Journal of Autism and Developmental Disorders, Vol. 32, No. 3, June 2002 (© 2002)

The Changing Prevalence of Autism in California

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We conducted a population-based study of eight successive California births cohorts to examine the degree to which improvements in detection and changes in diagnosis contribute to the observed increase in autism prevalence. Children born in 1987–1994 who had autism were identified from the statewide agency responsible for coordinating services for individuals with developmental disabilities. To evaluate the role of diagnostic substitution, trends in prevalence of mental retardation without autism were also investigated. A total of 5038 children with full syndrome autism were identified from 4,590,333 California births, a prevalence of 11.0 per 10,000. During the study period, prevalence increased from 5.8 to 14.9 per 10,000, for an absolute change of 9.1 per 10,000. The pattern of increase was not influenced by maternal age, race/ethnicity, education, child gender, or plurality. During the same period, the prevalence of mental retardation without autism decreased from 28.8 to 19.5 per 10,000, for an absolute change of 9.3 per 10,000. These data suggest that improvements in detection and changes in diagnosis account for the observed increase in autism; whether there has also been a true increase in incidence is not known.

KEY WORDS: Autistic spectrum disorders; epidemiology; prevalence; mental retardation.

INTRODUCTION

Autism is a neurodevelopmental disorder characterized by impairments in social interaction, delays and deviancies in communication, and restricted and repetitive patterns of interests and behaviors (American Psychiatric Association [APA], 1994). This triad of impairments is often accompanied by cognitive deficits ranging from mild to profound (Wing, 1997). Although the cause of autism is not known, evidence from family and twin studies has consistently suggested a strong genetic influence (Cook, 1998).

Autism was first described in 1943 by Kanner (1943), who presented case histories of 11 children who shared a pattern of behavior that included social remoteness, stereotypy, and echolalia. Since that time, a broad spectrum of disorders with similar core behavioral symptomatology has been identified and grouped under the common label of pervasive developmental disorders (PDD) (APA, 1980, 1987, 1994). There has been a growing clinical consensus that the umbrella "pervasive developmental disorders" actually represents an "autistic spectrum" (Wing, 1997).

A dramatic increase in the number of children identified with autism has been reported by clinicians, schools, and service agencies worldwide (Bax, 1994; Department of Developmental Services, 1999). Published estimates based on epidemiologic studies have also indicated an increase in prevalence (Filipek *et al.*, 1999). The first survey, which was conducted in the United Kingdom in 1966, reported a prevalence of 4.5

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0162-3257/02/0600-0207/0

per 10,000 (Lotter, 1966). Subsequent estimates ranged from 4 to 5 per 10,000 in the 1970s (Brask, 1972; Wing and Gould, 1979; Wing *et al.,* 1976) and from 2.5 to 16 per 10,000 in the 1980s (Bohman *et al.,* 1983; Bryson *et al.,* 1988; Burd *et al.,* 1987; Cialdella and Mamelle, 1989; Gillberg, 1984; Hoshino *et al.,* 1982; Ishii and Takahashi, 1982; Matsuishi *et al.,* 1987; McCarthy *et al.,* 1984; Ritvo *et al.,* 1989; Sugiyama and Abe, 1989; Tanoue *et al.,* 1988). Data published in the 1990s indicate even higher prevalences, with estimates ranging from 5 to 31 per 10,000 (Arvidsson *et al.,* 1997; Baron-Cohen *et al.,* 1996; Deb and Prasad, 1994; Fombonne and Du Mazaubrun, 1992; Gillberg *et al.,* 1991; Honda *et al.,* 1996; Magnusson and Saemundsen, 1999; Nordin and Gillberg, 1996; Sponheim and Skjeldal, 1998; Webb *et al.,* 1997; Wignyosumarto *et al.,* 1992). The Centers for Disease Control and Prevention (CDC) recently reported a prevalence of autistic disorder in Brick Township, NJ, of 40 per 10,000 children aged 3–10 years (CDC, 2000). Variability in reported prevalence estimates could reflect differences in case definitions, ascertainment strategies, or population demographic characteristics.

