ARTICLE

Differences Among States in the Identification of Autistic Spectrum Disorders

David S. Mandell, ScD; Raymond Palmer, PhD

Objective: To explore variation among the 50 US states in the administrative prevalence of autistic spectrum disorders (ASDs) and factors associated with that variation.

Design: This survey study used secondary data from all 50 states obtained from the US Department of Education, Washington, DC, and the American Board of Pediatrics, Chapel Hill, NC.

Main Outcome Measure: The outcome of interest was the proportion of children identified with ASD in the academic year 2000-2001. Linear regression was used to examine its association with education and health system characteristics.

Results: States ranged in the proportion of children diagnosed with ASD from 0.6 per 1000 to 4.6 per 1000 in 2000-2001. In adjusted analyses, education-related spending, the number of pediatricians in the state, and the number of school-based health centers in the state were positively associated with the administrative prevalence of ASD.

Conclusions: Variation in the administrative prevalence of ASD is associated with education-related spending, which may be associated with better-trained educational staff who can recognize the problem, and more and better trained in-school specialists who can provide screening. It is also associated with the availability of health care resources. Increased access to pediatricians and school-based health centers may lead to improved recognition of ASD. Interstate variability in the identification of ASD should be taken into account when interpreting the results of prevalence studies based on administrative data and the associated system characteristics taken into account by policy makers working to improve the recognition of ASD.

Arch Pediatr Adolesc Med. 2005;159:266-269

Author Affiliations:
Departments of Psychiatry and Pediatrics, Center for Mental Health Policy and Services Research, University of Pennsylvania School of Medicine, Philadelphia (Dr Mandell); University of Texas Health Science Center at San Antonio, San Antonio (Dr Palmer).

AUTISTIC SPECTRUM DISORDERS (ASDs) are a disabling continuum of disorders, the defining features of which include deficits in verbal and nonverbal communication, impaired socialization, and restricted patterns of behavior.[1] Studies in a number of industrialized countries suggest a prevalence of 3 to 6 per 1000 children, with more recent studies finding higher prevalence.[2] In the United States, children with ASD are eligible for special education services through the Individuals with Disabilities Education Act (IDEA). In 1990, ASD was categorized as a separate condition that qualifies children for special education services, and the US Department of Education, Washington, DC, began tracking the number of children with ASD served by each state.[3] Because of challenges associated with studying low-prevalence conditions, these data often are used to study ASD. Sometimes they are presented without further investigation,[4-7] and sometimes they are used as the first stage of a multistage screening process.[8,9] In both cases, they form a critical component of our current understanding of the prevalence and associated characteristics of ASD.

Administrative agencies sometimes perform suboptimally in identifying children with ASD. For example, in their study of the prevalence of ASD, Yeargin-Allsopp et al[9] screened all children receiving special education services in Atlanta, Ga. They found that 18% of children diagnosed with ASD by the investigators were not identified as such by the special education system. Croen et al[4] found that as the prevalence of children diagnosed with ASD increased in California, the prevalence of severe mental retardation decreased, also suggesting diagnostic substitution.

Local systems vary in their diagnostic criteria and policies regarding services for which children with ASD are eligible.[10] Appropriate screening and assessment are expensive, and there is an insufficiency of professionals in the United States who are

adequately trained in the diagnosis and treatment of ASD.[11] Services for children with ASD, which can include specialized classrooms, 1-on-1 instruction, and intensive behavioral interventions,[1,12,13] are costly and not available in many communities.[10,14] Palmer et al[7] investigated the hypothesis that educational and familial resources are associated with greater recognition of ASD and found that school districts in Texas with greater per-pupil spending and a lower proportion of impoverished students served proportionally more children with ASD and showed greater rates of increase in the proportion of students diagnosed with ASD from 1994 to 1995 to 2000 to 2001. Their study, however, like the prevalence studies referenced earlier,[4-6,8,9] relied on data from 1 state. It may be that state characteristics affect the identification of children with ASD. Certainly, there is considerable variability in states' education-related spending,[15] and differences in state policies are predictive of the administrative prevalence of learning disabilities.[16] Examining state differences may provide insight into the policies that affect recognition of children with ASD and the feasibility of using administrative data for epidemiologic purposes.

