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Health Care Expenditures for Children with Autism Spectrum Disorders in Medicaid

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Abstract

Objective—To study trends in health care expenditures associated with autism spectrum disorders (ASDs) in state Medicaid programs.

Method—Using Medicaid data from 42 states from 2000–2003, patients aged 17 years and under who were continuously enrolled in fee-for-service Medicaid were studied. Patients with claims related to autistic disorder (autism) were identified, as were patients with claims for any ASD other than autism. Total expenditures per treated patient consisted of Medicaid reimbursements from inpatient, outpatient, and long-term care and prescription drugs. Inflation-adjusted expenditures were compared over time and with expenditures associated with other mental health disorders.

Results—A total of 2,184,677 children were diagnosed with some type of mental disorder during the study period. Of these children, 69,542 had an ASD, with 49,921 having autism and the rest having another ASD. Mean total health care expenditures per child with ASD were \$22,079 in 2000 (in 2003 US dollars), and rose by 3.1% to \$22,772 in 2003. The treated prevalence of autism per 10,000 covered lives rose by 32.2 % from 40.6 to 53.6, the highest rate of increase among all mental disorders. Total health care expenditures for ASDs per 10,000 covered lives grew by 32.8% from \$1,270,435 in 2000 (in 2003 dollars) to \$1,686,938 in 2003.

Conclusions—Medicaid-reimbursed health care expenditures for ASD were quite substantial. Although the per patient expenditures grew slightly over time, the large increase in treated prevalence caused a considerable rise in total ASD-associated health care expenditures.

Keywords

Health Care Expenditures; Autism; Autism Spectrum Disorder; Medicaid; Child Mental Health

Introduction

The prevalence of autism spectrum disorders (ASDs) diagnoses is increasing.^{1–8} The Centers for Disease Control and Prevention (CDC) reported that the prevalence of ASD was 1 in 110 children in 2006 and increased at an average annual rate of 57% between 2002 and 2006.⁹ The rising prevalence has raised concerns about the financial burden of ASDs on the

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private and public health care systems. Health care expenditures associated with ASD have not been adequately studied, with most of the few existing studies using data from private insurers or survey data.^{10–13} Little is known about corresponding expenditures in Medicaid programs. To our knowledge, the only study of ASD-related Medicaid expenditures used data from a single county in Pennsylvania from 1994–1999.¹⁴ Our study extends this literature by using Medicaid data from 42 states from 2000–2003 to determine ASD-associated health care expenditures among children. Medicaid is a major provider of health care services for children with ASD, as these children, who may not otherwise qualify for Medicaid, often are eligible for Medicaid-reimbursed health care services if their state of residence has a Home and Community Based Services (HCBS) waiver program for mental retardation and developmental disorders (which often includes ASDs) from the Centers for Medicare and Medicaid Services (CMS) under section 1915(c) of the Social Security Act.¹⁵ As of 2004, all but three states had a HCBS waiver program that either covered ASDs specifically or mental retardation/developmental disorders more generally.

It is important to understand the financial burden of ASDs on Medicaid programs for several reasons. First, state Medicaid programs have long waiting lists for eligible children with ASD, requiring waits as long as several years in some cases.^{16, 17} Hence, it is important for states to know the cost to Medicaid of providing services to individuals with ASDs in planning for Medicaid enrollment expansion. Second, coverage of services for ASDs varies across Medicaid programs, due to heterogeneity of HCBS waiver programs and state Medicaid plans.¹⁵ State policymakers need to understand the typical economic burden of ASDs in deciding what services to cover. Third, as some states have implemented – and more states are considering – legislation requiring private insurers to cover autism-related services,¹⁸ it is of interest to compare the expenditures in the private sector with those in the public sector. The objective of this study is to fill this gap in the literature by examining trends in health care expenditures associated with ASDs across multiple state Medicaid programs.

Method

Medicaid Analytic eXtract (MAX) files for the years 2000 through 2003 were obtained from CMS for 42 states. All states are required to submit their Medicaid individual eligibility data and claims data to CMS on a quarterly basis. MAX data are personal-level administrative claims data and are organized into five files: a Personal Summary File containing enrollment information, and four claims files including Inpatient Hospital, Long-Term Care, Other Services and Prescription Drug files. Health care expenditures considered in this study consisted of Medicaid reimbursements contained in these four claims files, and excluded payment from third parties.