Repeated population-based studies within the same geographical area have been performed only in Sweden and France. Using the same methodology over time, the Swedish studies demonstrated an increase in autism prevalence from 4.0 per 10,000 in 1980 to 7.6 per 10,000 in 1984 to 11.5 per 10,000 in 1988 (Gillberg and Wing, 1999). The increase was attributed in part to better detection of children with non–Kanner-type autism and children of immigrant origin. The study samples in these three investigations were not mutually exclusive, and prevalence estimates were not derived for specific birth cohorts. More recently, trends over time in the prevalence of autism were examined in a geographically defined population in France (Fombonne *et al.,* 1997). When case definition and identification methods were held constant, no increase in the prevalence of autism was demonstrated.

The extremely large annual birth population in California and the existence of a statewide service delivery system in which the majority of children with full spectrum autism are enrolled provided an opportunity to examine trends in autism prevalence over several successive annual birth cohorts. We report here on the overall prevalence of autism in California and how it has changed over time with regard to selected clinical and demographic characteristics. The role of changes in detection and diagnosis is explored.

METHODS

In California, individuals with autism, mental retardation (MR), cerebral palsy (CP), epilepsy, and other neurologic conditions closely related to MR are eligible to receive services through the Department of Developmental Services (DDS), a statewide service delivery system that coordinates the diagnosis and provision of services for individuals with developmental disabilities. Services are provided through a system of 21 locally based regional centers. Eligibility is determined on the basis of diagnostic parameters without financial or citizenship stipulations.

Study Population

All children born between 1987 and 1994 and enrolled with DDS at any time between January 1, 1987, and July 7, 1999, were identified from computerized data files maintained by DDS. These files contain diagnostic information recorded on the Client Development Evaluation Report (CDER) at the time of initial intake and are supposed to be updated at all subsequent scheduled evaluations.

We identified 6943 children with a diagnosis of autism ("full syndrome," "suspected," or "residual") on their most recent CDER. Only children with a diagnosis of autism "full syndrome" ($n = 5991$) were eligible for inclusion in this study. *Full syndrome autism* is defined by DDS as "a syndrome first appearing in the early years of life—usually before the age of three—which is characterized by extreme withdrawal, language disturbance, inability to form affective ties, frequent lack of responsiveness to other people, monotonously repetitive behaviors, inappropriate response to external stimuli, and an obsessive urge for maintaining sameness." Asperger's disorder, childhood disintegrative disorder, Rett's disorder, and PDD-NOS are *not* included in this definition and are not DDS-eligible conditions. Eligibility is based on diagnoses provided by qualified professionals (e.g., licensed psychologists, psychiatrists, pediatricians, neurologists). Diagnoses are generally established according to criteria outlined in the most current *Diagnostic and Statistical Manual (DSM).* During the study period, *DSM-III-R* (APA, 1987) and *DSM-IV* (APA, 1994) were the predominant criteria in use. Information on the version of the DSM used to diagnose each child was not available.

Although not all individuals who meet eligibility requirements are enrolled for services, we estimate that children with autism enrolled in this system represent

at least 75–80% of the total population of children with this diagnosis in the state. This estimate is based on results of electronic data linkage of the DDS and California Department of Education, Special Education databases. A total of 1993 children born in 1987–1994 who were not enrolled for services with DDS were identified in the Special Education database with a primary disability code of "autism," and the proportion of children with autism who were uniquely enrolled in Special Education did not change over the study birth years. Information on diagnostic criteria used to classify children in the Special Education system was not available, however, and the group of children uniquely enrolled in Special Education likely includes children with a broader spectrum of disorders than those eligible for services through DDS.

To examine the impact of diagnostic substitution on the change in autism prevalence over time, we identified all children enrolled with DDS during the same time period with a diagnosis of MR (IQ $<$ 70) of "unknown etiology" who did not also have a diagnosis of autism or cerebral palsy (n = 13,822). The diagnosis of MR was based on results of age-appropriate standardized tests of general cognitive ability. Etiology was considered "unknown" unless MR was attributed to chromosomal abnormalities (International Classification of Diseases [ICD] 758.0–758.9), congenital infections (ICD 001.0–139.9, 771.0–771.9), metabolic or endocrine disorders (ICD 240.0–279.9), accidents or injuries (ICD 800.0–999.9), or diseases (ICD 320.0–341.9), anomalies (ICD 740.0–742.9), or neoplasms (ICD 140.0–239.9) of the brain.

