers and policy makers should be aware that children with autism who are covered only by private insurance are potentially at risk for being underinsured (Fox and Newacheck 1990). Other provisions may be necessary for privately insured children to obtain needed ASD-specific services.

Another explanation is that Medicaid covers different services than private insurance, and some of these services are expensive. For instance, children enrolled in private insurance received almost no long-term care services, whereas children in Medicaid received a considerable amount of long-term care, mainly in the form of intermediate care facility use for children with intellectual disabilities, resulting in an average cost of \$2,694 per child with ASD.

Interestingly, expenditures were similar for hospital care, with Medicaid actually having lower inpatient costs. The average number of hospitalizations (0.1 vs. 0.2 times per child with ASD) and the number of hospitalization with a diagnosis of a mental disorder (0.04 vs. 0.05) were lower in Medicaid than private insurance per child with ASD, suggesting a potential substitution effect between outpatient and inpatient services found in a previous study (Mandell, Xie et al.).

Some limitations of the study deserve comment. First, claims data do not contain information about socioeconomic status at the individual patient level. We used county-level socioeconomic variables by the child's county of residence. In addition, using the employer's county to proxy the county of residence in the MarketScan sample may not be accurate, yet it is reasonable to assume that employees usually live in counties close to their employer, thus sharing some similarities in county characteristics. A second limitation is that the data used for this study were from 2003. However, the findings are highly relevant to current ASD care. Although many states have passed bills mandating private insurance coverage of ASD, about 20 states have not enacted an autism mandate (AutismSpeaks 2012). Our findings of much lower spending on ASD in private insurance at a time when no autism mandates were in place highlights the importance of autism insurance mandates that enable privately insured children with ASD to get more ASD-related services. A third limitation is that our findings are from the payer's perspective: what Medicaid or private insurance paid, which may be just a proportion of ASD services received by a child with ASD. Privately insured children may also be enrolled in Medicaid due to certain Medicaid waivers and get services from Medicaid. Moreover, insurance claims data do not contain the services that children with ASD may get beyond what health insurers paid, such as services paid by out-of-pocket costs that are not submitted to insurers, services provided by early intervention and special education. This needs to be considered when interpreting our findings.

Despite these limitations, our results show that children with ASD in Medicaid received more ASD-specific and overall health care services than those with private insurance. This conclusion is robust to various inclusion criteria, as shown by various sensitivity analyses that varied the inclusion criteria such as reducing the number of enrollment months and

including children in MarketScan who had no prescription drug data. Further study is needed to determine whether the higher spending in Medicaid results in better health outcomes and greater patient satisfaction with care. In addition, the availability of ASD providers may also affect service utilization and costs and should be examined in future research.

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Table 1

Characteristics of Children in Each Insurance System

	Medicaid ^a	MarketScan ^b	P-value
All enrolled children			
N	2,906,819	2,123,047	NA
% male	51.6%	51.2%	<0.0001
age in years (mean±SD)	8.5±5.0	9.2±5.1	<0.0001
% in urban counties ^c	69.7%	85.9%	<0.0001
median household income by county	\$39,083	\$45,626	<0.0001
% white residents by county	74.1%	72.6%	<0.0001
Children with ASD			
N	18,108	2,366	NA
Treated prevalence per 10,000 children	62.3	11.1	<0.0001
% male	78.8%	81.7%	0.003
age in years (mean±SD)	10.0±5.4	8.2±4.2	<0.0001
% in urban counties	79.6%	90.2%	<0.0001
median household income by county	\$43,509	\$48,511	<0.0001
% white residents by county	77.6%	75.8%	<0.0001

^aContinuously enrolled for 12 calendar months in fee-for-service plan; age 17.

^bContinuously enrolled for 12 calendar months with medication use information; age 17.

^cThe county variable in Table 1 refers to the county of residence for children enrolled in Medicaid, and the county of parental employment for children enrolled in MarketScan.

