CALIFORNIA DEPARTMENT OF DEVELOPMENTAL SERVICES

AUTISTIC SPECTRUM DISORDERS

Changes In The California Caseload
An Update: 1999 Through 2002

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California Health and Human Services Agency • State of California
This report & the 1999 Autism Report are available at www.dds.ca.gov

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Executive Summary

Autism is a lifelong neurological disorder that primarily strikes males. Communication and social interactions are severely impaired for persons with autism. Unable to learn from the natural environment as most children do, the child with autism generally shows little interest in the world or people around him. Although some children with autism develop normal and even advanced skills, most exhibit a wide range of behavioral problems. Autism, in reality, is a lifelong developmental disability that profoundly affects the way a person comprehends, communicates and relates to others.

Since the 1980s, California has experienced dramatic increases in the number of children diagnosed with autism. Autism, once a rare disorder, is now more prevalent than childhood cancer, diabetes and Down Syndrome. The sustained increase in the population of persons with autism, compared to other developmental disabilities, is causing fundamental changes in the Developmental Services System. The information contained in this report, along with other formal epidemiological studies, confirms that the increase in prevalence of autism in California is real and requires special attention.

From December 1998 to December 2002, the population of persons with autism in California's Developmental Services System nearly doubled. This unprecedented 97 percent increase in four years did not include children less than three years of age, persons classified with less common forms of autism, or persons who are suspected of having autism but are not yet diagnosed. The total number of persons with autism served statewide increased from 10,360 in December 1998 to 20,377 in December 2002. Between 1987 and December 2002, the population of persons with autism (Codes 1 & 2) increased by 634 percent.

The average age of persons with autism entering the system has shifted toward much younger children in recent years. The increase in the number of younger children diagnosed with autism means that entitlement services required by each individual with autism would occur for a significantly longer duration. Primarily two age groups will drive the fiscal impact on the State's budget - very young children and young adults. For very young children, the national emphasis on early intervention delivered to the young child in the natural environment has created increased demand for earlier and more intensive behavioral and educational interventions. As more young children with autism reach late adolescence and adulthood, the need for out-of-home residential services will increase and have a substantial impact on the Department's budget. By December 2002, 84 percent of the entire population of persons with autism was under 25 years of age, with 70 percent of the population under 14 years old.

The increase in the autism caseload has continued to accelerate in recent years with no sign of lessening. If this trend continues, in approximately four years the number of person with autism in the Developmental Services system will equal each population of persons with cerebral palsy and epilepsy in the system. Even after the number of persons with autism entering the system is adjusted for an increasing California population, the prevalence of persons with autism continues to accelerate. The long-range implication of this sustained increase in the number of persons with autism is a profound and enduring impact on the affected children, their families, public services, the state budget and the overall health status of California citizens.

Preface

The California regional center system consists of 21 nonprofit and independent agencies, which are under contract with the Department of Developmental Services to provide services to persons with developmental disabilities. California's Developmental Services System was created in 1969. Originally, autism was not included in the Lanterman Developmental Disabilities Services Act that established the statewide system of services. Autism, a low incidence disorder in 1969, was added to the Lanterman Act in 1971 largely because the impact of autism on children was substantially disabling and expected to be a lifelong condition. California's Developmental Services System recognizes only professionally diagnosed individuals with mental retardation, autism, epilepsy, cerebral palsy and conditions similar to mental retardation as conditions eligible for services. Persons diagnosed with one of the other Pervasive Developmental Disorders (PDD) including Pervasive Developmental Disorder, Not Otherwise Specified (PDD, NOS), Asperger's Disorder, Rett's Disorder and Childhood Disintegrative Disorder are not eligible for regional center services unless they have impairments that constitute a substantial handicap as defined by California Code of Regulations Title 17. Eligibility for PDD, NOS and Asperger's is determined on a case-by-case basis according to each individual's functional ability.