Identification of California-Born Children

CDER records were electronically linked to the live birth certificate computer files for the cohort of 4,590,333 California births occurring in 1987–1994. The linkage procedure included multiple rounds of computer matching using algorithms based on combinations of the child's name (first, middle, last), the mother's maiden name, and the child's birth date, sex, race, and county of residence. All questionable matches were reviewed by hand. A birth certificate match was found for 5038 (84.1%) children with autism and 11,114 (80.4%) children with MR. The percentage of children who were matched to a birth certificate did not differ significantly by birth year, sex, or ethnicity (Table I).

Table I. Characteristics of the DDS Population that Matched to a California Birth Certificate

	Live births (n = 4,590,333)	Autism (n = 5038)		Mental retardation[a] (n = 11,114)	
	n	n	Percent of total DDS population	n	Percent of total DDS population
Birth year					
1987	504,853	292	78.5	1452	76.6
1988	534,174	365	79.9	1401	78.2
1989	570,976	433	81.4	1368	78.3
1990	613,336	542	84.4	1369	81.1
1991	610,701	771	86.2	1557	82.0
1992	602,269	916	84.6	1488	81.5
1993	585,761	873	85.5	1370	83.8
1994	568,263	846	85.4	1109	82.5
Sex					
Male	2,350,287	4116	84.4	7027	81.0
Female	2,240,020	921	82.8	4087	79.5
Race/ethnicity					
White	1,884,556	2361	86.6	4189	84.2
Hispanic	1,845,765	1382	88.4	4239	80.7
Black	367,611	604	86.3	1650	81.3
Asian	267,685	389	76.7	518	76.3
Other	198,052	288	70.8	459	64.6

[a] Excludes children with mental retardation as a result of chromosomal abnormalities (ICD 758–758.9), congenital infections (ICD 001.0–139.9, 771.0–771.9), metabolic or endocrine disorders (ICD 240.0–279.9), accidents or injuries (ICD 800.0–999.9) or diseases (ICD 320.0–341.9), anomalies (ICD 740.0–742.9), or neoplasms (ICD 140.0–239.9) of the brain.

Data on infant and maternal characteristics were obtained from birth certificates. Characteristics under study included the child's sex, plurality (singleton vs. multiple birth), maternal age (≤19, 20–24, 25–29, 30–34, ≥35), maternal race/ethnicity (white, Hispanic, black, Asian, other), and maternal education (none, less than high school, high school graduate, some college, postgraduate).

Evaluation of Autism and Mental Retardation Diagnoses

Because of the size of the study population, it was not possible to validate the autism and MR diagnoses obtained from the CDER data file through direct examination or medical record review for all study children. To evaluate the reliability of the CDER diagnoses and changes in reliability over the study period, we reviewed medical records compiled by the regional centers for two randomly selected groups of children: one based on a diagnosis of autism on their most recent CDER (53 born in 1983–1985, 38 born in 1993–1995) and the other based on a diagnosis of MR but not autism on their most recent CDER (75 born in 1983–1985, 80 born in 1990–1996). Developmental and symptomatic data recorded in these medical records were reviewed by a trained developmental specialist, who systematically recorded all autism spectrum diagnoses, all MR diagnoses, the dates of diagnosis, the professional specialty of the evaluator making the diagnosis, and the criteria used to assign the diagnosis.

Statistical Analysis

Autism and MR prevalence estimates for California-born children were computed for the entire 8-year period combined and separately for each birth year. The χ^2 test for trend (Cochran, 1954) was used to analyze trends in prevalence over time. A multivariable Poisson regression model (Selvin, 1995) was used to explore the relationship between the prevalence of autism and the simultaneous influences of several infant and maternal characteristics. A close "fit" of this additive model to the observed data, measured by a χ^2 goodness-of-fit statistic, indicates that the relationship between autism prevalence and birth year is essentially the same for all levels of the other variables in the model.

