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County-Level Variation in the Prevalence of Medicaid-Enrolled Children with Autism Spectrum Disorders

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Abstract

This study examined how county-level resources are associated with the identification of children with autism spectrum disorders (ASD) in Medicaid. Medicaid claims from 2004 were combined with county-level data. There were 61,891 children diagnosed with ASD in the Medicaid system in 2004. Counties with lower per-student education expenditures, more students, a greater proportion of students in special education, higher per capita number of pediatricians and pediatric specialists, and a greater proportion of Medicaid enrollees and white residents had higher Medicaid prevalence. Within states, counties differ in how they implement Medicaid policies. The results suggest the substitution of education and Medicaid-reimbursed services. Our findings highlight the need for geographically targeted outreach to minority groups and clinicians to improve recognition of ASD.

Keywords

Autism spectrum disorders; Medicaid; Geographic variation; Prevalence

Introduction

Children with autism spectrum disorders (ASD) have needs that straddle the traditional boundaries between the healthcare and education systems (Lord and McGee 2001; Newschaffer and Curran 2003; Shattuck and Grosse 2007). The US Department of Health and Human Services' Interagency Autism Coordinating Committee has called for rigorous national examination of publicly funded care provided to children with ASD, with particular emphasis on the roles of the public education system and Medicaid, which a growing number of states

use to pay for healthcare for children with autism, regardless of family income (Braddock 2002; Krauss et al. 2003; Walsh et al. 1997).

The Individuals with Disabilities Education Act (IDEA) of 1990 required that schools provide a free and appropriate education to qualified children with autism. It also requires that the education system provide assistance to these children even during preschool years to ready them for school. In the last decade, the number of children identified with autism in the special education system has risen dramatically from 54,064 to 258,305, an average increase of 17% a year (www.ideadata.org). While little data are available on the educational costs associated with these children, a report commissioned by the Government Accountability Office found that the average annual expenditure during the 1999–2000 academic year for children with autism was \$18,000, almost three times that of children not in special education, and the second highest average expenditure among all special education categories (Chambers et al. 2004). These services often include specialized classrooms, one-on-one instruction, intensive behavioral interventions (Lord et al. 1989), and speech, language and occupational therapy, for children to receive an education in the least restrictive environment appropriate to their individual needs (Koppelman 2004; Noel and Shreve 2006; Parrish et al. 2004; Rodman et al. 1999).

Because many of these services can be construed as medical, states often turn to Medicaid to help offset the economic burden associated with this care. In fact, some have argued that Congress's original intent with both Medicaid and IDEA legislation was for Medicaid to cover these medically necessary expenses (Mandell et al. 2008a; Noel and Shreve 2006). States have incentive to rely on Medicaid rather than IDEA funds, because the federal match for IDEA services is 17–19%, compared with between 50 and 75% for Medicaid services. The Center for Medicaid Services, however, has clarified that they consider themselves the payer of last resort for many of these services, especially behavioral therapies provided in educational settings, creating mounting tension and confusion regarding who should pay for care (Shattuck and Grosse 2007).

States have set various policies to serve children with ASD through their Medicaid programs. Most have expanded eligibility through waiver services for children with developmental disabilities and arrangements between Medicaid and special education (Parrish et al. 1998, 2004; Stahmer and Mandell 2007; Thurlow et al. 2002). It is unclear, however, whether autism services offered through state Medicaid programs are a complement to the resources devoted to autism services delivered through the education system or whether they act as a substitute in places with fewer education resources.

Recent studies suggest that, with the exception of a few prominent outliers, the community prevalence of ASD is relatively consistent across geographic area in the US (CDC 2007). Differences in local policies, practices and resources, however, could result in variation in the extent to which children with ASD are diagnosed and receive care in the Medicaid system. Separate from state policies, counties may differ in how aggressively they pursue enrolling children in Medicaid, and the education and healthcare resources they make available for children with developmental disabilities. The purpose of this study, therefore, was to examine how county-level education resources are associated with the identification of children with ASD in the Medicaid system. We hypothesized that counties with fewer—or greater strain on—education resources would be more likely to turn to the Medicaid system for support, resulting in greater Medicaid prevalence of ASD.