As the caseload of persons with autistic spectrum disorder (ASD) has increased in California, services have expanded, along with a growing interest in and demand for objective measures that describe the population of persons with ASD served by the regional center system. Requests for data on autism from the Department of Developmental Services (Department) range from simple counts of persons with ASD to annual purchase of service figures. Data requests come from families, regional centers, the Association of Regional Center Agencies, allied agencies, universities, and individual scientists researching the phenomena related to ASD.

In response to increased demands for information on the population of persons with ASD in California, the Department is publishing this four-year report entitled Autistic Spectrum Disorders - Changes in the California Caseload, An Update: 1999 through 2002 (Update Report) to update its last report released in 1999[1]. The 1999 Report documented that beginning in the early 1980s California began to see an increasing and dramatic rise in the number of persons with ASD. The number of persons with autism increased 273 percent from 1987 through 1998 compared to increases ranging from 35 and 49 percent over the same time period for other eligible conditions including mental retardation, cerebral palsy, and epilepsy. This Update Report presents information on selected characteristics of the population of persons with ASD that are of greatest interest to families, regional center staff, legislators, health professionals, vendors, service agencies and research scientists. In some cases, selected population characteristics are compared to population characteristics in prior years to highlight the scope of change. It is the intent of the Department to make fundamental information about California citizens with ASD available to all groups that need the information to plan and develop resources and to ascertain a better understanding of ASD in California. It is the Department's hope that this report will encourage the scientific community to further pursue the investigation of autism epidemiology, i.e., to subject the numbers reported in this document to scientific scrutiny in order to establish the highest level of certainty regarding changes in the population of persons with autism in California.

Note to Readers

The information presented in this report is purely descriptive in nature and standing alone, should not be used to draw scientifically valid conclusions about the incidence or prevalence of ASD in California. The numbers of persons with ASD described in this report reflect point-in-time counts and do not constitute formal epidemiological measures of incidence or prevalence. The information contained in this report is limited by factors such as case finding, accuracy of diagnosis and the recording, on an individual basis, of a large array of information contained in the records of persons comprising California's Developmental Services System. Finally, it is important to note that entry into the California Developmental Services System is voluntary. This may further alter the data presented herein relative to the actual population of persons with autism in California.

[1] The 1999 Report, Changes in the Population of Persons with Autism and Pervasive Developmental Disorders in California's Developmental Services System can be downloaded at http://www.dds.ca.gov/autism/pdf/autism_report_1999.pdf

Introduction

Background

In 1999, the Department reported a rapidly growing and unexplained substantial increase in the number of persons with autism entering California's 21 regional centers statewide. The 1999 report, Changes in the Population of Persons with Autism and Pervasive Developmental Disorders in California's Developmental Services System, tracked figures throughout the state between 1987 and 1998. This Update Report includes counts of persons with autism previously reported, i.e. from 1987 to 1998, and brings up to date the number of persons with autism in the past four years 1999 through December 2002.

At the same time the Department was reporting an unexpected and unexplained rise in the number of persons with autism in California, other states were reporting substantial increases in the number of new cases as well. Concomitantly, beginning in the late 1990s, formal studies of incidence and prevalence[2] were initiated both within the United States and in countries around the world including the United Kingdom, Ireland, Australia, Japan and Israel. At the time of this report, other reports on populations within the United States and from other countries have documented consistent increases in the prevalence of autism and other spectrum disorders, causing some scientists and others in the United States and around the world to describe the reported increases in autism as an "epidemic."

"From December 1998 to December 2002, the population of persons with autism in California's Developmental Services System nearly doubled."

Reports of higher prevalence rates of autism and the broader ASD spectrum including PDD, NOS and Asperger's Disorder have stirred controversy and debate about what is causing the increase, e.g., Wing & Potter, 2002. The controversy about the cause(s) of the increase in prevalence not withstanding, it is now generally accepted by the scientific community that the prevalence of ASD is much higher than previously thought (Charman, 2002). An international discussion is underway regarding the significance of the changes in measured rates of incidence and prevalence of persons with ASD. The outcome of that discussion will depend on the results of more carefully controlled long-range studies. In the meantime, there is growing worldwide concern over the rising number of persons who require and expect services to better manage the effects of ASD. The long-term fiscal impact of an increasing caseload on the health care delivery system has not yet been determined. Importantly, there is more funding for basic research into finding the cause(s) of ASD. Concerned about the increase in the number of persons with ASD, the California Legislature and Governor in 1998 created and funded the Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute at the University of California, Davis Medical Center. With continuing support from Governor Gray Davis and the current Administration, the M.I.N.D. Institute was created for the purpose of finding answers to questions about the causes of ASD as well as developing effective treatments and a cure for this disorder.