RESULTS

The overall prevalence of full syndrome autism among the 1987–1994 California live birth cohort was 11.0 per 10,000 (95% confidence interval = 10.7–11.3 per 10,000). Prevalence ranged from 5.8 per 10,000 for children born in 1987 to 14.9 per 10,000 for children born in 1994 (Fig. 1), a statistically significant increase (χ^2 test for trend = 515.3, $p < .001$). The prevalence of autism increased at a rate of 17.6% per year for 1987–1990 births, followed by a marked jump in the rate of increase for 1990–1992 births, and a leveling off for the 1993–1994 birth cohort (Fig. 1). By comparison, the prevalence of MR of unknown cause decreased during this 8-year period, from 28.8 per 10,000 for 1987 births to 19.5 per 10,000 for 1994 births, with an observed increase during the 1990–1991 period (Fig. 1).

The pattern of increase in autism prevalence shown in Figure 1 was essentially the same for males and females; singletons and twins; whites, Hispanics, blacks, and Asians; and each stratum of maternal age and maternal education. Furthermore, multivariable Poisson regression analyses strongly indicated the independent influence of these demographic characteristics on autism prevalence (χ^2 goodness-of-fit = 2281.7, $p = .99$). To illustrate this independent influence, the ratios of the 1994 prevalence to the 1987 prevalence (RR) for each level of maternal age were calculated. The magnitude of the increase in prevalence during these 8 birth years was essentially the same for all levels of maternal age (RR = 1.9, 2.6, 2.9, 2.6, and 2.0 for maternal age <20, 20–24, 25–29, 30–34, and ≥35, respectively) and did not vary by child's sex-plurality, maternal race/ethnicity, or maternal education. A similar independence of demographic characteristics was observed for autism with MR and autism without MR.

The majority of children with autism (62.8%) did not have a diagnosis of MR recorded on their most recent CDER evaluation (Table II). Prevalence estimates for children with autism without MR increased from 3.1 to 9.9 per 10,000 during this 8-year birth cohort. Among children for whom some degree of MR was recorded, prevalence increased from 2.6 to 4.9 per 10,000 (Fig. 2).

The age at which children entered the service delivery system decreased for each successive birth year (Fig. 3). The mean age at entry was 6.9 years among 1987 births and 3.3 years among 1994 births. Children born in each successive year had 1 less year of opportunity to enter the service delivery system (i.e., the data are truncated). Nonetheless, the total number of children with autism enrolled with DDS was almost three times higher for 1994 births ($n = 846$) than for 1987 births ($n = 292$), and the prevalence of autism was

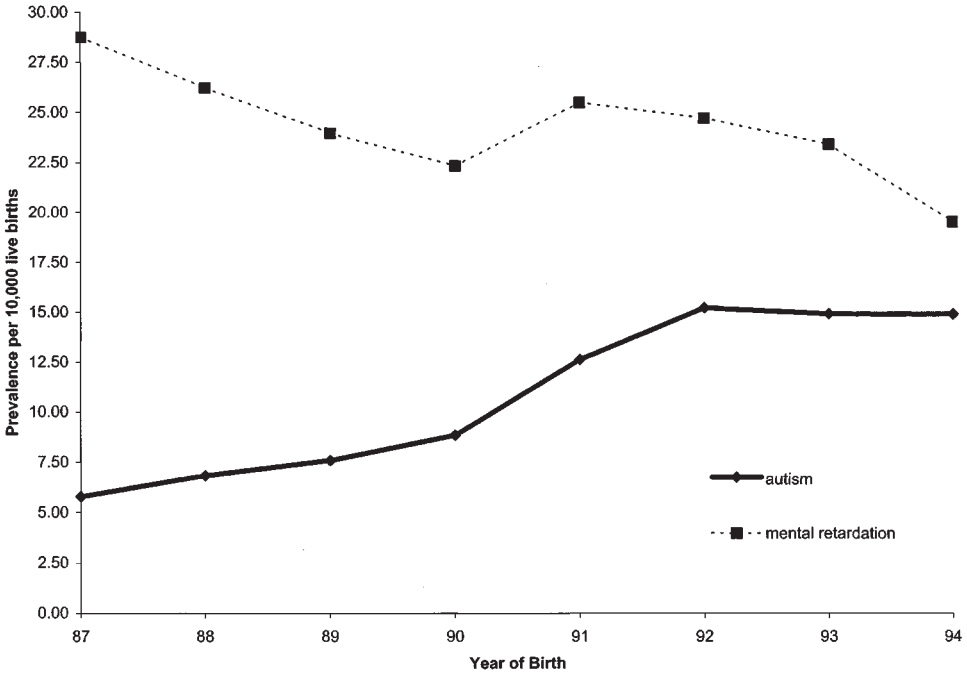

Fig. 1. Prevalence of autism and mental retardation of unknown cause in California.