This study examined variation by state in the proportion of children diagnosed with ASD. Based on previous research, we hypothesized that education-related spending and the proportion of children living in poverty are associated with the recognition of ASD. We also hypothesized that medical resources such as the availability of pediatricians would be associated with the identification of ASD.

METHODS

Data were obtained from the US Department of Education Office of Special Education and Rehabilitative Services and the American Board of Pediatrics, Chapel Hill, NC. The Department of Education reports annually to Congress on the implementation of the IDEA. These reports contain information on the prevalence of various developmental disorders and education-system characteristics for each state by academic year.[3] The American Board of Pediatrics provided information on the number of pediatricians in each state.[17]

MEASURES AND INDICATORS

The proportion of children with ASD was calculated for each academic year by dividing the number of children aged 6 to 21 years in the ASD category of the IDEA by the number of students aged 6 to 21 years in each state. The number of children receiving special education services included all children aged 6 to 21 years receiving IDEA-funded services. Per-pupil spending was provided by the Department of Education for each state. The number of children living in poverty was calculated as the number of children receiving free or reduced-cost lunches. The pupil-teacher ratio was calculated by dividing the number of students aged 6 to 21 years in the state by the number of teachers for first through 12th grade. Ethnicity was provided by the Department of Education as African American, American Indian, Asian, European American, and Latino. The number of school-based health clinics was provided by the Department of Education. The number of pediatricians included all board-certified pediatricians in each state.

ANALYSES

Means and 95% confidence intervals were calculated for all variables of interest within each tertile of per-pupil, education-related spending (the main independent variable of interest). Differences by tertile were tested using χ^2 tests. Linear regression was used to examine the association between state characteristics and the proportion of children identified with autism in the 2000-2001 academic year. To avoid spurious correlations[18] that may occur when examining the association between 2 ratios that share a common component,[19] independent variables of interest were entered as absolute numbers rather than per-student ratios. The number of students aged 6 to 21 years in each state was added to the model to adjust for the size of the student body. The dependent variable of interest, the proportion of children diagnosed with ASD, was transformed by taking its natural logarithm so that the resulting exponentiated coefficients minus 1 could be interpreted as the percentage change in prevalence associated with 1 unit increase in each independent variable.[20]

RESULTS

Table 1 provides information on state characteristics, stratified by tertile of education spending. Statistically significant differences at $P<.05$ were found among tertiles for the proportion of students with ASD, the average number of students, per-pupil spending, the proportion of children served in the special education system, the average number of pediatricians per child, and the proportion living in poverty.

The **Figure** shows the proportion of children diagnosed with ASD as a function of states' per-pupil spending, with a mean fitted regression line and 95% confidence bands. The Figure also identifies the 4 states from which data were used for published prevalence studies. States ranged more than 7-fold in their identification of children with ASD, from 0.6 to 4.6 per 1000 children. States that provided data for published prevalence studies ranged from 1.3[9] per 1000 to 2.9[6] per 1000 children. In this unadjusted analysis, each $1000 increase in per-pupil spending was associated with a 0.19 per 1000 children increase in the prevalence of ASD.

Table 2 presents the results of the linear regression predicting the percentage change in prevalence associated with each unit increase in the independent variable. Adjusting for the other variables in the model, each additional $1 million in states' education spending was associated with a 0.02% increase and each additional pediatrician was associated with a 0.06% increase in the prevalence of ASD. The only other variable that approached statistical significance at $P<.05$ was the number of school-based health centers. Each additional center was associated with a 0.6% increase in the prevalence of children with ASD.

COMMENT

This study found considerable range in the proportion of children with ASD served among the 50 states, with few states having an administrative prevalence approaching the reported community prevalence rate.[2] As in previous research,[7] educational spending was associated with

Table 1. State Characteristics by Tertile of Per-Pupil Education Spending in 50 States*

