

Executive Summary

Autism is a neurological or brain disorder that profoundly affects a person's ability to communicate, form relationships with others, and respond appropriately to the environment. Those affected by autism fall along a spectrum of "high-functioning" individuals to individuals who lack any means of communicating with others. The prevalence of autism in the population is not well described. It was once thought that autism was relatively rare, occurring in 4-5 per 10,000 persons. More recent estimations put the prevalence of autism at 10-12 per 10,000 persons. A clear cause has not been identified, although there is evidence for genetic predisposition. Autism is more common in males and is more common in certain medical conditions. Families with one autistic child are more likely have another child with autism. However, a purely genetic basis for autism does not fully explain the increasing autism prevalence. Other theories that attempt to better explain the observed increase in autism cases include environmental exposures to substances such as mercury; viral exposures; autoimmune disorders; and childhood vaccinations.

In California, persons diagnosed with full syndrome autism and other developmental disabilities qualify for services coordinated by a system of local Regional Centers. Established by the Lanterman Act in 1969, the Regional Centers are unique as a service mechanism through which the needs of developmentally disabled citizens are addressed.

In March 1999, the Department of Developmental Services issued a report titled "Changes in the Population of Persons with Autism and Pervasive Developmental Disorders in California's Developmental Services System: 1987 through 1998." The report documented an increase of 273% in reported cases of autism in California over this time period. Because of the concern over this apparent increase in autism, the State Legislature requested that the University of California's Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute conduct a comprehensive pilot study to examine factors that may be associated with this increase.

The study methods are presented in detail in the full report to the Legislature. A California-wide sample of 684 children from English- or Spanish-speaking families enrolled to participate in this study. Information regarding children from two different birth year cohorts (1983-1985 and 1993-1995) was systematically collected from families of 375 children with a diagnosis of full syndrome autism and 309 children with a diagnosis of mental retardation without full syndrome autism. Data for the study came from four main sources:

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- 1) Data from the Department of Developmental Services Client Development Evaluation Report (CDER form);
- 2) Regional Center records;
- 3) The Autism Diagnostic Interview — Revised (ADI-R); and
- 4) a detailed study questionnaire.

The primary findings of the study are summarized in the following list of principal aims:

- **Study Aim 1:** *To investigate whether changes over time in the criteria used to diagnosis CDER status 1 autism account for a significant proportion of the increased number of cases of autism.*

The Regional Center designation of full syndrome autism, CDER status 1 autism, closely matched DSM-IV criteria for autism, and this did not change over time. (88% of the 1983-85 cohort met DSM-IV criteria compared to 89% of the 1993-95 cohort.) In addition, no differences over time were found in comparisons of the number of criteria met within specific components of the ADI-R. There is no evidence that a loosening in the diagnostic criteria has contributed to increased number of autism clients served by the Regional Centers.

There is no evidence that loosening in diagnostic criteria contributed to an increase in the number of children with autism.

- **Study Aim 2:** *To investigate whether the misclassification of some cases of autism as mental retardation in the past has contributed to an apparent increase in the number of children with autism.*

A portion of children reported by the Regional Centers as having mental retardation without full syndrome autism did meet DSM-IV criteria for autism. Of the 1983-85 cohort, 18% met criteria for autism, compared to 19% of children in the 1993-95 cohort. However, these numbers cannot be used to make reliable estimates of the number of children with autism not being counted (and not being treated), because 1) we had a relatively low response rate by families with mentally retarded children, and 2) families were more likely to agree to enroll if their mentally retarded child also had an autism spectrum disorder.

- **Study Aim 3:** *To investigate whether temporal changes in children with autism moving into California for services accounts for a significant proportion of the increased cases of autism reported to DDS.*

The proportion of the study children with autism who are California-born is 87% of the 1983-85 group and 93% of the 1993-95 group. Thus, autistic

children in the Regional Center System are largely native to the State and are not coming disproportionately from outside California.

■ **Study Aim 4:** *To describe how characteristics of children with autism have changed over time.*

Comparisons between the two age groups show many similarities and some differences. There are no significant differences in sex, race, and maternal and paternal education. Hispanic children are more likely to be included in the younger autistic group (28% in the 1983-85 group and 39% in the 1993-95 group). Parents of the older group were more likely to report that their autistic child also had mental retardation (41% vs. 21%). This is consistent with the review of Regional Center records that found a decrease in diagnosed mental retardation in the younger group (50% in the 1983-85 group vs. 22% in the 1993-95 group). Regression of developmental milestones, as determined from the ADI-R interview, did not significantly change over time (28% vs. 34%). Compared to the older group, parents of the younger group were more likely to report improvement in their child's condition over time (81% vs. 93%). Older children with autism were more likely to be reported as having tic disorders, obsessive-compulsive disorders, depression, and bipolar disorder, but this may be due to an age effect rather than a cohort effect. There were few differences over time in factors associated with the pregnancy. Gastrointestinal symptoms were more commonly reported during the first 15 months of life for the 1993-95 cohort than the older cohort. Wheat allergy was significantly more frequent (12%) for the younger group than the older group (4%). None of these differences fully explain the increase in autism cases in California.

Parent-reported regression of developmental milestones did not change over time.

■ **Study Aim 5:** *To ascertain what parents of children with autism believe caused their child's autism, and to determine if this has changed over time.*

The most common parental response in both groups was no response or "Don't know" (46% and 48%). Genetics was the second most common response for both groups (31% and 27%). Immunizations were reported as a contributing factor by 18% of the older cohort and 33% of the younger cohort. Birth events were cited by about 15% of parents in both groups. Autism was attributed to environmental exposures by about 11% of the study families.

- **Study Aim 6:** *To determine if vaccination with MMR vaccine is associated with an increase in the recurrence rate of autism in subsequent siblings.*

Avoidance or delay of at least one vaccine for the autistic child enrolled in this study was reported by 8% of older cohort parents and 22% of younger cohort parents. Similar patterns were reported with regard to avoiding/delaying vaccination of any younger siblings (10% vs. 21%). Anecdotal information prior to this study suggested that 50% of families with autistic children were avoiding immunization in their younger children, but our results show that vaccine avoidance is less common than had been suggested. As a result, the number of children necessary to answer this study aim question is far in excess of the size of this study (approximately 7,000). Until a study of that size can be done, this study aim will remain unanswered.

Major Findings

The major findings of this study are that:

- The observed increase in autism cases cannot be explained by a loosening in the criteria used to make the diagnosis.
- Some children reported by the Regional Centers with mental retardation and not autism did meet criteria for autism, but this misclassification does not appear to have changed over time.
- Children served by the State's Regional Centers are largely native born and there has been no major migration of children into California that would explain the increase in autism.
- A diagnosis of mental retardation associated with autism had declined significantly between the two age groups.
- The percentage of parent-reported regression (loss of developmental milestones) did not differ between the two age groups.
- Gastrointestinal symptoms in the first 15 months of life were more commonly reported by parents in the younger group.

Without evidence for an artificial increase in autism cases, we conclude that some, if not all, of the observed increase represents a true increase in cases of autism in California, and the number of cases presenting to the Regional Center system is not an overestimation of the number of children with autism in California.