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### The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education

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#### **ABSTRACT** -

OBJECTIVE. Growing administrative prevalence of autism has stirred public controversy and concern. The extent to which increases in the administrative prevalence of autism have been associated with corresponding decreases in the use of other diagnostic categories is unknown. The main objective of this study was to examine the relationship between the rising administrative prevalence of autism in US special education and changes in the use of other classification categories.

METHODS. The main outcome measure was the administrative prevalence of autism among children ages 6 to 11 in US special education. Analysis involved estimating multilevel regression models of time-series data on the prevalence of disabilities among children in US special education from 1984 to 2003.

RESULTS. The average administrative prevalence of autism among children increased from 0.6 to 3.1 per 1000 from 1994 to 2003. By 2003, only 17 states had a special education prevalence of autism that was within the range of recent epidemiological estimates. During the same period, the prevalence of mental retardation and learning disabilities declined by 2.8 and 8.3 per 1000, respectively. Higher autism prevalence was significantly associated with corresponding declines in the prevalence of mental retardation and learning disabilities. The declining prevalence of mental retardation and learning disabilities from 1994 to 2003 represented a significant downward deflection in their preexisting trajectories of prevalence from 1984 to 1993. California was one of a handful of states that did not clearly follow this pattern.

CONCLUSIONS. Prevalence findings from special education data do not support the claim of an autism epidemic because the administrative prevalence figures for most states are well below epidemiological estimates. The growing administrative prevalence of autism from 1994 to 2003 was associated with corresponding declines in the usage of other diagnostic categories.

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Key Words autism, prevalence

#### Abbreviations

ASD—autism spectrum disorder MR—mental retardation LD—learning disabilities OHI—other health impairments CDC—Centers for Disease Control and Prevention OR—odds ratio TBI—traumatic brain injury DD—developmental delay

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THE SPECIFIC AIM of this study was to test for evidence of diagnostic substitution as a contributing factor behind the growing identification of autism spectrum disorders (ASDs) in US special education. Social service enrollment data from a variety of sources, including special education, have depicted dramatic increases in the administrative prevalence of ASDs through the 1990s.<sup>1-7</sup> In the California Developmental Disabilities Service system, the number of clients with an autism diagnosis as a percentage of all clients rose from 4.9% to 9.4% during the 1994–2003 period.1 In US special education, the total reported number of children ages 6 to 21 enrolled under the autism category among the 50 states and the District of Columbia increased from 22 445 in the 1994–1995 school year to 140 254 in the 2003–2004 school year.8,9 These administrative trends have been featured prominently in popular press reports and are often interpreted, in the absence of good quality national surveillance data, by reporters and policy makers as evidence of an ASD epidemic.<sup>10–13</sup> This has recently sparked Congressional hearings and investigation14,15 and has prompted the federal government to outline a coordinated interagency plan of action in response.<sup>16</sup> However, despite all the attention and research on this topic, we still do not have a good understanding of why the administrative prevalence of autism has been growing (the word "autism" will be used throughout as synonymous with "ASD").

One proposed explanation for the increase in autism's administrative prevalence is known as "diagnostic substitution." The basic premise is that the same child who might have received some other disability label 15 years ago is now being identified with autism because of shifting referral and diagnostic practices. The prediction that flows from this general premise is that growing autism prevalence in recent years would have been accompanied by a corresponding decrease in the administrative prevalence of some other disability (or disabilities).

Analysis of data from California's social service system suggests that diagnostic substitution does not account for the growing enrollment of children with autism.<sup>17,18</sup> Specifically, from 1987 to 1994 there was little change in the probability of being identified as mentally retarded for state services by age 4, whereas the probability of being identified with autism increased nearly fivefold from 2 to 10 of 10 000 births.18 Examination of Minnesota special education data from 1991 to 2001 revealed an increase in autism prevalence but no corresponding declines in prevalence among other special education disability categories.<sup>4</sup> A similar analysis of nationwide special education cohort data from 1992 to 2001 likewise found no decreases in prevalence for the mental retardation or speech/language impairment categories.6

Despite the lack of evidence for diagnostic substitution from recent studies, the question is still worth analyzing for a number of reasons. First, the idea of diagnostic substitution accounting for some of the increased prevalence of autism is popularly held among clinicians and is seen as plausible because of the well-documented broadening of the diagnostic criteria for autism that has occurred over the past several decades.<sup>19–21</sup> Second, prior research has established a precedent of diagnostic substitution in special education enrollment. From 1976 to 1992 the number of children in the mental retardation (MR) category decreased by 41%, whereas the number in the learning disabilities (LD) category increased 198%.<sup>22</sup> There is considerable evidence that suggests this was because of a growing likelihood that schools would use the LD label for children with mild MR, presumably because a label of LD was increasingly seen as carrying less stigma than MR.<sup>22-26</sup> Finally, a recent epidemiological study depicted a downward deflection in the incidence trend of other developmental disorders just as the trend for autism made a sharp upturn in the early 1990s, again suggesting the possibility of diagnostic substitution.27