	Tertile of Per-Pupil Spending		
	First	Second	Third
Education system characteristics			
Students diagnosed with ASD, % (95% CI)	0.12 (0.10 to 0.14)	0.15 (0.11 to 0.20)	0.20 (0.17 to 0.23)
Education spending, $1 million	4056 (2133 to 5978)	8496 (2794 to 14 199)	8325 (4245 to 12 405)
No. of students aged 6-21 y, 1000s	656 (302 to 1010)	1226 (398 to 2055)	1007 (546 to 1469)
Per-pupil education spending, $	5865 (5597 to 6133)	6980 (6795 to 7164)	8816 (8218 to 9415)
Pupil-teacher ratio	16.0 (14.6 to 17.4)	15.5 (14.4 to 16.7)	14.9 (13.9 to 15.8)
Students in special education, % (95% CI)	11.7 (11.0 to 12.5)	12.2 (11.3 to 13.1)	13.5 (12.5 to 14.5)
State resources, No. of			
School-based health centers per 1000 students	0.03 (0.01 to 0.05)	0.03 (0.01 to 0.04)	0.05 (0.02 to 0.08)
Pediatricians per 1000 children	86 (26 to 14)	166 (51 to 280)	208 (87 to 330)
Student characteristics, % (95% CI)			
Students living in poverty	43.4 (36.6 to 50.3)	35.5 (30.5 to 40.4)	30.1 (27.3 to 32.9)
African American	17.6 (8.6 to 26.7)	12.2 (5.7 to 18.6)	13.6 (8.3 to 18.8)
American Indian	3.3 (1.1 to 6.7)	1.4 (0.1 to 2.6)	2.2 (0.0 to 5.3)
Asian	1.6 (0.9 to 2.3)	7.0 (0.0 to 15.8)	3.4 (2.4 to 4.3)
Hispanic	11.3 (3.4 to 19.2)	10.6 (3.7 to 17.5)	8.0 (5.0 to 11.0)

Abbreviations: ASD, autistic spectrum disorder; CI, confidence interval.
*Values are expressed as mean (95% CI) unless otherwise indicated.

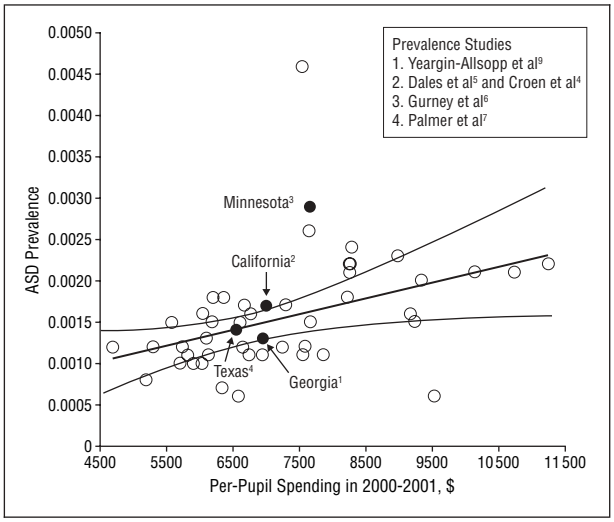

Figure. Prevalence of autistic spectrum disorders (ASDs) in the academic year 2000-2001 as a function of per-pupil spending (N=50 states), with a mean fitted regression line and 95% confidence bands. Four states are shown in which data were used for published prevalence studies.

Table 2. Linear Regression Predicting the Administrative Prevalence of Autistic Spectrum Disorder (ASD) in 50 States*

	Percentage Change in Prevalence (95% Confidence Interval)
Education system characteristics	
No. of students aged 6-21 y in the state, 1000s	–0.10 (–95.02 to 171.83)
State education spending, $1 million	0.02 (0.01 to 0.03)
No. of elementary and secondary school teachers, 100s	0.02 (–98.20 to 195.63)
No. of students receiving special education services, 1000s	0.32 (–99.75 to 172.82)
State resources, No. of	
School-based health centers in the state	0.60 (–0.05 to 1.18)
Pediatricians in the state	0.06 (0.02 to 0.10)
Student characteristics, No. of	
Students living in poverty	–0.04 (–84.30 to 193.23)
African American students	0.04 (–63.21 to 638.90)
American Indian students	–0.40 (–36.79 to 342.81)
Asian students	0.23 (–86.47 to –994.36)
Hispanic students	–0.05 (–74.84 to 816.63)

*Prevalence was modeled as the natural log of the proportion of children with ASD. Resulting coefficients were then exponentiated. The parameters are presented as the percentage increase in the prevalence of ASD associated with 1 unit increase in each variable, adjusting for the other variables in the model.

the administrative prevalence of ASD. Additionally, health-related resources, namely the availability of pediatricians and school-based health clinics, were associated with the identification of ASD.