Methods

Data Sources and Sample

This study combined three data sources. The 2004 Medicaid Analytic eXtract (MAX) database, the most recent year for which data were available, provided information on ASD prevalence in the Medicaid system and total Medicaid enrollment by county. Children were included only if they were Medicaid enrolled for ≥ 9 months in 2004. County level data about education staffing, revenue and number of children in the special education system were obtained from the National Center for Education Statistics' Common Core of Data (<http://nces.ed.gov/ccd/>). The US Department of Education collects these data from states as part of their Individuals with Disabilities Education Act (IDEA) reporting requirements. County-level demographic and healthcare resource variables were obtained from the 2004 Area Resource File (ARF 2004). ARF is created from the Bureau of the Census, the American Hospital Association, the American Medical Association and the Centers for Disease Control and Prevention, among other agencies.

Variables

Number of Medicaid-enrolled children diagnosed with ASD was identified using all Medicaid claims except pharmacy claims because they do not contain diagnoses. Individuals were considered to be diagnosed with ASD if they had outpatient claims on at least two separate days in 2004 or one inpatient claim associated with an ICD-10 diagnosis of 299, 299.0x, 299.1x or 299.8x. This strategy was used to avoid including individuals who received the diagnosis as part of a rule-out evaluation or through coding error (Mandell et al. 2008b).

County Education Characteristics included total expenditures per student, the proportion of students in special education, the total number of elementary and secondary education students, and the pupil/teacher ratio.

County Healthcare Resources included the per capita number of pediatricians and the per capita number of pediatric specialists (child psychiatrists, neurologists, occupational therapists, audiologists, physical therapists, speech-language pathologists, and psychologists).

County Demographic Characteristics included the median income, percentage of white residents, the percent of residents living in poverty, and the percent of Medicaid-enrolled individuals ≤ 21 years of age.

Analysis

The purpose of the analysis was to examine the prevalence of diagnosed ASD in US counties and the association of prevalence with counties' education system, healthcare system and demographic characteristics. To facilitate comparisons among levels of each variable, county characteristics were categorized by quartile. The exceptions were: the number of pediatricians, which was categorized as none, and then a median split of the remaining counties (low vs. high); and the number of pediatric specialists, which was categorized as any vs. none.

Bivariate associations between each variable and the number of children diagnosed with ASD in the Medicaid rolls were estimated using negative binomial regression models to capture overdispersion (Agresti 2002). We chose the negative binomial model over the Poisson model because the negative binomial model is less restrictive in terms of variance and yields better coverage probabilities for confidence intervals. The number of children with ASD from birth to 21 years of age in each county was the dependent variable in this model. The model included an offset term of the total number of children ages 0–21 years in each county, which functions as a denominator to calculate prevalence. Adjusted results were presented as the percentage

difference in prevalence across levels of the variable. All models included fixed effects for states.

Results

The Table 1 presents the unadjusted prevalence and adjusted percentage change in prevalence for children with a diagnosis of ASD in the 2004 Medicaid claims; 61,891 children were diagnosed with ASD in the Medicaid system in the 3,124 counties. Overall, 70.1 per 100,000 children in the US received a diagnosis of ASD in the Medicaid system. The unadjusted prevalence varied as a function of most county characteristics, including the proportion of students in special education, education expenditures per student, per capita pediatricians and pediatric specialists, the proportion of Medicaid-enrolled children, median income, percentage living in poverty, and total number of students in preschool, elementary or secondary education.

In the adjusted analysis, some education variables continued to be associated with Medicaid ASD prevalence. Counties with greater per-student education expenditures had a lower Medicaid ASD prevalence (11.2% lower in the 4th quartile than in the 1st quartile). While not every quartile comparison was statistically significant at $p < 0.05$ for these two variables, counties with more students ≤ 12 th grade and those with a higher proportion of students receiving special education services also had a higher Medicaid ASD prevalence.

Variables measuring healthcare resources maintained significant associations with Medicaid autism prevalence in the adjusted analysis. Counties with higher per capita number of pediatricians (15.1% higher in counties with “high” vs. “none”) and pediatric specialists (8.9% higher in counties with “any” vs. “none”) had greater Medicaid ASD prevalence.