highest among the cohort of children with the fewest years of follow-up.

Results from the medical record review studies suggest that the reliability of the CDER diagnosis among children qualifying for services on the basis of autism did not change over the study period. Of 53 children born in 1983–1985 with a CDER diagnosis of autism, 45 (85%) met criteria for "autistic disorder" and 8 (15%) met criteria for PDD-NOS (4 according to *DSM-III*, 28 according to *DSM-III-R*, and 10 according to *DSM-IV*). Likewise, 32 (84%) of the 38 children born in 1993–1995 with a CDER autism diagnosis met full DSM-IV criteria for "autistic disorder" and 6 (16%) met criteria for PDD-NOS. None of the children had a diagnosis totally outside the autism spectrum. In contrast, the reliability of the CDER diagnosis among children qualifying for services on the basis of MR did change during the study period. Of 75 children born in 1983–1985 with a diagnosis of MR but not autism on their most recent CDER, diagnostic information contained in regional center medical records indicated a diagnosis of autism in 10%. Among a sample of 80 children born in 1990–1996, this dropped to 3.7%.

Table II. Level of Cognitive Impairment among Children with Autism Born in California in 1987–1994 and Enrolled with the Department of Developmental Services

	Autism (n = 5038)	
Mental retardation level	*n*	%
Normal IQ	3166	62.8
Mild (IQ 50–70)	867	17.2
Moderate (IQ 35–49)	332	6.6
Severe (IQ 20–34)	73	1.5
Profound (IQ <20)	7	0.1
Unspecified	593	11.8

DISCUSSION

These data demonstrate a dramatic increase in the prevalence of full syndrome autism among children born in California between 1987 and 1994 and enrolled with DDS. This increase was not accounted for by changes in population demographic characteristics. The most marked increase was among children without a diagnosis of MR, although prevalence of autism among children with reported MR increased as well. During the same time period, a decrease of comparable mag-

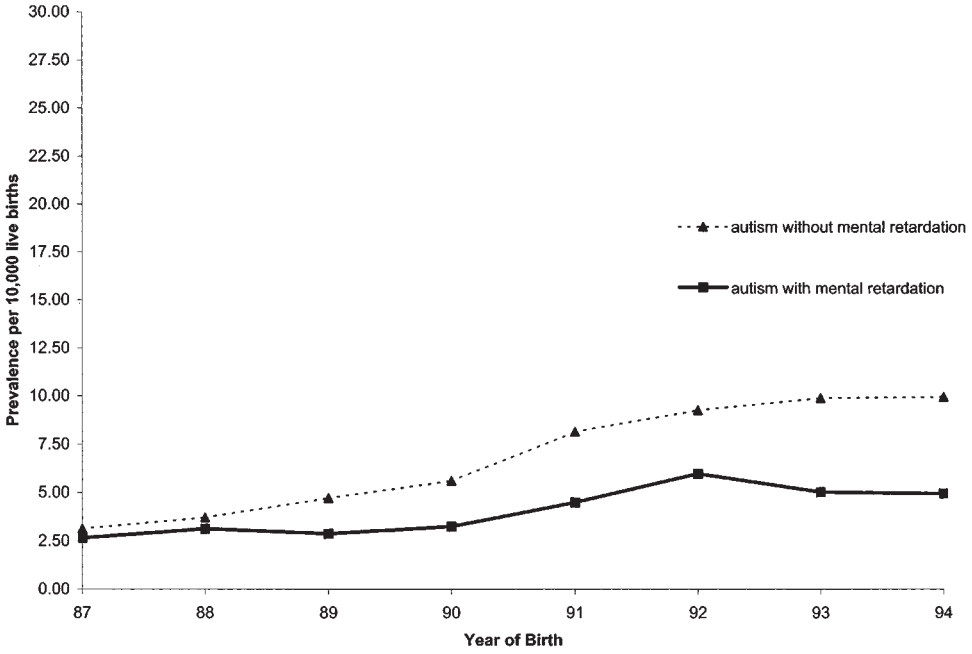

Fig. 2. Prevalence of autism among children with and without mental retardation.