At least 3 study limitations should be considered. Perhaps most important, the state-level prevalence of ASD is not known. Variation in prevalence could affect the proportion of children identified in each state. Recent studies suggest no difference in the prevalence of ASD across a variety of factors. It is possible, however, that parents of children with ASD may move to states with greater resources, inflating the prevalence for those states. This in and of itself would be an important finding, since it suggests that some states are meeting the needs of these families better than others. A second limitation is that states provide a relatively gross unit of analysis, with the potential for much intrastate variation. Variables such as education-related spending may vary widely among school districts within states. This limitation, however, would most likely result in an attenuation of the findings, suggesting that the observed associations are robust. Finally, studies at the state level do not provide adequate power to test for smaller differences or to conduct more sophisticated analyses.

Despite these limitations, there are a number of important implications related to these findings. Published prevalence studies that used administrative data

were based in states that varied more than 2-fold in their 2000-2001 administrative prevalence. Results from this study suggest that dependence on data from 1 state may provide a skewed picture of the national prevalence of ASD. Recently established multisite surveillance efforts by the Centers for Disease Control and Prevention, Atlanta, Ga, should provide insight into this issue.[21]

The results also provide more evidence that education-related spending is associated with the administrative prevalence of ASD. Given the small proportion of children with ASD, it is unlikely that costs associated with the care of these children are driving observed spending. Rather, states with higher spending may attract better-trained staff that has a greater awareness of the symptoms of ASD. Spending also may be related to the availability of programs for identifying and caring for children with developmental problems such as ASD, such as early intervention services and specialized classrooms. Finally, states that spend more on education may also have developed programs in other areas that support children with ASD. For example, Indiana, which had the third highest diagnosed prevalence of ASD, has a specific Medicaid program for reimbursing services for individuals with ASD,[22] as does Maryland,[23] whose prevalence is almost 1 SD more than the mean. Oregon and Minnesota, however, with the first and second highest prevalence in the country, respectively, do not have such programs.

The results of this study also suggest that access to health care resources may be associated with improved identification of children with ASD. For children with developmental problems such as ASD, recognition and referral by primary care physicians are usually the first step toward diagnosis.[24,25] The positive association between the number of pediatricians and the prevalence of ASD may result from increased access leading to improved problem recognition and is in line with previous findings that increased supply of pediatricians results in decreased unmet need for routine and specialty care.[26,27]

The positive association between the number of school-based health centers and the administrative prevalence of ASD is intriguing and requires further exploration. Although these centers serve only 2% of schoolchildren in the United States, their use has been associated with improved asthma care[28] and decreased emergency department use.[29] There does not appear to be any published literature on the role of these centers in the care of children with developmental disorders, although child psychiatrists, who may diagnose and treat ASD, are increasingly likely to be affiliated with them.[30] These findings should be taken into account as researchers and policy makers attempt to determine the true prevalence of ASD and improve recognition and care of children with this disorder.

Accepted for Publication: November 4, 2004.
Correspondence: David S. Mandell, ScD, Center for Mental Health Policy and Services Research, University of Pennsylvania School of Medicine, 3535 Market St, 3rd Floor, Philadelphia, PA 19104 (mandelld@mail.med.upenn.edu).
Additional Information: Dr Mandell is a senior fellow at the Leonard Davis Institute of Health Economics, Philadelphia, Pa.