#### METHODS

#### **Description of Data**

Special education enrollment is tracked categorically by type of disability, although treatment plans are supposed to be individually tailored. Autism is now 1 of 13 primary disability identification categories mandated by the Individuals with Disabilities Education Act after being added in 1990 as part of Public Law 101–476.<sup>28</sup> Before Public Law 101–476, there was no separate autism category, and children with autism enrolled in special education were included in the legal definition of the "other health impairments" (OHI) service category. However, no reliable data exist that would indicate how the enrollment of children with autism was actually distributed among other enrollment categories before the 1990s.

States were required to begin using the new autism reporting category as of 1993. However, the autism time series examined in the present analyses begins with 1994, because this was the first year where every state actually used the new autism category.

Massachusetts and Iowa were excluded from analysis, because they historically used noncategorical approaches for identifying children in special education and did not report actual counts of children for much of the period examined in this study.<sup>29,30</sup>

For the present analyses, annual state-by-state counts of children ages 6 to 11 with disabilities in special education came from the 1984–2003 annual Special Education Child Counts published by the US Department of Education. Corresponding US Census data were used in the denominator for prevalence estimates (note that Oregon included 5-year-olds in its age 6–11 child

counts, and the denominators have been adjusted accordingly).<sup>31</sup> Census data for the 1980s were linearly weighted estimates of the 1980 and 1990 decennial census counts. Data for 1991-1999 came from published annual population estimates. Denominator counts for 1990 and 2000-2003 came from the 1990 and 2000 decennial census, respectively. The 6 to 11 age range is one of the available aggregatations of data (individuallevel data are not available) and was chosen as the closest possible match to recent Centers for Disease Control and Prevention (CDC) surveillance studies that focused on children ages 3 to 10 to facilitate comparisons.<sup>32,33</sup> Also, limiting analysis to the 6 to 11 age range avoids confounding from the corresponding shifts in special education child counts that have been documented to occur between 11 and 12 years of age, when many children transition to middle school.<sup>34</sup>

It is important to note that schools do not necessarily use standard Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition criteria for assigning a label of autism to children in special education. The Federal Department of Education definition of autism is very broad, and states and districts are left to operationalize diagnostic criteria as they see fit. However, recent surveillance research in the United States suggests that the vast majority of children reported in the special education autism category also meet case criteria for ASD.<sup>32,33</sup> Furthermore, the Special Education Child Counts data only reports counts of primary classifications. So, if a child had a primary classification of MR and a secondary classification of autism, then he would only be represented in the total count of children with MR and would be missing from the total count of children with autism. If a child has  $\geq 2$  special education diagnoses, then there is no official guideline directing schools to use one or the other category as the primary classification.

#### Analytic Strategy

A multipronged analytic strategy was used to maximize the convergent validity of findings. Three factors must be established to strongly imply that another identification category was involved in a putative process of diagnostic substitution. First, the aggregate national prevalence of the other category must have decreased significantly during the same period that autism prevalence increased. Second, within-state analyses should demonstrate that the other category's decreasing prevalence was significantly associated with autism's growing prevalence. Finally, the decreasing prevalence of the other category must have marked a significant downward deflection in its preexisting trajectory, thereby ruling out a spurious association with autism's increase. These 3 possibilities were tested using 3 different types of random coefficient logistic regression models.

Random coefficient logistic regression analysis (also called multilevel regression analysis) is a method that

can be used for analyzing longitudinal proportion data.<sup>35</sup> States were the level 2 units of analysis in the following models. Thus, in nontechnical terms, the resulting parameter estimates can be interpreted as predicted values (in logit units) for an "average" state or as the predicted nationwide estimate "averaged" across states (quotation marks indicate the word "average" is being used loosely as an analogy to facilitate understanding among readers who may not be familiar with this method). The variance component associated with each regression coefficient indicates the amount of variability across states. The Bayesian Information Criteria goodness-of-fit statistic allows for comparisons of how well different predictor models fit the same set of outcome data.<sup>35</sup> HLM 6.0 software was used.<sup>36</sup>