nitude was observed in the prevalence of children enrolled with DDS with a diagnosis of MR of unknown etiology.

This is the first study to examine changes in autism prevalence in one geographic area over several successive birth cohorts while controlling for several population demographic factors. Our study population is larger than the total number of children surveyed in all previous epidemiologic studies of autism combined (Fombonne, 1999). The symptomatology of autism is relatively stable over the first several years of childhood (Kadesjo *et al.*, 1999) and then may change as children approach adolescence. Because our study population was limited to relatively young children, the ability to identify and diagnose autism was similar for all study participants.

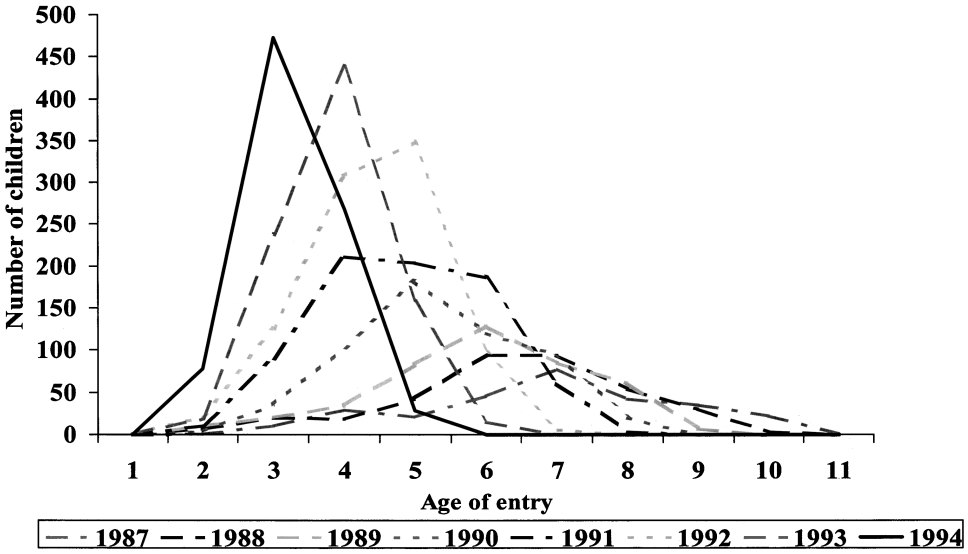

Fig. 3. Age at entry to service delivery system for children with full syndrome autism.

Two important methodologic limitations of this investigation require discussion. First, the study population was restricted to children enrolled with the service delivery system and might not be representative of the total population of children with autism who were born in California. Children with autism enrolled exclusively with the Special Education system were not included, nor were community surveys conducted. In addition, the identification of autism among the youngest children in the study was most likely incomplete. Thus, the observed prevalence is an underestimate of the true prevalence of autism among California-born children.

Second, the autism diagnosis we used was that recorded on the most recent CDER and was not validated by clinical examination. CDER diagnoses typically reflect the diagnosis at initial enrollment and are rarely updated, although periodic clinical evaluations are conducted and recorded in client charts. A review of these diagnostic reports for a small random sample of children indicated that the CDER diagnosis of autism corresponded to the more detailed diagnostic information for the large majority of children.

The observed prevalence of 11.0 per 10,000 is comparable to the "most reasonable conservative estimate" proposed by Gillberg and Wing (1999) of 10 per 10,000. Our estimate of 14.9 per 10,000 for 1994 births is similar to estimates from Europe and Japan published in the past decade and reflects a 2.6-fold increase over the observed prevalence for 1987 births. Our observation of a higher rate of increase of autism in children without reported MR is consistent with data from Sweden showing that the proportion of children with autism with IQs > 70 has increased over time (Gillberg *et al.,* 1991). Our results, however, may be biased to an unknown degree by underreporting of MR among children with autism.