The largest adjusted percentage increase in prevalence was observed for counties with a high proportion of Medicaid-enrolled children (57.1% higher in the 4th quartile than in the 1st quartile). Counties with a high percentage of white residents also had a higher Medicaid ASD prevalence (27.1% higher in the 4th quartile than in the 1st quartile).

Discussion

In 2004, the Medicaid-enrolled prevalence of ASD was 70.1 per 100,000, using all US children as the denominator. As hypothesized, counties in the highest quartile of per-student education spending had lower prevalence, suggesting the substitution of education and Medicaid-reimbursed services. Because the needs of children with ASD cross the boundary between education and healthcare, counties with fewer education resources may turn to Medicaid to pay for their services (Koppelman 2004; Noel and Shreve 2006; Parrish et al. 2004; Rodman et al. 1999). Counties with more students and those with a greater proportion of students receiving special education services (both measures of potential system stressors) tended to have greater Medicaid-enrolled prevalence, adding some evidence to this hypothesis.

Medicaid-enrolled ASD prevalence varied greatly as a function of other county characteristics. Even after adjusting for poverty, the proportion of Medicaid-enrolled children in the county was associated with prevalence. While states have considerable latitude in how they use Medicaid to fund healthcare services for children, our analysis included state as a fixed effect, meaning that our results represent variation within states. The observed association between Medicaid enrollment and ASD prevalence may be due to counties taking differential advantage of their state’s Medicaid policies, perhaps because of local knowledge or the availability of education or other resources unmeasured in this study. Alternatively, families may change county of residence to be closer to better healthcare resources. The finding that counties with more pediatricians and pediatric specialists per capita enrolled a greater proportion of children

with ASD in Medicaid may be due to families moving to be closer to these resources or a higher prevalence of pediatric specialists resulting in more diagnosing.

Counties with a greater proportion of white residents had higher Medicaid-enrolled ASD prevalence, which is in line with previous findings about racial and ethnic disparities in the diagnosis of autism (Mandell et al. 2002, 2006, 2009). Membership in a traditionally underserved minority group may play a more important role in accessing services than income, which was not associated with ASD prevalence. While there is no known difference in the population prevalence of ASD among ethnic groups, one study found that African American and Latino children meeting research criteria for ASD were much less likely than white children to be identified as such in their healthcare or education records (Mandell et al. 2009). Researchers have hypothesized that physicians may be less likely to diagnose ASD among ethnic minorities; there may also be more stigma or other barriers associated with ASD and accessing publicly funded services among ethnic minority parents.

Interpretation of study findings are limited by a number of factors, primary among them that the ASD diagnosis in the Medicaid claims has not been validated. While its accuracy has not been specifically examined, Fombonne et al. (2004) found 97% positive predictive value for chart diagnoses and a diagnosis of ASD administered by a trained research team, and Yeargin-Allsopp et al. (2003) found that 98% of children with a chart diagnosis met research criteria for ASD. A second limitation is the absence of other county variables (e.g., ASD-specific intervention resources, county-level administrative prevalence of autism in the special education system) that may relate to identification in the Medicaid system.

Despite these limitations, there are important implications related to these findings. Within states, counties appear to differ in how they take advantage of Medicaid policies. The impact of these different arrangements between Medicaid and education on the coordination, intensity and quality of care for children with autism has yet to be determined. When Medicaid and education resources both are tapped to provide services for children with ASD, it can increase the potential volume of care and range of services these children receive. On the other hand, a large body of research suggests that when multiple systems are responsible for providing related care to the same child, it can result in considerable gaps and inefficiencies in care (American Academy of Pediatrics 2002; Dickens et al. 1992; US Department of Health and Human Services 1999).

Our findings also provide further evidence for the need for outreach to minority groups and clinicians working with them to improve recognition of the developmental differences associated with ASD. Our focus on the county—rather than the individual—as the unit of analysis suggests that outreach might be geographically as well as ethnically targeted.

The findings raise a number of questions, such as the potential for families' small-area migration to obtain services, which could have significant economic consequences for counties. It also raises questions regarding how state Medicaid and education policies interact with local practices and resources in the use of publicly funded services for children with ASD. States take varied approaches to using Medicaid to address the needs of children with ASD, including different eligibility requirements and arrangements between Medicaid and Special Education (Fox et al. 1993, 2000; Stahmer and Mandell 2007). Even within states, difficulties in coordinating services across systems may deter local education authorities from drawing on available resources from other systems. Understanding these policies and their implementation at the local level will help different jurisdictions develop effective decision rules regarding the identification and care of children with ASD.