Subsequent to the reported increase in the number of persons with ASD in California in 1999, the Department launched its Autistic Spectrum Disorders Initiative that included, among other activities, support for several important research studies designed to investigate qualitative and quantitative changes in the population of persons with ASD. In 1999, the California Legislature, through the Department, requested and funded a study by the M.I.N.D. Institute that investigated whether or not family migration to California could account for the increase in persons with ASD, and whether or not changes in the interpretation of diagnostic criteria in DSM III-R (American Psychiatric Association, 1980) and DSM IV (American Psychiatric Association, 1994) could have contributed to the increase. Robert Byrd, M.D., MPH, and principle investigator, completed this study entitled Epidemiology of Autism in California[3] (M.I.N.D. Institute,

[2] Incidence is the number of new cases occurring in a specified population in a specified time, such as one year. Prevalence is the number of cases in existence in a defined population at any one time.

[3] The full text of this study can be viewed at http://mindinstitute.ucdmc.ucdavis.edu/news/report.htm.

The Epidemiology of Autism in California study reported a number of important results:

1. The cumulative prevalence of autism in California increased from 7.5 per 10,000 for the sample 1983-85 birth cohort to 20.2 per 10,000 for the 1993-95 birth cohort, an increase of 269 percent. Other studies examining populations outside of California have found similar increases in prevalence rates equal to or greater than those in the Autism in California study (Yeargin-Allsopp, et al, 2003).
2. Families immigrating into the state for services were not a factor affecting prevalence in California.
3. Any shift in the interpretation of diagnostic criteria could not explain the increased prevalence.
4. The regional centers had achieved high levels of diagnostic accuracy, i.e., 89 percent of the children with autism selected for the study were accurately diagnosed by regional centers. Interestingly, the study also concluded that 18 to 19 percent of persons in the study diagnosed with mental retardation and without full syndrome autism met DSM IV criteria for autism. The study supported the interpretation that the increased prevalence of autism in California is a valid phenomenon and is driven by factors beyond improved identification and diagnosis.

In a second effort to formally document the rise in the number of persons with ASD, the Department offered support to the California Department of Health Services, Environmental Health Investigations Branch for an epidemiological study sponsored by the federal Centers for Disease Control and Prevention (CDC). This study is a multiyear research effort that will in the near future provide formal measures of incidence and prevalence for selected areas of the state.

CDER Definitions of Autism

The numbers presented in this report were taken from the Client Development Evaluation Report (CDER) used by the Department to document diagnostic and functional level of development for the majority of persons age three and above who are served by the 21 non-profit regional centers. Autism is recorded on the CDER as one of three different codes, i.e., Code 1, Code 2 or Code 9. Code 1 corresponds to the DSM IV (APA, 1994) classification of Autistic Disorder (DSM IV code 299.00). Code 2 corresponds to the earlier DSM III (APA, 1980) classification of Infantile Autism, Residual State. Code 9 is used in cases where a diagnosis of autism is "suspected" but not yet formally determined, e.g., for very young children whose diagnostic status has not yet been clarified. **The counts for autism presented in this report reflect only persons who were referred to and/or voluntarily entered the Developmental Services System and who met eligibility criteria for regional center services based on a professional diagnosis of autism (Codes 1 & 2, page 3, item 23 on the CDER instrument). None of the numbers for autism (Codes 1 & 2) include counts of persons with the Other PDDs. The counts of persons with autism for the time period covered in this Update Report very likely underestimate the actual California population of persons with autism.** It is estimated (Croen, et al, 2002) that only 75 to 80 percent of the total population of persons in California with autism are enrolled in the developmental service system.