The states studied include the District of Columbia and all states except for the following nine: Colorado, Delaware, Michigan, Montana, North Dakota, South Dakota, Tennessee, Utah and Washington. The states that were not included in our study had a relatively high proportion of managed-care enrollees during the study period. Medicaid claims information for managed-care enrollees is typically not as complete as those for fee-for-service enrollees.¹⁹

Study Sample

Children aged 17 years and under (as of the last day of the year) who were continuously enrolled during the year in fee-for-service Medicaid with any diagnosis of a mental disorder were identified using Medicaid claims data. Based on International Classification of Diseases, Ninth Revision (ICD-9) codes, classification of mental disorders were as follows (with ICD-9 codes in the parentheses): autism (299.0); other ASDs (299.1, 299.8);

adjustment disorder (309.0, 309.2); anxiety disorder (300.0–300.3, 307.20–307.23, 308, 313.0–313.2); bipolar disorder (296.0–296.1, 296.4–296.81, 296.89–296.9); depression (296.2–296.3, 296.82, 300.4–300.5, 301.10, 309.1, 311); hyperactivity (314); mental retardation (317–319); psychosis (295, 297–298); substance abuse (291–292, 303–305); conduct disorder (309.3, 309.4, 312.0–312.9, 313.3–313.9); post-traumatic stress disorder (309.81); learning disorder (315.0–315.9); and other mental disorders not elsewhere classified (290–319, not elsewhere specified). These classifications were consistent with other studies of children with mental disorders.^{10, 12, 20} Patients with at least one inpatient claim or two outpatient claims not on the same day related to autism were grouped into the autism category. Other patients with at least one inpatient claim or two outpatient claims not on the same day related to an ASD other than autism were grouped into the other ASDs category. The remaining patients were then grouped into the mental disorder category that was responsible for the highest proportion of mental health expenditures.

Analysis

Total health care expenditures for a patient were calculated as the sum of all health care expenditures reimbursed by Medicaid during the year irrespective of diagnosis associated with the claim, although the majority of total health care expenditures for patients with a mental disorder were related to mental health. Mean and median total health care expenditures per treated patient were then computed for each diagnostic group. To reduce potential bias from extreme values, costs were winsored at the 1% level in calculating the mean: i.e., expenditures below the 1st percentile were set to equal to the 1st percentile expenditure; and expenditures above the 99th percentile were set to equal to the 99th percentile.

The treated prevalence was calculated for each diagnostic group as the number of cases per 10,000 covered lives, where covered lives refers to individuals enrolled in Medicaid in a study year. We then computed mean total health care expenditures per 10,000 covered lives by multiplying the expenditures per patient by the treated prevalence. All expenditures were converted to 2003 dollars using the medical care component of the Consumer Price Index.²¹ To test the trend from 2000 to 2003 in the proportion of patients with ASDs, we used simple logistic regression with year as the predictor. This is preferred over standard Chi-square tests because the possibility that subjects are enrolled across multiple years would violate the assumption of independence of observations required by the Chi-square test.

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

Results

The state Medicaid programs included in this study covered more than 2.5 million individuals each year who were aged 17 years and under and who were continuously enrolled in fee-for-service Medicaid, adding up to a total of 10,690,434 person-years from 2000 through 2003. Sample characteristics are presented in Table 1. The number of patients with a mental disorder rose from 508,561 in 2000 to 572,701 in 2003, representing 21.2% of the studied population in 2003. The mean age among those with a mental disorder ranged from 9.5 to 9.7 years. The number of children with an ASD rose from 14,552 in 2000 to 20,099 in 2003. Although the proportion of those with an ASD was relatively small, ranging from 2.9% to 3.5% among those with a MD, it increased by 20.7% over the study period, a rate of increase higher than any of the other diagnostic groups except anxiety disorder.