The first set of analyses used unconditional logistic growth models (ie, no other predictors besides time) to examine rates of change for 6 special education classification categories: MR, LD, emotional disturbance, speech and language impairment, multiple disabilities (MD), and OHI. These models evaluate whether there was a significant rate of change, "averaged" across states, from 1994 to 2003 for each category. Each model's intercept represents the estimated logit value of prevalence in 1994. The slope represents the annual rate of change in logit prevalence. The odds ratio (OR) of the slope represents the factor by which the odds of classification in the given category multiplied each year. At very low prevalence values like the ones seen for autism, the OR can also be interpreted as approximately the factor by which the probability of being classified is multiplied each year.37

The second set of logistic multilevel models tested for significant within-state association between autism prevalence and the prevalence of the 2 categories identified as having significant rates of decline in the first set of growth models, MR and LD. The outcome in these models was autism prevalence per year, per state. Predictors were the prevalence per 1000 of MR and LD recentered within each state so that the initial value in each state's time series was zero and the values of subsequent years represented the amount of change in prevalence since 1994.

Third, piecewise logistic growth models were estimated for the MR and LD categories. This type of model allows one to test for significant shifts in the rate of change at specific points in time. Each model has 2 types of coefficient. One type represents the annual rate of change between 2 given points in time. The other type represents the difference in rates of change between the 2 time spans on either side of a specific point in time (also called a "knot").

In the course of this research, it became clear that the prevalence of other identification categories was also increasing significantly during the 1990s. This raised the possibility that changes in the prevalence of autism may have been part of a broader process of diagnostic substitution that involved several categories simultaneously. A fourth set of logistic multilevel associational models was estimated to test for this possibility. The outcome in these models was the combined prevalence of 4 special education identification categories that all exhibited significant growth from 1994 to 2003: autism, traumatic brain injury (TBI), developmental delay (DD), and OHI. The combined prevalence (per 1000) of MR and LD was the predictor.

#### RESULTS

## Description of Changing Autism Prevalence in Special Education

Figure 1 depicts changes in autism prevalence for the US overall and for Minnesota (the state with the greatest increase in prevalence) and New Mexico (the state with the least change). Two lines representing CDC epidemiological estimates, from 1996 (Atlanta) and 1998 (New Jersey), of the prevalence of autism among children aged 3 to 10 years are presented for comparison and can be considered as establishing a reference range that represents our current best estimate of the true prevalence of ASDs.<sup>32,33</sup> The wide gap between the CDC estimates is likely a function of their different ascertainment strategies and target population size. The New Jersey study was conducted in a relatively small geographic area and involved in-person diagnostic evaluations to determine caseness.32 The Atlanta study used a record review protocol on a much larger population and likely represents an underestimate.<sup>33</sup> Of the 2, the higher prevalence estimate from New Jersey was closest to other recent epidemiological surveys yielding estimates of 61.3 per 100038 and 57.9 per 1000.39

As of 2003, the mean prevalence of autism in special education had not reached the lower boundary of the



#### FIGURE 1

Autism special education prevalence per 1000 among children aged 6 to 11: average US prevalence, and the 2 states with the most (Minnesota) and the least (New Mexico) change from 1994–2003 compared with recent CDC population-based findings for children aged 3 to 10.

reference range. The significant growth in autism's administrative prevalence during this period seems to be an indication of the rate at which special education counts are catching up with the counts one would expect given the population reference range. The definition of the word "epidemic" is the occurrence of a given disorder that is substantially higher than expected.<sup>40</sup> The overall level of special education prevalence is still lower than expected and, therefore, cannot be validly used to support claims of an autism epidemic.

#### **Growth Models**

The odds of being classified in the autism category multiplied by a factor of 1.21 per year during the 1994-2003 period (Table 1). The LD and MR categories exhibited significant rates of decrease in prevalence during this period, with ORs of 0.98 and 0.97, respectively. Examination of the raw data revealed that only 6 states (Florida, Indiana, Ohio, Oklahoma, Pennsylvania, and South Carolina) exhibited LD prevalence increases, and 5 states (California, Colorado, Michigan, New Jersey, and West Virginia) showed increases in MR prevalence from 1994-2003. The prevalence of all disabilities, net of autism, actually declined from 110.2 per 1000 in 1994 to 105.2 per 1000 in 2003, although the rate of change was not statistically significant. This argues against the notion that growing autism prevalence was simply a reflection of the growing prevalence of overall special education enrollment. The other health impairment category exhibited a significant rate of increase in prevalence during this time. The rate of change from 1994 to 2003 was not significant for the prevalence of speech and language impairment, emotional disturbance, and multiple disabilities. Altogether, these results suggest that the LD and the MR categories are the most likely candidates for a putative process of diagnostic substitution, because these were the only 2 categories that exhibited significant rates of decline during the period when autism prevalence was increasing rapidly.