The DSM IV classification of Pervasive Developmental Disorders[4] includes four additional disorders: Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder, Not Otherwise Specified (PDD, NOS). For individuals diagnosed with one of these four conditions, and who meet regional center eligibility criteria as substantially handicapped,

[4] The terms Pervasive Developmental Disorder and Autistic Spectrum Disorder are synonymous as used in this report. See Appendix A for discussion related to the history and use of these terms.

the disorder is typically coded on the CDER under Other Type of Developmental Disability (items 33a and 33b) or in the Mental Disorders section of the CDER (items 50a through 53a). However, the Pervasive Developmental Disorders data presented in this document were taken from all diagnostic fields in the CDER. Searching all CDER diagnostic data fields enabled identification of persons diagnosed with a Pervasive Developmental Disorder (Other PDDs) other than Autistic Disorder. Because the DSM IV numeric codes are the same for three different ASDs, i.e., Asperger's Disorder, PDD, NOS and Rett's Disorder, the exact count for each one of these three types of ASD could not be derived from the CDER database.

The count of persons with either autism or Other PDDs reported for a given year was taken from the total number of CDERs on the electronic file at the end of the year reported. The Department estimates that approximately 95 percent of all active cases, excluding most children under age three, but including persons in the developmental centers, have a completed CDER on file.

The following tables and figures report the number of persons with autism Codes 1 and 2 only, unless otherwise noted. Status Code 9 is reported separately. **None of the caseload counts for autism (Codes 1 & 2) includes counts of persons with the Other PDDs. Unless otherwise noted, counts for persons with Other PDDs include only persons who did not have autism (Codes 1 & 2) nor suspected autism (Code 9) recorded on the CDER.**

Birth To Three (Early Start Program)

In California, infants and toddlers presenting with suspected developmental delays from birth through three years of age receive early intervention services through the federally sponsored Early Start Program with individual services provided by each of the 21 regional centers. Infants and toddlers may be eligible for early intervention services if they have one or more developmental delays or an established risk of known etiology with a high probability of delayed development; or are at high risk of having a substantial developmental disability due to a combination of risk factors.

In 1992, the Department began recording demographic data for children enrolled in the Early Start Program. Data describing these children are reported on the Early Start Profile. **As the majority of children in the Early Start Program who have ASD have not received a diagnosis by the time they turn three years old, this Updated Report does not include data on ASD for children less than three years old.**