Among children with an ASD, as shown Table 2, more than 75% were male, higher than the 62% male proportion among patients with other mental disorders (Table 1). Although

children with ASD rarely had a diagnosis of bipolar disorder or substance abuse/dependence, they often had comorbid hyperactivity, mental retardation, conduct disorder or learning disorder. Children with an ASD were about half a year younger than those with other mental disorders.

As indicated in Table 3, the treated prevalence of ASDs per 10,000 covered lives in fee-for-service Medicaid ranged from 57.5 in 2000 to 74.1 in 2003, which was relatively low compared to hyperactivity, conduct disorder or learning disorder. However the treated prevalence of ASDs rose by 28.7% from 2000 to 2003, the largest increase among all the mental disorder diagnostic groups. In particular, the treated prevalence of autism as a subcategory of ASDs increased by 32.2% from 40.6 to 53.6 per 10,000 covered lives.

Table 4 reports total health care expenditures per treated patient for ASDs and for other mental disorders in 2003 dollars. Mean total health care expenditures per treated child were \$22,079 in 2000 (in 2003 dollars), with mean expenditures for autism and any other ASDs being \$22,833 and \$20,342, respectively. Mean expenditures for ASDs were higher than those for the other diagnostic groups except mental retardation and psychosis. The median expenditures for ASDs were a little above half of the mean, indicating that a relatively small proportion of heavy spenders had driven up mean expenditures, despite the winsoring. Median expenditures were higher for ASD patients than any other diagnostic group. The mean expenditures for ASDs increased by just 3.1% from 2000 to 2003, whereas the increase was 17% for bipolar disorder and 20% post-traumatic stress disorder.

Health care expenditures per 10,000 covered lives for ASDs were \$1,270,435 in 2000 (in 2003 dollars) and \$1,686,938 in 2003 (see Table 5). These expenditures were in the middle range, with hyperactivity, mental retardation, conduct disorder and learning disorder being relatively expensive and bipolar disorder and anxiety disorder being relatively inexpensive. ASD-related expenditures per 10,000 covered lives increased by 32.8% from 2000 to 2003, the highest rate of increase of all the diagnostic groups. In particular, health care expenditures per 10,000 covered lives for autism as a sub-category of ASDs increased 37.0%.

Discussion

To our knowledge, this study is the first to use nationwide Medicaid claims data to document health care expenditures for children with autism and other ASDs. We identified 49,921 children with autism in our database, a much larger sample than other related studies.^{10, 12, 14, 20} The treated prevalence in our study was 74.1 per 10,000 covered lives in 2003, slightly lower than the estimate of 1 in 110 children by CDC,⁹ which may suggest that some children with autism may not have insurance to cover needed treatment. Our study found that total health care expenditures per treated patient for ASDs were high, and grew steadily over time. In terms of health expenditures per 10,000 covered lives, ASDs had the largest rate of increase of all the mental disorders studied, due to a much higher rate of increase in the treated prevalence. Potential explanations for the increase in Medicaid-treated prevalence might include the expansion of enrollment by some states' HCBS waiver programs and changes in provider awareness of ASDs and the way they are diagnosed.³

Annual health care expenditures per treated ASD patient averaged \$22,772 in 2003 in our Medicaid data, much higher than the estimates of \$7,003 by Leslie et al.¹⁰ and \$6,830 by Shimabukuro et al.,¹¹ both of which were based on 2003 private health insurance claims data. This difference may be due to wider coverage of mental health services by Medicaid programs compared with private insurance. The majority of children with an ASD receive services through Medicaid rather than through private insurance.^{22, 23} Our expenditure

estimates are also higher than the \$2,715 expenditures for patients aged 2–18 in a California managed care system in 2003–2004 by Croen et al.²⁴ Potential explanations for their lower cost estimate include: (1) expenditures associated with some services (such as dental care) were not available; and (2) the services covered by the managed care plan that they studied did not include a variety of services covered by the Medicaid programs in our study, such as intensive in-home treatment. Expenditures in 2000 in our study were \$22,079 (in 2003 dollars), again higher than the \$13,353 (converted to 2003 dollars) Medicaid expenditures in Allegheny county, Pennsylvania in 1998 by Mandell et al.¹⁴ The lower expenditures in their study may be attributed to (1) the fact that their expenditures did not include prescription drugs and non-traditional health services such as speech therapy; and (2) county-level variation within a state of how Medicaid policies are implemented to cover ASD,²⁵ so that the small sample size in one county might lead to a biased estimate. Finally, our expenditure estimates are also much higher than those based on 31 patients identified with autism from the Medical Expenditure Panel Survey (MEPS) in 1997–2000.¹³ Liptak et al. estimated yearly health-related expenditures for these patients to be \$6,132; however, there were not enough details in their paper for us to speculate on why their expenditures were lower than in our study.