#### Associational Models

The second condition that needs to be established to confirm the existence of diagnostic substitution is a significant inverse association between autism prevalence and changes in the prevalence of categories that showed significant decline during the same period. The negative association coefficients in Table 2 indicate that growing autism prevalence tended to be associated with decreasing LD and MR prevalence within states. Further examination indicated that this inverse association was manifest in the vast majority of states. Only 2 states had positive association coefficients for the LD model, Oklahoma and Pennsylvania. For the MR category, there were only 5 states with positive coefficients indicating that higher autism prevalence tended to be associated with higher MR prevalence in these states (California,

	-							
Fixed Effects	Autism	All Disabilities but Autism	LD	MR	Speech Language	Emotionally Disturbed	Multiple Disabilities	OHI
Initial status	-7.45ª	-2.04ª	— 2.99ª	-4.63ª	-3.20ª	—5.22ª	-6.36ª	-6.08ª
Proportion per 1000	0.58	115.07	47.88	9.66	39.17	5.38	1.73	2.28
Rate of change	0.19ª	-0.005 <sup>b</sup>	-0.02ª	-0.04ª	-0.003	-0.0003	0.002	0.15ª
OR (95% CI)	1.21 (1.19–1.22)	1.00 (0.99-1.00)	0.98 (0.97-0.98)	0.97 (0.96-0.97)	1.00 (0.99-1.00)	1.00 (0.99-1.01)	1.00 (0.98-1.03)	1.16 (1.13–1.19)
Variance components								
In initial status	0.211ª	0.03ª	0.06ª	0.36ª	0.13ª	0.52ª	0.81ª	1.32ª
3.0 - 001								

TABLE 1	Random Coefficient Logistic Regression, Unconditional Growth Model Results: Prevalence of Select Disabilities in Special Education
	Among Children Aged 6 to 11: 1994–2003, States as Level 2 Units of Analysis

 $^{a}P < .001.$ 

<sup>b</sup>*P* < .01.

TARLE 2	Random Coefficient Logistic Regression: Associational Model Results
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Variables	LD	MR	OHI
Fixed effects			
Initial status	-6.68ª	-6.81ª	-7.22ª
Proportion per 1000	1.25	1.10	0.73
Association coefficient	-0.07ª	-0.28 <sup>b</sup>	0.25ª
OR (95% CI)	0.93 (0.91-0.95)	0.76 (0.60-0.96)	1.29 (1.21–1.36)
Variance components			
Level 2			
In initial status	0.14ª	0.14ª	0.25ª
In rate of change	0.003ª	0.58ª	0.03ª
Goodness of fit			
BIC	3851	3822	3169
BIC difference vs BIC from the unconditional growth model of autism (4172) <sup>c</sup>	344	350	d

Autism prevalence among children aged 6 to 11, 1994–2003, is the outcome, prevalence of selected disability categories (per 1000) as predictors, states as level 2 units of analysis. Cl indicates confidence interval; BIC, Bayesian Information criteria.

<sup>a</sup> *P* < .001.

 $^{b}P < .05.$ 

<sup>c</sup> Interpreting BIC differences: 0 to 2, weak, 2 to 6, positive, 6 to 10, strong, >10, very strong.<sup>35</sup>

<sup>d</sup> These models are not comparable because of missing data at level 1 in the associational model for this variable.

the District of Columbia, Michigan, New Jersey, and West Virginia).

The OHI category had a significant rate of increasing prevalence (Table 1) and had a positive association with autism prevalence (Table 2). Together, these findings suggest that states with higher rates of autism prevalence increase tended to also have higher rates of OHI prevalence increase. This raises the possibility that the OHI category was also involved in a process of diagnostic substitution whereby a declining usage of other categories was offset by growing usage of the autism and OHI categories simultaneously. This possibility will be revisited below.

#### **Piecewise Models**

The remaining condition that needs to be established to suggest a process of diagnostic substitution for the MR and LD categories is the presence of a significant downward deflection in their historical trajectories of prevalence that coincided with the introduction of autism as its own reporting category in the early 1990s. The negative difference-between-slopes coefficients in the first 2 piecewise regression models of Table 3 indicate significant downturns in the trajectories of LD and MR prevalence when comparing the slopes from 1984 to1993 to those from 1994 to 2003. Visual inspection of trends data revealed that the prevalence of LD took another downturn around 1999 (see Fig 2). Therefore, another piecewise regression model was estimated, with LD prevalence as the outcome, adding 1999 as a turning point (model C, Table 3). The significant coefficients for the 2 knots indicate there was a significant downward deflection in the trajectory of LD prevalence at both 1994 and 1999.