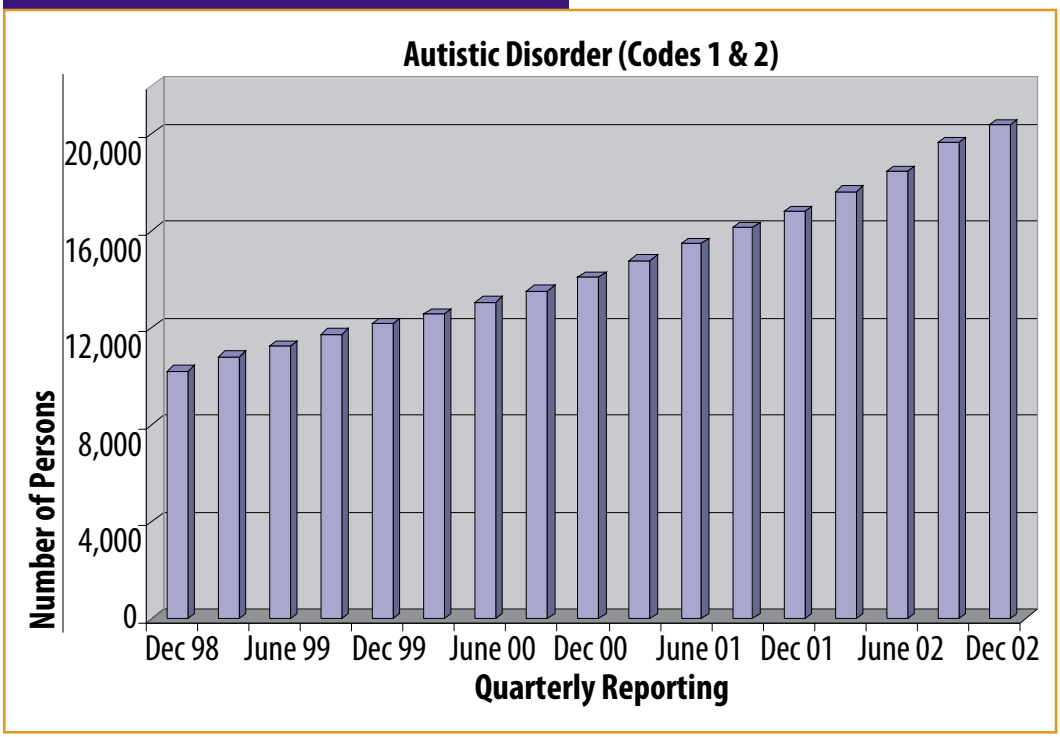
Findings

Caseload Changes

For the four-year period from December[5] 1998 to December 2002, there was a net increase of 10,017 individuals (a 97 percent increase) in the autism caseload. At the end of December 1998, there were 10,360 persons with autism Codes 1 and 2 served by all 21 regional centers, and by the end of December 2002, the total was 20,377.

Quarterly increases in persons with autism (Codes 1 & 2) from December 1998 through December 2002 are shown in Figure 1. The increasing numbers of new cases of autism (Codes 1 & 2), first documented in the 1999 Report, have continued through this Update Report period of December 1998 through December 2002, with no sign that the growth rate is diminishing. Figure 1 suggests that the rate of growth has increased over the past four years. In the time span from December 1998 through December 2002, the fastest growing developmental disability group entering the regional center system was persons with autism (Codes 1 & 2). Of the regional center eligible developmental disabilities including autism, mental retardation, cerebral palsy, epilepsy and conditions similar to mental retardation, autism (Codes 1 & 2) is proportionally the number one single disorder entering California's Developmental Services System.

Figure 1 - Quarterly Growth in Number of Persons with Autism (Codes 1 & 2) from December 1998 through December 2002



[5] Throughout this report, a data extraction date of December implies December 31 for any year.

Yearly increases for the fifteen years from December 1987 through December 2002 are shown in Figure 1A. Growth through this longer span of time in the annual number of persons entering the system has accelerated, especially in the more recent years.

In late 1993, the Department began reporting quarterly numbers for its entire population of persons with developmental disabilities. (See Appendix B for a summary of the quarterly counts released by the Department beginning in 1993 to the end of 2002). The Department began posting the Quarterly Client Characteristics Report (QCCR) on its website at www.dds.ca.gov beginning September 2002. The QCCR can be accessed at the end of the second week of January, April, July and October of each year. Information on developmental disabilities, including autism, for each of California's 58 counties started in September 2002 and can be accessed from the website as well.

Figure 1A - Annual Growth in Number of Persons with Autism (Codes 1 &2) from December 1987 through December 2002