Some limitations of our study deserve comment. As with all claims data, the identification of individuals with autism based on diagnostic codes may not be completely accurate.²⁶ Consistent with other studies,¹⁴ we required at least two outpatient claims or one inpatient claim with a diagnosis of autism or other ASD to increase the specificity of claims-derived diagnosis. Although not reported here, we repeated the analyses using just one claim with an ASD diagnosis for classification, and the results were similar. Also, health care expenditures captured only what were contained in the claims data. Services that were not covered and were paid out-of-pocket were not included in the expenditures estimate, and they may represent a substantial financial burden on patients' families.^{27–29} Our study also did not cover societal costs (such as lost productivity and caregiver burden) and long-term economic costs, which are also considerable.^{30–32} Finally, our data are from 2003, which is now slightly dated. However, this was the most recent year available when the data were purchased, and we have no reason to suspect the results would be substantially different had we used more recent data.

Despite these limitations, it is clear that Medicaid expenditures associated with children with ASDs are large and growing rapidly due to increasing prevalence of the disorder. Further research is needed to evaluate the effects of these expenditures on ASD outcomes and the financial burden on families caring for children with ASDs.³³ Efforts should be made to ensure that adequate resources are in place to reduce barriers to care for this particularly vulnerable population.

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Table 1

Characteristics of patients with mental disorders (fee-for-service patients only)

	2000	Year 2001	2002	2003	% Change 00-03	P-value ^a
Covered lives, total, age≤17	2,529,050	2,757,056	2,691,116	2,713,212	7.3	
Female	1,222,245	1,333,639	1,301,660	1,312,788	7.4	
Male	1,306,805	1,423,417	1,389,456	1,400,424	7.2	
Total Patients with a mental disorder	508,561	549,302	554,113	572,701	12.6	
Female	191,014 (37.6%)	206,705 (37.6%)	208,995 (37.7%)	216,355 (37.8%)	13.3	
Male	317,547 (62.4%)	342,597 (62.4%)	345,158 (62.3%)	356,346 (62.2%)	12.2	
Age (±sd)	9.55±4.35	9.53±4.42	9.62±4.44	9.66±4.46	1.2	
Primary Diagnosis ^b						
Any ASD	14,552 (2.9%)	16,812 (3.1%)	18,079 (3.3%)	20,099 (3.5%)	20.7	<.0001
Autism	10,261 (2.0%)	12,171 (2.2%)	12,936 (2.3%)	14,553 (2.5%)	25.0	<.0001
other ASD	4,291 (0.8%)	4,641 (0.8%)	5,143 (0.9%)	5,546 (1.0%)	25.0	<.0001
Adjustment disorder	26,076 (5.1%)	27,861 (5.1%)	28,101 (5.1%)	28,899 (5.0%)	-2.0	0.07
Anxiety disorder	10,960 (2.1%)	12,082 (2.2%)	13,454 (2.4%)	14,737 (2.6%)	23.8	<.0001
Bipolar disorder	442 (0.1%)	516 (0.1%)	468 (0.1%)	484 (0.1%)	0.0	0.33
Depression	39,084 (7.7%)	42,476 (7.7%)	44,185 (8.0%)	44,880 (7.8%)	1.3	<.0001
Hyperactivity	118,662 (23.2%)	129,853 (23.6%)	135,677 (24.4%)	149,357 (26.1%)	12.5	<.0001
Mental retardation	30,141 (5.8%)	31,529 (5.7%)	30,014 (5.3%)	29,218 (5.1%)	-12.1	<.0001
Conduct Disorder	95,148 (18.7%)	98,183 (17.9%)	97,649 (17.5%)	100,097 (17.5%)	-6.4	<.0001
PTSD	10,349 (2.0%)	10,949 (2.0%)	11,247 (2.0%)	11,327 (2.0%)	0.0	0.11
Learning Disorder	119,139 (23.4%)	131,603 (24.0%)	127,224 (22.8%)	125,896 (22.0%)	-6.0	<.0001
Other mental disorder	28,825 (5.7%)	30,629 (5.6%)	30,195 (6.1%)	29,682 (5.2%)	-8.8	<.0001
Psychosis	4,119 (0.8%)	4,404 (0.8%)	4,265 (0.8%)	4,434 (0.8%)	0.0	0.01
Substance abuse	11,064 (2.2%)	12,405 (2.3%)	13,555 (2.4%)	13,591 (2.4%)	9.1	<.0001