#### **Combined Model**

Lastly, we return to the possibility that there was >1 process of diagnostic substitution occurring during the 1994 to 2003 period. Another set of associational models was estimated. The outcome for these analyses was the combined prevalence, per state per year, of children ages 6 to 11 enrolled in the autism, OHI, TBI, and DD categories. The TBI category was added as a new reporting category the same year that autism was added and has grown significantly since then.<sup>31</sup> The DD category has grown steadily since being added in the 1997 revision of

TABLE 3	Random	Coefficient	Logistic	Regression,	Piecewi	se Model	Results
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Variables	Model A,	Model B,	Model C,
	MR	LD	LD
Fixed effects			
Initial status	$-4.88^{a}$	-3.34ª	— 3.33ª
Proportion per 1000 in 1984	7.54	34.22	34.56
Rate of change, 1984–1993	0.02 <sup>b</sup>	0.04ª	0.03ª
OR (95% CI)	1.02 (1.01-1.03)	1.04 (1.03-1.05)	1.03 (1.03-1.04)
Difference between slopes (1984–1993 vs 1994–1998)	$-0.05^{a}$	$-0.05^{a}$	-0.03ª
OR (95% CI)	0.96 (0.95–0.97)	0.95 (0.94–0.96)	0.98 (0.96–0.99)
Difference between slopes (1994–1998 vs 1999–2003)			$-0.05^{a}$
OR (95% CI)			0.95 (0.94–0.96)
Variance components			
In initial status	0.330ª	0.089ª	0.092ª
In rate of change	0.001ª	0.001ª	0.001ª
In slope difference, 1994 knot	0.001ª	0.001ª	0.002ª
In slope difference, 1999 knot			0.002ª

Prevalence among children aged 6 to 11, 1994–2003, for MR and LD, with states as level 2 units of analysis.

 $^{a}P < .001.$ 





FIGURE 2

Prevalence of selected reporting categories in US special education among children aged 6 to 11: 1984–2003. Low Prev Combo indicates the combined prevalence of the autism, OHI, TBI, and DD categories as used in the analyses reported in Table 4.

the Individuals with Disabilities Education Act.<sup>31,41</sup> The 2 predictors were the prevalence per 1000 of LD and MR per state per year centered within state so that each state's initial value was 0 and subsequent values indicated the amount of change since 1994.

Table 4 presents the results from 3 associational models. Model A indicates that higher values of combined (autism + OHI + TBI + DD) prevalence within states over time tended to be associated with decreasing prevalence of LD as indicated by the negative coefficient. Model B indicates that higher values of combined prevalence also tended to be associated with decreasing prevalence of MR. Model C combines both predictors in 1 model. The significant effect of LD vanishes when MR is controlled for, whereas the MR coefficient and OR remained significant. However, the explanatory power of model C was much greater than for model B, as indicated by the substantial difference in the Bayesian Information Criteria statistics. This suggests that both variables are important in explaining the outcome, despite the vanishing statistical effect of LD in model C. Figure 2 graphs the annual mean (across all states) prevalence per 1000 for LD and MR from 1984 to 2003 and for combined prevalence and autism from 1994 to 2003.

There was significant variability around all of the coefficients in all 3 associational models in Table 4, indicating that these associations varied substantially among states. No state saw a decline in the combined prevalence of autism, OHI, TBI, and DD. Only 1 state (Pennsylvania) saw an increase in the combined prevalence of LD and MR from 1994 to 2003. The mean increase in combined prevalence of autism, OHI, TBI, and DD was 12 per 1000. The mean decrease in the combined prevalence of LD and MR, -11 per 1000, was almost exactly the same absolute magnitude. For the 48 states that saw a decrease in combined LD and MR prevalence, a new variable was created representing the difference between changes in combined autism, OHI, TBI, and DD prevalence versus changes in combined LD and MR prevalence from 1994 to 2003. A value of zero would indicate that the combined prevalence of autism, OHI, TBI, and DD increased by exactly the same amount that the combined prevalence of MR and LD decreased. A positive value would indicate that the combined prevalence of autism, OHI, TBI, and DD increased by more than the combined prevalence of LD and MR decreased, thereby suggesting that there were more new cases of autism, and so forth, than diagnostic substitution alone could account for. Twenty-eight states had positive values. A negative value would indicate the combined prevalence of autism, and so forth, increased by less than the combined prevalence of LD and MR decreased, thereby suggesting that diagnostic substitution in these states could potentially have accounted for all new cases of autism, OHI, TBI, and DD. Twenty states had negative values.