REFERENCES

1. Volkmar F, Lord C, Bailey A, Schultz R, Klin A. Autism and pervasive developmental disorders. *J Child Psychol Psychiatry*. 2004;45:135-155.
2. Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *J Autism Dev Disord*. 2003;33:365-382.
3. US Department of Education. *Twenty-Fifth Annual Report to Congress on the Implementation of the Individuals With Disabilities Education Act*. Jessup, Md: Bureau of Special Education; 2003.
4. Croen L, Grether J, Hoogstrate J, Selvin S. The changing prevalence of autism in California. *J Autism Dev Disord*. 2002;32:207-215.
5. Dales L, Hammer S, Smith N. Time trends in autism and in MMR immunization coverage in California. *JAMA*. 2001;285:1183-1185.
6. Gurney J, Fritz M, Ness K, Sievers P, Newschaffer C, Shapiro E. Analysis of prevalence trends of autism spectrum disorder in Minnesota. *Arch Pediatr Adolesc Med*. 2003;157:622-627.
7. Palmer R, Blanchard S, Jaen C, Mandell D. The association between school district resources and identification of children with autistic disorder. *Am J Public Health*. 2005;95:125-130.
8. Bertrand J, Mars A, Boyle C, Bove F, Yeargin-Allsopp M, Decoufle P. Prevalence of autism in a United States population: the Brick Township, New Jersey, investigation. *Pediatrics*. 2001;108:1155-1161.
9. Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. *JAMA*. 2003;289:49-55.
10. Jacobson J, Mulick J. System and cost research issues in treatments for people with autistic disorders. *J Autism Dev Disord*. 2000;30:585-593.
11. Jacobson J, Mulick J, Green G. Cost-benefit estimates for early intensive behavioral intervention for young children with autism: general model and single state case. *Behav Interventions*. 1998;13:201-226.
12. Matson J, Benavidez D, Compton L, Paclawskyj T, Baglio C. Behavioral treatment of autistic persons: a review of research from 1980 to the present. *Res Dev Disabil*. 1996;17:433-465.
13. Volkmar F. Pharmacological interventions in autism: theoretical and practical issues. *J Clin Child Psychol*. 2001;30:80-87.
14. Jarbrink K, Knapp M. The economic impact of autism in Britain. *Autism*. 2001;5:7-22.
15. Parrish T, Hikido C, Fowler W. *Inequalities in Public School District Revenues*. Washington, DC: US Department of Education; 1998.
16. Lester G, Kelman M. State disparities in the diagnosis and placement of pupils with learning disabilities. *J Learn Disabil*. 1997;30:599-607.
17. Guerin R. *The American Board of Pediatrics 2003-04 Workforce Data*. Chapel Hill, NC: American Board of Pediatrics; 2004.
18. Pearson K. Mathematical contributions to the theory of evolution: on a form of spurious correlation which may arise when indices are used in the measurement of organs. *Proc R Soc Lond*. 1897;60:489-497.
19. Kronmal R. Spurious correlation and the fallacy of the ratio standard revisited. *J R Stat Soc [Ser A]*. 1993;156:379-392.
20. Duan N, Manning W, Morris C, Newhouse J. A comparison of alternative models for the demand for medical care. *J Bus Econ Stat*. 1983;1:115-126.
21. National Center for Birth Defects and Developmental Disabilities Autism Information Center: state activities [Centers for Disease Control and Prevention Web site]. Available at: http://www.cdc.gov/ncbddd/dd/aic/states/default.htm.
22. Agency ILS. *Annual Report of the Indiana Commission on Autism*. Indianapolis: Indiana Legislative Council; 2003.
23. Anonymous. *Medicaid Home and Community-Based Services Waiver for Children with Autism Spectrum Disorder*. Baltimore: Maryland Department of Health and Mental Hygiene; 2002.
24. Dulcan M, Costello E, Costello A, Edelbrock C, Brent D, Janiszewski S. The pediatrician as gatekeeper to mental healthcare for children: do parents' concerns open the gate. *J Am Acad Child Adolesc Psychiatry*. 1990;29:453-458.
25. Palfrey J, Singer J, Walker D, Butler J. Early identification of children's special needs: a study in five metropolitan communities. *J Pediatr*. 1987;111:651-659.
26. Mayer M, Skinner A, Slifkin R. Unmet need for routine and specialty care: data from the national survey of children with special health care needs. *Pediatrics* [serial online]. 2004;113:e109-e115. Available at: http://pediatrics.aappublications.org/cgi/content/full/113/2/e109.
27. Newacheck P, McManus M, Fox H, Hung Y, Halfon N. Access to health care for children with special health care needs. *Pediatrics*. 2000;105:760-766.
28. Webber M, Carpiniello K, Oruwariye T, Lo Y, Burton W, Appel D. Burden of asthma in inner-city elementary schoolchildren: do school-based health centers make a difference? *Arch Pediatr Adolesc Med*. 2003;157:125-129.
29. Young T, D'angelo S, Davis J. Impact of a school-based health center on emergency department use by elementary school students. *J Sch Health*. 2001;71:196-198.
30. Rappaport N. Psychiatric consultation to school-based health centers: lessons learned in an emerging field. *J Am Acad Child Adolesc Psychiatry*. 2001;40:1473-1475.