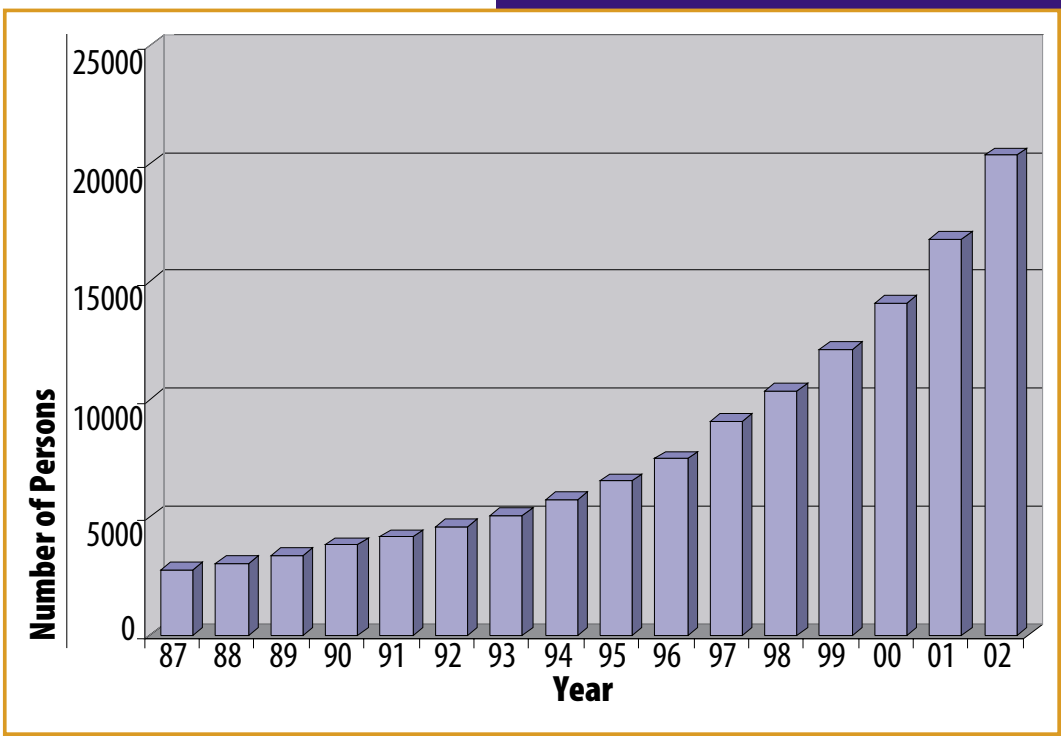


Table 1 - Number of Persons with Autism (Codes 1 & 2), Other PDDs, and Suspected Autism 1987 through 2002

	Dec-87	Dec-02	Dec. 87 to 02 % Change	Dec-98	Dec-02	Dec. 98 to 02 % Change
Persons with Autism (Codes 1 & 2)	2,778	20,377	633.51%	10,360	20,377	96.69%
Persons with Other PDD DSM-IV Codes	64	2,036	3081.25%	1,137	2,036	79.07%
Persons with Suspected Autism (Code 9)	1,086	2,119	95.12%	1,635	2,119	29.60%

Note: References to "Persons" and "Population" include only individuals with CDERs.

Table 1 shows the total numbers and percent change for the population of persons with autism Codes 1 and 2, the Other PDDs and suspected autism (Code 9) in the 15-year period from 1987 to 2002, and the most recent 4 years from December 1998 to December 2002. The Other PDDs include Asperger's Disorder, PDD, NOS, Rett's Disorder and Childhood Disintegrative Disorder. Asperger's, PDD, NOS and Rett's cannot be distinguished from the CDER because all three disorders share the same DSM IV numeric code (299.80). Childhood Disintegrative Disorder is searched for separately using DSM IV code 299.1.

Table 1 shows that there was a 634 percent increase in autism (Codes 1 & 2) in the 15 years from 1987 to 2002. The biggest percent change was in the number of persons with Other PDDs who came into the system between 1987 and 2002. In the 15 years between 1987 and 2002, the number of persons with Other PDDs increased by 3,081 percent, i.e., from 64 to 2,036 persons. In the most recent four years from December 1998 to December 2002, the number of persons with autism (Codes 1 & 2) nearly doubled. The number of persons coming into the system with Other PDD codes increased by 79 percent in the most recent four years. Persons with Suspected Autism (Code 9) increased by 30 percent in the four years ending in December 2002. The total number of persons of all three classifications including autism, Other PDDs and Autism Suspected is 24,532.

Table 2 - Number of Persons with Autism (Codes 1 & 2) in 1987, 1998, and 2002

	Dec. 1987	Dec. 1998	Dec. 2002
Total Population with CDERs	80,389	129,169	163,791
Persons with Autism (Codes 1 & 2)	2,778	10,360	20,377
Percent of Total Population with Autism	3.46%	8.02%	12.44%

Note: References to "Persons" and "Population" include only individuals with CDERs.