Note: ASD = Autism spectrum disorder; PTSD = Posttraumatic stress disorder.

^aP-value was based on simple logistic regression with year as the predictor.^bpercentages in parentheses are among those with a mental disorder

Table 2

Comorbid conditions of patients with an autism spectrum disorder (ASD)

	Year				% Change 00-03
	2000	2001	2002	2003	
Total Patients with an ASD	14,552	16,812	18,079	20,099	38.1
Female	3,137 (21.6%)	3,485 (20.7%)	3,791 (21.0%)	4,152 (20.7%)	32.4
Male	11,415 (78.4%)	13,327 (79.3%)	14,288 (79.0%)	15,947 (79.3%)	39.7
Age (±sd)	8.98±3.86	9.06±3.84	9.18±3.84	9.27±3.87	3.2
Co-morbid condition					
Adjustment disorder	254 (1.7%)	305 (1.8%)	335 (1.9%)	354 (1.9%)	11.8
Anxiety disorder	616 (4.2%)	725 (4.3%)	987 (5.5%)	1,065 (5.3%)	26.2
Bipolar disorder	51 (0.4%)	49 (0.3%)	64 (0.4%)	59 (0.3%)	-25.0
Depression	770 (5.3%)	807 (4.8%)	950 (5.3%)	925 (4.6%)	-13.2
Hyperactivity	3,387 (23.3%)	3,935 (23.4%)	4,417 (24.4%)	5,099 (25.4%)	9.0
Mental retardation	4,081 (28.0%)	4,808 (28.6%)	5,098 (28.2%)	5,416 (26.9%)	-3.9
Conduct Disorder	2,685 (18.5%)	2,961 (17.6%)	3,202 (17.7%)	3,497 (17.4%)	-5.9
PTSD	257 (1.8%)	283 (1.7%)	337 (1.9%)	310 (1.5%)	-16.7
Learning Disorder	4,227 (29.0%)	5,014 (29.8%)	5,278 (29.2%)	5,822 (29.0%)	0.0
Other mental disorder	1,048 (7.2%)	1,279 (7.6%)	1,429 (7.9%)	1,464 (7.3%)	1.4
Psychosis	542 (3.7%)	621 (3.7%)	627 (3.5%)	627 (3.1%)	-16.2
Substance abuse	64 (0.4%)	66 (0.4%)	79 (0.4%)	55 (0.3%)	-25.0

Note: PTSD = posttraumatic stress disorder

Table 3

Treated prevalence of mental health disorders per 10,000 covered lives^a

	Year				% Change 00-03
	2000	2001	2002	2003	
ASD	57.5	60.9	67.2	74.1	28.7
Autism	40.6	44.1	48.1	53.6	32.2
Other ASD	17.0	16.8	19.1	20.4	20.5
Adjustment disorder	103.1	100.9	104.4	106.5	3.3
Anxiety disorder	43.3	43.7	50.0	54.3	25.3
Bipolar disorder	1.7	1.9	1.7	1.8	2.1
Depression	154.5	153.8	164.2	165.4	7.0
Hyperactivity	469.2	470.2	504.2	550.5	17.3
Mental retardation	119.2	114.2	111.5	107.7	-9.6
Conduct Disorder	376.2	355.5	362.9	368.9	-1.9
PTSD	40.9	39.6	41.8	41.7	2.0
Learning Disorder	471.1	476.5	472.8	464.0	-1.5
Other mental disorder	114.0	110.9	112.2	109.4	-4.0
Psychosis	16.3	15.9	15.8	16.3	0.3
Substance abuse	43.7	44.9	50.4	50.1	14.5

Note: ASD = autism spectrum disorder; PTSD = post-traumatic stress disorder

^a Only children 17 years old or younger who were in fee-for-service Medicaid were considered.