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Table 1
Prevalence of Medicaid-enrolled children with autism by county characteristics ($n = 3,124$ counties)

	Prevalence per 100,000	Unadjusted % change	p value	Adjusted % change	p value
<i>Total</i>	70.1				
Total expenditures per student					
1st quartile (2,094–7,886)	66.2	Ref	–	Ref	–
2nd quartile (7,887–8,856)	60.6	–8.5	0.769	–4.4	0.219
3rd quartile (8,857–10,317)	67.0	1.3	0.237	–5.6	0.176
4th quartile (10,318–10,750)	81.0	22.5	0.048	–11.2	0.026
Proportion of students in special education					
1st quartile (0–0.122)	58.1	Ref	–	Ref	–
2nd quartile (0.122–0.145)	79.6	37.0	0.095	4.5	0.230
3rd quartile (0.145–0.168)	72.8	25.4	0.002	9.3	0.027
4th quartile (0.168–0.680)	77.2	32.9	0.006	8.0	0.100
Pupil/teacher ratio					
1st quartile (4.1–12.6)	94.7	Ref	–	Ref	–
2nd quartile (12.7–14.3)	66.5	–29.8	0.963	–2.9	0.511
3rd quartile (14.4–15.8)	75.3	–20.5	0.231	–2.3	0.657
4th quartile (15.9–28.6)	66.0	–30.3	0.883	–4.6	0.451
Per capita pediatricians (per 1,000)					
None (0)	69.6	Ref	–	Ref	–
Low (0.03–0.32)	75.3	8.1	0.003	5.2	0.199
High (0.321–5.35)	68.8	–1.2	< 0.001	15.1	0.001
Per capita pediatric specialists (per 1,000)					
None (0)	74.1	Ref	–	Ref	–
Any (0.02–35.84)	69.6	–6.1	0.003	8.9	0.024
Medicaid-enrolled population 0–21 years/Total Population					
1st quartile (0.027–0.265)	50.1	Ref	–	Ref	–
2nd quartile (0.265–0.364)	66.7	33.0	< 0.001	25.1	< 0.001
3rd quartile (0.364–0.478)	88.1	75.7	< 0.001	48.4	< 0.001
4th quartile (0.478–0.956)	74.6	48.9	< 0.001	57.1	< 0.001
In poverty (%)					
1st quartile (2.3–9.7)	55.4	Ref	–	Ref	–
2nd quartile (9.8–12.7)	76.3	37.8	< 0.001	3.8	0.401
3rd quartile (12.8–16.6)	68.0	22.7	< 0.001	–1.6	0.789
4th quartile (16.7–49.1)	89.5	61.6	< 0.001	13.5	0.117
Median income (\$)					
1st quartile (16,610–29,618)	78.6	Ref	–	Ref	–
2nd quartile (29,619–34,216)	81.9	4.2	0.4872	2.6	0.598
3rd quartile (34,233–39,907)	97.8	24.4	0.5810	9.5	0.131

		Prevalence per 100,000	Unadjusted % change	p value	Adjusted % change	p value
White (%)	4th quartile (39,928–93,927)	56.4	–28.2	< 0.001	–1.8	0.813
	1st quartile (4.51–76.87)	67.8	Ref	–	Ref	–
	2nd quartile (76.90–91.16)	58.0	–14.5	0.995	8.9	0.023
	3rd quartile (91.19–96.68)	87.0	28.3	0.173	22.2	< 0.001
	4th quartile (96.70–99.74)	111.8	64.8	0.150	27.1	< 0.001
Total number of students ≤12th grade (1,000s)	1st quartile (0.01–1.85)	63.4	Ref	–	Ref	–
	2nd quartile (1.85–4.27)	74.9	16.2	0.005	9.3	0.077
	3rd quartile (4.27–10.58)	85.5	32.6	< 0.001	13.5	0.029
	4th quartile (10.59–1,706.00)	67.9	5.4	< 0.001	12.9	0.082