Table 2 shows that the population of persons with autism Codes 1 and 2 in 1987 represented 3.46 percent of the entire population served including persons with mental retardation, cerebral palsy, epilepsy and other conditions requiring treatment similar to mental retardation. In the 15-years from the end of 1987 to the end of 2002, the proportion of persons with autism in the total population of developmentally disabled persons increased to 12.44 percent, nearly a four-fold increase between 1987 and 2002.

The growth curves in Figure 2 are based on the number of persons in each category of disability beginning in December 1994. Figure 2 shows the cumulative growth percent for autism (Codes 1 & 2) (253 percent) as compared to the other developmental disabilities through the end of 2002. Growth in the number of persons with mental retardation, epilepsy and cerebral palsy coming into the system is consistent with population growth with no drop in growth recorded and stable prevalence rates for those populations. Growth in mental retardation, epilepsy and cerebral palsy follows a linear trend for the eight-year period contrasted to autism, which continued to increase at a significantly higher rate.

Figure 2 - Percent Change in All Disabilities from 1994 through 2002

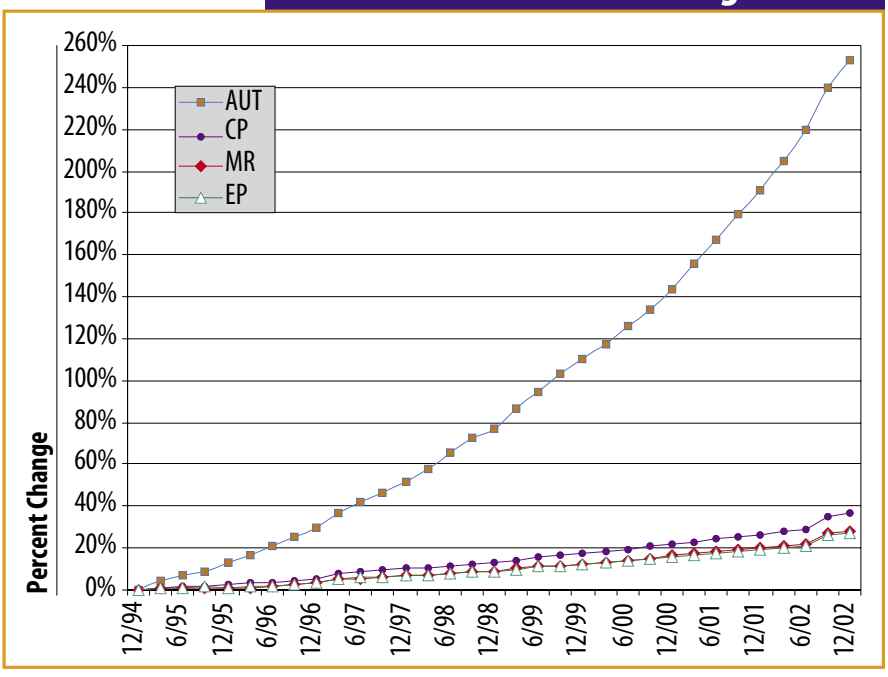


Table 3 - Percent Increase in All Diagnostic Populations from 1987 to 2002 and from 1998 through 2002

	Dec-87	Dec-02	Dec. 87 to 02 % Change	Dec-98	Dec-02	Dec. 98 to 02 % Change
Persons with Autism (Codes 1 & 2)	2,778	20,377	633.51%	10,360	20,377	96.69%
Persons with Mental Retardation	72,987	130,722	79.10%	108,563	130,722	20.41%
Persons with Epilepsy	22,683	35,689	57.34%	30,656	35,689	16.42%
Persons with Cerebral Palsy	19,972	33,071	65.59%	28,529	33,071	15.92%
Total Population with CDERs	80,389	163,792	103.75%	129,169	163,792	26.80%

Note: References to "Persons" and "Population" include only individuals with CDERs. Also, combining the numbers found in each diagnosis results in a number that exceeds the total population because some individuals have more than one of the above diagnoses and are therefore counted in multiple categories.