TABLE 4	Random Coefficient Logistic Regression: Associational Model Results
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Variable	Model A,	Model B,	Model C,	
	LD	MR	LD and MR	
Fixed effects				
Initial status	— 5.03ª	-5.20ª	-5.33ª	
Proportion per 1000	6.50	5.49	4.82	
LD association coefficient	-0.07ª		-0.03	
OR (95% CI)	0.93 (0.91-0.95)		0.98 (0.95-1.01)	
MR association coefficient		-0.27 <sup>b</sup>	-0.24ª	
OR (95% CI)		0.76 (0.64-0.90)	0.79 (0.72-0.86)	
Level 2 variance components				
In initial status	0.351ª	0.352ª	0.434ª	
In LD association	0.003ª		0.001ª	
In MR association		0.296ª	0.060ª	
Goodness of fit				
BICc	4628	4440	4308	

Outcome is the combined prevalence (per 1000) of children aged 6 to 11 classified in the autism, traumatic brain injury, OHI, and DD categories from 1994 to 2003. Predictors (prevalence per 1000) have been centered within states on their 1994 initial values. BIC indicates Bayesian Information criteria.

ª P < .001.

 $^{b}P < 01$ 

<sup>c</sup> Interpreting BIC differences: 0 to 2, weak, 2 to 6, positive, 6 to 10, strong, >10, very strong.<sup>35</sup>

#### Comment

Several key findings emerged from these analyses. First, changes in the special education prevalence of autism varied tremendously among states despite a common federal mandate to create a separate special education reporting category for children with autism.

Second, the administrative prevalence of autism, as of 2003, in the majority of states was below what we would expect based on recent epidemiological estimates of the prevalence of autism among children ages 3 to 10 in the United States, which ranged from 3.4 to 6.8.32,33 The mean administrative prevalence of autism in US special education among children ages 6 to 11 in 1994 was only 0.6 per 1000, less than one-fifth of the lowest CDC estimate from Atlanta (based on surveillance data from 1996). Therefore, special education counts of children with autism in the early 1990s were dramatic underestimates of population prevalence and really had nowhere to go but up. This finding highlights the inappropriateness of using special education trends to make declarations about an epidemic of autism, as has been common in recent media and advocacy reports. By 2003, there were only 17 states whose special education autism prevalence had passed into the expected reference range of 3.4 to 6.8 established by the CDC studies. However, the US mean prevalence of autism in special education among children ages 6 to 11 (3.1 per 1000) was still below this reference range. Steep growth in administrative prevalence after introducing a new category is a common pattern that was also seen in the other 2 reporting categories newly introduced in the 1990s (TBI and DD). As with autism, in the first few years these categories were used it was not uncommon for states to report very few children with a primary diagnosis of TBI or DD. The prevalence for these categories also had

nowhere to go but up. Suggestions that special education trends substantiate the existence of an autism epidemic would logically also have to either claim an epidemic of brain injury and DD or explain why the same pattern of growth in these 2 categories does not represent an epidemic as it does for the autism category.

Although special education trends cannot substantiate or refute the presence of an actual epidemic of autism, they do represent very real challenges for schools. The growing administrative prevalence of autism in schools can be seen as part of a broader historical trend toward a growing understanding about the uniqueness of various developmental disorders and a concomitant differentiation in terms of interventions and parental expectations regarding treatment. As knowledge and treatment options evolve, so too do expectations about what constitutes appropriate intervention. Autism is no exception, and schools are struggling to create best practices based on a rapidly developing body of research to meet the educational needs of more and more children who are being identified using the autism classification category.

Another important finding that bears on the public debate about the changing prevalence of autism was the uniqueness of California's pattern of changing autism prevalence. Recent reports from California's statewide program of services (not public schools) for people with developmental disabilities have found no corresponding decline in the prevalence of other disability categories. This finding has been used to dismiss the possibility that a process of diagnostic substitution may be partly responsible for the rapid growth in the administrative prevalence of autism across the country.<sup>1,10-13,17,18</sup> However, California was 1 of only 5 states that saw an increase in MR prevalence in special education among

children ages 6 to 11 from 1994 to 2003. Also, California was 1 of only 5 states that did not show an association between increasing autism prevalence and decreasing MR prevalence in special education during this period. California's special education and state service trends seem to mirror one another, thereby suggesting that California's experience has not been typical of the rest of the country. This finding does not minimize or invalidate what may actually be a very troubling pattern of change in California that merits additional study and intervention. However, the implications for national policy are clear: California's changes are unique and should not be the foundation for nationwide policy responses. Combined with the findings of variability among states in special education autism prevalence, this also underscores the continuing need for autism surveillance in multiple states.