Because our study was restricted to California-born children, the observed increase in prevalence cannot be explained by in-migration of children born out of state who enrolled for services with DDS.

Several factors that may account for the observed increase in autism prevalence, including improvements in case recognition and changes in diagnosis, deserve consideration. During the past 20 years, awareness of autism has grown among clinical specialists, general pediatricians, and the lay public. A variety of standardized autism assessment tools (Krug *et al.,* 1980; Schopler *et al.,* 1986) and screening instruments (Baron-Cohen *et al.,* 1992) have been developed and put into use. Improved recognition of autism and similar disorders at the primary care level may have resulted in an increased flow of referrals to the service agency during the study period.

The marked increase in the prevalence of autism and MR observed for children born in 1990–1992 provides support for the hypothesis that improvements in detection may have contributed to our results. In 1986, Federal legislation (Part H [currently Part C] of the Individuals with Disabilities Education Act) mandated that states provide early intervention services to all infants and toddlers aged 0–3, with or at risk for developmental delay or disability. In response, the California state legislature enacted the Early Intervention Services Act (Early Start-Government Code Section 95000–95004), and by 1994, early intervention services were implemented statewide. In the early 1990s, extensive outreach was conducted by DDS to heighten public awareness of the Early Start program. Our results suggest that this effort was successful in bringing an increasing number of children into the service delivery system and at younger ages.

Intensive autism intervention programs, such as the behavioral treatment program developed by Lovaas (1987), became more widely available during the early 1990s. Families who otherwise would not have sought services through the regional centers may have entered the service delivery system to gain financial support for these costly interventions.

Better screening and identification of autism among children with normal intelligence could account for our findings of a higher rate of increase in autism prevalence among children without MR. Gillberg and Wing (1999) postulate that the increasing autism prevalence observed in Sweden is due in part to better screening and coverage among children with higher levels of intelligence. Alternatively, our finding could be an artifact of biased IQ measurement or MR categorization. In this population, the proportion of children without recorded MR (63%) was unusually high, suggesting that many children who were given an autism diagnosis were not tested for IQ. Because more recently born cohorts were younger at intake, they may not have had adequate IQ testing, as this is difficult in young children and often not done until an older age.

Changes in diagnostic practices during the study period might also have contributed to the observed increase. Although we did not have information to determine the actual diagnostic criteria used, children born in 1987–1990 were most likely diagnosed with the *DSM-III* or *DSM-III-R* criteria, whereas children born after 1990 were diagnosed according to the *DSM-IV* criteria. "Autistic disorder" is defined by both *DSM-III-R* and *DSM-IV*, but children who were diagnosed

more recently may represent a broader phenotypic spectrum.

The observed increase in autism prevalence may also be due in part to the reclassification of children from the MR diagnostic category to the autism category. We observed that during the study period, the prevalence of autism increased an absolute 9.1 per 10,000, whereas the prevalence of MR of unknown cause declined an absolute 9.3 per 10,000. With better recognition and detection of autism, children who previously qualified for services based on a diagnosis of MR may have increasingly qualified for services based on a diagnosis of autism. Data from the record review studies we conducted support this hypothesis.

Finally, in an era when other disorders in the autistic spectrum became more widely recognized and interventions became more available, pressure may have increasingly been put on the system to give children with Asperger's disorder and PDD-NOS a diagnosis of full syndrome autism so that they could qualify for regional center services.

Whether the observed increase in prevalence in part reflects a true increase in incidence or is totally an artifact of improved recognition and detection combined with a broadening of the diagnostic definition remains to be clarified. However, these data clearly demonstrate that autism is much more common than previously believed. Research into the underlying causes of autism is needed.

ACKNOWLEDGMENTS

We gratefully acknowledge Dr. Laura Jelliffe for the instrumental role she played in the collection of medical record data, and Carrie Theis, Drs. Ron Huff, MaryLu Hickman, and Roberta Marlowe for their assistance with access to and interpretation of the Department of Developmental Services data.

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