

# Health Care Expenditures for Children With Autism Spectrum Disorders in Medicaid

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**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 to 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. *J. Am. Acad. Child Adolesc. Psychiatry*, 2010;49(11):1165–1171. **Key Words:** health care expenditures, autism, autism spectrum disorder, Medicaid, child mental health

The prevalence of autism spectrum disorders (ASDs) diagnoses is increasing.<sup>1-8</sup> The Centers for Disease Control and Prevention (CDC) reported that the prevalence of ASD was one in 110 children in 2006 and increased at an average annual rate of 57% between 2002 and 2006.<sup>9</sup> The rising prevalence has raised concerns about the financial burden of ASDs on the 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.<sup>10-13</sup> 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 to 1999.<sup>14</sup> Our study extends this literature by using Medicaid data from 42 states from 2000 to 2003 to determine ASD-associated health care expenditures among children. Medicaid is a major provider of health care services for children with ASDs, 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.<sup>15</sup> As of 2004, all but three states had an 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 ASDs, requiring waits as long as several years in some cases.<sup>16,17</sup> 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, because of heterogeneity of HCBS waiver programs and state Medicaid plans.<sup>15</sup> 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,<sup>18</sup> 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.<sup>19</sup>

### Study Sample

Children and adolescents aged 17 years and less (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); posttraumatic 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.<sup>10,12,20</sup> 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.

### Data 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 first percentile were set to equal to the first percentile expenditure; and expenditures above the 99<sup>th</sup> percentile were set to equal to the 99<sup>th</sup> 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.<sup>21</sup> 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  $\chi^2$  tests because the possibility that subjects are enrolled across multiple years would violate the assumption of independence of observations required by the  $\chi^2$  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 or under and who were continuously enrolled in fee-for-service Medicaid, adding up to a total of 10,690,434

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