Table 4

Total health care expenditures per treated patient with a mental disorder^a

	2000		2001		2002		2003		% change, 00-03	
	mean	median	mean	median	mean	median	mean	median	mean	median
ASD	22,079	12,014	23,424	13,245	23,578	13,082	22,772	13,017	3.1	8.3
Autism	22,833	13,161	24,115	14,471	24,480	14,275	23,657	14,360	3.6	9.1
Other ASD	20,342	9,807	21,660	10,547	21,331	10,995	20,417	10,659	0.4	8.7
Adjustment Disorder	4,498	2,436	4,724	2,460	4,853	2,371	4,902	2,368	9.0	-2.8
Anxiety Disorder	5,362	2,260	5,643	2,290	5,607	2,406	5,556	2,450	3.6	8.4
Bipolar Disorder	16,673	6,384	18,070	7,420	21,758	7,036	19,509	7,875	17.0	23.4
Depression	10,316	3,961	10,637	4,077	10,186	3,882	9,746	3,907	-5.5	-1.4
Hyperactivity	4,989	1,974	5,334	2,108	5,265	2,125	5,331	2,220	6.9	12.4
Mental retardation	25,833	8,426	26,870	9,284	27,174	9,576	24,890	8,965	-3.6	6.4
Conduct Disorder	8,535	2,955	9,217	3,062	9,257	3,078	9,109	3,100	6.7	4.9
PTSD	12,855	4,539	14,087	5,107	14,790	5,246	15,421	5,587	20.0	23.1
Learning Disorder	7,075	1,989	7,406	2,042	7,422	1,984	7,296	2,051	3.1	3.1
Other mental disorder	7,177	1,923	6,799	1,808	6,919	1,748	6,566	1,790	-8.5	-6.9
Psychosis	26,591	9,552	25,585	10,590	25,708	10,275	25,183	10,670	-5.3	11.7
Substance abuse	7,038	3,201	7,474	3,188	7,263	3,183	7,040	3,028	0.0	-5.4

Note: ASD = autism spectrum disorder; PTSD = post-traumatic stress disorder

^aExpenditures were calculated for fee-for-service patients only, and are expressed in 2003 dollars.

Table 5

Total health care expenditures per 10,000 covered lives ^a

	Year				% Change 00-03
	2000	2001	2002	2003	
ASD	1,270,435	1,425,940	1,584,006	1,686,938	32.78
Autism	926,373	1,062,757	1,176,742	1,268,923	36.98
Other ASD	345,138	363,986	407,656	417,335	20.92
Adjustment disorder	463,758	476,613	506,734	522,174	12.60
Anxiety disorder	232,376	246,891	280,342	301,765	29.86
Bipolar disorder	29,140	33,761	37,839	34,802	19.43
Depression	1,594,222	1,635,991	1,672,412	1,612,181	1.13
Hyperactivity	2,340,966	2,508,192	2,654,548	2,934,680	25.36
Mental retardation	3,078,737	3,067,548	3,030,746	2,680,363	-12.94
Conduct Disorder	3,211,012	3,276,865	3,359,025	3,360,396	4.65
PTSD	526,052	558,494	618,110	643,788	22.38
Learning Disorder	3,332,722	3,528,925	3,508,648	3,385,651	1.59
Other mental disorder	818,018	754,031	776,358	718,354	-12.18
Psychosis	433,085	407,997	407,430	411,541	-4.97
Substance abuse	307,877	335,706	365,849	352,651	14.54

Note: ASD = autism spectrum disorder; PTSD = post-traumatic stress disorder

^a Only children 17 years old and younger who were in fee-for-service Medicaid were considered. Expenditures were expressed in 2003 dollars.