Finally, these findings illuminate the role of diagnostic substitution as a partial explanation for changes in the administrative prevalence of autism during the 1994 to 2003 period. The null hypothesis of no association between growing autism prevalence and corresponding declines in the prevalence of other categories was clearly disconfirmed using a multipronged analytic strategy. Increases in autism prevalence within states during this period were significantly associated with corresponding decreases in the prevalence of MR and LD. The second downward turn of LD prevalence after 1999 (see Fig 2) coincided with the release of a memo from the US Department of Education's Office of Special Education Programs instructing schools to use the OHI category for serving children with attention deficit disorder and attention-deficit/hyperactivity disorder,42 suggesting the possibility that many children with attention deficit disorder/attention-deficit/hyperactivity disorder had been classified in the LD category but were then reclassified into the OHI category.

The present analyses suggest that the changes in autism prevalence were part of a larger process whereby increases in the prevalence of several categories (autism, OHI, TBI, and DD) were associated with decreases in the combined prevalence of MR and LD. The exact mix of shifting category usage varied substantially among states. Every state showed an increase in the combined prevalence of the autism, OHI, TBI, and DD categories. Pennsylvania was the only state that did not display a decrease in the combined prevalence of LD and MR during this period. The magnitude of change suggests that diagnostic substitution could have completely accounted for the increases in about half the states. No evidence was found to indicate that growing autism prevalence was merely a facet of a broader increase in the prevalence of all developmental disorders.

These findings are consistent with those of Barbaresi et al,<sup>27</sup> who depicted a downward deflection in the incidence trend of other developmental disorders just as the

trend for autism made a sharp upturn in the early 1990s. However, the present findings seem, at first glance, to diverge from those of Newschaffer et al,6 who found no corresponding decrease in MR or speech/language impairments in US special education from 1992 to 2001 among children ages 6 to 17. The present analyses focused on states as units of analysis and directly modeled the statistical association between autism prevalence and the prevalence of MR and LD. The Newschaffer et al<sup>6</sup> analysis used nationally aggregated cohort data and relied on a visual comparison of charts to conclude a lack of association. Thus, 1 study is looking at variations among the time-series data trends of states, whereas the other examined variations among trends in cohorts. Counts of children with autism within states and cohorts are jointly nested within years, representing a potential confound. The ideal method for dealing with this would be to estimate a crossed random-effects model.43 The main goal of such an analysis would be to disentangle cohort and state effects. Unfortunately, there is no readily available enrollment data broken out simultaneously by cohort and state, thereby precluding this type of analysis.

Environmental explanations for growing autism prevalence have been advanced in recent years, especially the potential role of vaccines. The majority of recent studies have failed to establish a connection between measles-mumps-rubella vaccination or the use of mercury-based vaccine preservative and autism.<sup>20,44-48</sup> However, continuing inquiry into these posited links may yet reveal a connection between environmental exposure and consequent onset of autism. The present findings that support the plausibility of the role of changing identification practices being associated with increases in administrative prevalence should not be taken as a refutation of potential environmental explanations because growing administrative prevalence could very well have multiple causes including diagnostic substitution and environmental factors. Rather, the present findings serve to underscore how shifting identification practices can affect administration prevalence, just as broadening clinical diagnostic criteria have been used to understand changes in population-based estimates of prevalence.20,21,49

Several limitations of the present study should be noted. First, this study did not examine data at the level of individual children. A second limitation is the lack of analysis of variations within states. Recent findings from Texas demonstrate that there was substantial variability among school districts in changes in special education autism prevalence during the 1990s.<sup>7</sup> This is likely the case in other states as well, but intrastate data are not readily available for most states. Third, we do not have longitudinal population surveillance data on the prevalence of autism at the state level. Therefore, it is impossible to precisely quantify how much the variability among states in administrative prevalence is because of variations in true prevalence versus variations in classification practices. Because of a lack of population-based evidence, it is also impossible to verify the completeness or biases of these data. Fourth, this study does not shed light on the exact nature of changes in identification procedures on the front lines of school practices the way a case study could. Finally, the present study did not examine other predictors of changing autism prevalence beyond the diagnostic substitution hypothesis. A recent study from Texas that examined changing prevalence among 1040 school districts from 1994 to 2000 found that greater increases in prevalence were associated with higher school revenue and a lower percentage of economically disadvantaged children.<sup>7</sup>

Counterbalancing these limitations are several strengths. First, focusing analysis at the level of states has several advantages. There are some situations where ecological analysis is more desirable than individuallevel analysis.<sup>50</sup> One of these is where the implications for intervention and prevention are at the aggregate level. The most efficient and effective way to improve the quality and consistency of identification efforts across the largest number of schools possible is through policy and regulatory reform at the state level. Another advantage of state-level analyses is that they allow for greater generalizability of findings (compared with an analysis of the district-level data of just 1 state) and the ability to pinpoint which states' patterns of change are unique and, thus, not generalizable to other states. The case in point is California, for which idiosyncratic patterns of change have often been seen as representative of changes across the rest of the country. A second strength is that use of a multimethod approach for testing the diagnostic substitution hypothesis provides a level of convergent validity that would not be possible in a study that used only 1 method of analysis.