Table 2

Mean Health Care Services Use and Costs per Child with ASD by Insurance Type

	Medicaid	Private Insurance	P-value
Total health care costs	\$22,653	\$5,254	0.0001
Inpatient	\$719	\$1,079	0.07
Outpatient	\$19,948	\$3,045	<0.0001
Medication	\$1,985	\$1,129	<0.0001
Psychiatric care costs	\$12,851	\$2,293	<0.0001
Inpatient psychiatric	\$349	\$341	0.90
Outpatient psychiatric	\$11,033	\$1,207	<0.0001
Psychotropic medication	\$1,468	\$875	<0.0001
ASD-specific care costs	\$7,438	\$928	<0.0001
Inpatient ASD-specific costs	\$141	\$92	0.47
Outpatient ASD-specific costs	\$7,297	\$836	<0.0001
Specific outpatient procedures			
OT/PT			
Number of visits	6.4	0.9	<0.0001
Costs	\$271	\$45	<0.0001
Speech therapy			
Number of visits	13.0	3.6	<0.0001
Costs	\$569	\$227	<0.0001
Behavioral modification			
Number of visits	3.8	1.1	<0.0001
Costs	\$440	\$67	<0.0001

Table 3Costs for ASD in Individual States^{*}

State	Medicaid		MarketScan	
	Number of children	Avg. Expenditures	Number of children	Avg. Expenditures
AR	24	\$40,639	32	\$4,973
CA	21	\$39,936	527	\$3,851
CT	121	\$36,704	24	\$5,537
FL	138	\$29,392	86	\$6,384
GA	904	\$8,408	184	\$8,085
IL	1685	\$8,011	107	\$5,745
IN	575	\$31,708	91	\$7,352
KS	327	\$23,279	62	\$4,599
LA	206	\$18,795	24	\$3,832
MA	142	\$12,650	154	\$3,870
MN	1563	\$36,005	59	\$9,554
MO	877	\$11,745	81	\$4,731
MS	497	\$14,438	29	\$3,538
NC	476	\$47,082	58	\$6,458
NH	302	\$24,724	24	\$4,279
NJ	339	\$22,822	123	\$5,090
NY	2544	\$30,949	140	\$5,886
OH	1854	\$22,143	125	\$3,404
OK	68	\$41,411	24	\$5,082
PA	737	\$28,682	74	\$4,429
SC	1174	\$11,303	60	\$5,690
TX	1443	\$18,174	168	\$5,925
VA	229	\$18,971	46	\$4,264
WI	1862	\$25,951	66	\$6,647

Inclusion criteria in MarketScan: 12 calendar months enrollment, age 17, with prescription medication information available.

^{*}Inclusion criteria in Medicaid: 12 calendar months enrollment in fee-for-service plan, age 17.

Table 4

Modeling of Total Health Care Costs per Child with ASD

Variable	Unadjusted mean		Adjusted analysis	
	Unadjusted mean	p-value	mean	p-value
Gender		<0.0001		<0.0001
Male	\$22,258		\$19,565	
Female	\$20,213		\$18,138	
Urban		<0.0001		<0.0001
Yes	\$21,504		\$18,620	
No	\$18,738		\$17,665	
Age (by quartile)		<0.0001		<0.0001
Q1 (0-6 years)	\$14,389		\$14,456	
Q2 (7-9 years)	\$17,132		\$15,520	
Q3 (10-13 years)	\$20,140		\$18,292	
Q4 (13-17 years)	\$28,759		\$25,708	
Log(median income)		<0.0001		<0.0001
Q1 (<\$37,720)	\$17,874		\$15,752	
Q2 [\$37,720,\$42,723]	\$17,854		\$16,257	
Q3 [\$42,723, \$48,297]	\$23,514		\$21,032	
Q4 (\$48,297)	\$23,648		\$21,746	
Insurance type * % white		<0.0001		<0.0001
Medicaid				
Q1 of % White (<65%)	\$20,103		\$18,724	
Q2 of % White [65%-80%)	\$22,687		\$21,564	
Q3 of % White [80%-93%)	\$23,960		\$22,526	
Q4 of % White (93%)	\$23,880		\$23,923	
Private Insurance				
Q1 of % White (<65%)	\$5,059		\$5,662	
Q2 of % White [65%-80%)	\$5,102		\$5,600	
Q3 of % White [80%-93%)	\$5,735		\$5,747	
Q4 of % White (93%)	\$4,914		\$5,019	