The present study suggests several possibilities for future research. First, we need a closer examination of how referral and identification happens in schools to identify barriers that inhibit timely and accurate identification, as well as models of best practices from schools that seem to be particularly effective in this regard. Comparative case studies could reveal how local and state identification policies and practices differ and then, in turn, how these differences result in different identification and intervention outcomes.

Another important question to look at is how classifications change within students during the course of their time in special education. This would help pinpoint whether growing autism prevalence within cohorts was because of the first-time identification of children or the reclassification of children who had previously been in special education under a different category.

Finally, it is especially important for future research to address the consequences that delayed and inaccurate

classification have for the educational supports and outcomes of students with autism. Does it really matter which label a child gets, given that packages of support are supposed to be tailored to each child's unique needs regardless of diagnosis? Do children obtain more or fewer supports depending on which category they are classified into, controlling for degree of disablement and need for support? Answering questions like these would require analysis of individual-level data.

#### CONCLUSIONS

This study has advanced our understanding of the changing patterns of autism prevalence in special education. Comparisons with population surveillance findings indicate that special education trends cannot be legitimately used to support claims of an autism epidemic. Given the prominent role of special education in the overall process of referral and diagnosis in US society, current large-scale awareness interventions should focus on influencing identification practices in schools as much as they do on primary health care settings.<sup>51,52</sup> Future research and policy needs to focus on improving the timeliness of identification and intervention and on ensuring that the ideal of individualized support promised by federal law is actually realized in the intervention plans and school experiences of children with autism and other disabilities, regardless of which administrative category they are counted in.

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An error appeared in the article by Cianferoni et al, titled "Visceral Larva Migrans Associated With Earthworm Ingestion: Clinical Evolution in an Adolescent Patient" published in the February 2006 issue of *Pediatrics Electronic Pages* (doi: 10.1542/peds.2005-1596). On page e337, the legend for Figure 2 reads: "Hematoxylin-eosin stain of transbronchial biopsy that demonstrates organizing eosinophilic pneumonitis." It should read as follows: "Hematoxylin-eosin stain of transbronchial biopsy demonstrating increased numbers of intracapillary circulating eosinophilis." The authors would also like to acknowledge Dr Sara O. Vargas from the Division of Pathology at Children's Hospital Boston for providing the photomicrographs for Figures 2 and 3.

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# Shattuck PT. The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education. PEDIATRICS 2006;117:1028–1037.

Errors appeared in the article by Shattuck titled "The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education" that was published in the April 2006 issue of *Pediatrics* (doi:10.1542/peds.2005-1516). On page 1029, lines 8 through 11 in the first paragraph, the author wrote: "In the California Developmental Disabilities Service system, the number of clients with an autism diagnosis as a percentage of all clients rose from 4.9% to 9.4% during the 1994–2003 period.<sup>1</sup>" It should have read as follows: "In the California Developmental Disabilities Service system, the number of clients with an autism diagnosis as a percentage of all clients rose from 4.9% to 9.4% during the 1987–1998 period.<sup>1</sup>"

On page 1031, the last sentence of the first paragraph of the Results section, the author wrote: "Of the 2, the higher prevalence estimate from New Jersey was closest to other recent epidemiological surveys yielding estimates of 61.3 per 1000<sup>38</sup> and 57.9 per 1000.<sup>39</sup>" It should have read as follows: "Of the 2, the higher prevalence estimate from New Jersey was closest to other recent epidemiological surveys yielding estimates of 6.26 per 1000<sup>38</sup> and 5.87 per 1000.<sup>39</sup>"

On page 1037, Reference number 39 reads: Baird G, Charman T, Baron-Cohen S, et al. A screening instrument for autism at 18 months of age: A 6-year follow-up study. *J Am Acad Child Adolesc Psychiatry*. 2000;39:694–702.

Reference 39 should be: Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children: Confirmation of high prevalence. *Am J Psychiatry*. 2005;162:1133–1141.

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#### The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education

Paul T. Shattuck Pediatrics 2006;117;1028

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