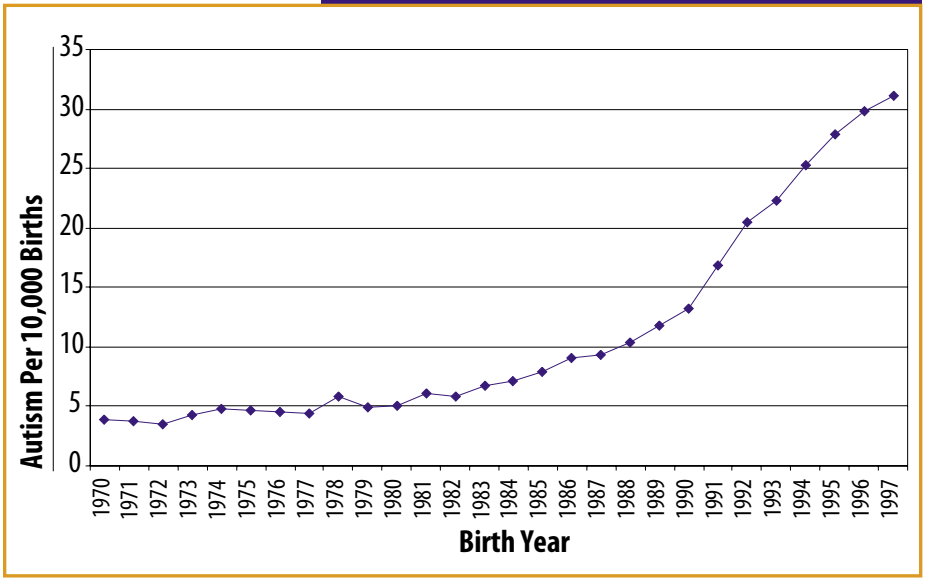
Table 3 shows the total population numbers and percent changes for the four primary types of developmental disabilities between December 1987 and December 2002 and between December 1998 and December 2002. Table 3 shows that relative to the other developmental disabilities, the far greatest percentage increase during both periods was in the population of persons with autism (Codes 1 & 2). Table 3 suggests that if the current rate of increase in autism continues, the number of persons with autism will grow to equal the number of persons with cerebral palsy or epilepsy within three to four years. The bottom row of Table 3 shows the total number of persons with CDERs as of December for each relevant year.

Estimated Prevalence

Figure 3 shows uncorrected birth-year prevalence rates from 1970 to 1997 for persons with autism (Codes 1 & 2), not including Other PDDs. Yearly prevalence rates in Figure 3 were calculated by dividing the number of persons with autism (Codes 1 & 2) in each birth year between 1970 and 1997 based on the autism population (N=15,897 persons on CDER file) at the end of December 2002 by the number of California births for that same year multiplied by 10,000. The total number of California births for each year was taken from the California Department of Finance Demographics website at www.dof.ca.gov.

Consumer Demographics

Figure 3 - Uncorrected Birth Year Prevalence Rates from 1970 through 1997 for the 2002 Population of Persons with Autism (Codes 1 & 2)



In 1970, the uncorrected birth year cohort prevalence rate for autism (Codes 1 and 2) was 4 per 10,000 (1 case per 2,500 births). By 1997, the rate was 31 per 10,000 (1 case per 323 births), a 774 percent increase in prevalence. Note that the rate of 31 per 10,000 applies to children, who were born in 1997 and were five years of age at the time of data collection for this analysis. Because prevalence rates tend to be significantly understated for children under five years of age (see Figure 4), this analysis was truncated at the end of 1997. Figure 3 ends in 1997 because it takes about five years, i.e., from 1997 to 2002 or longer, for children to have a diagnosis recorded on the CDER. After 1997, the birth year prevalence rates are far less reliable and will almost certainly rise in the coming years as more diagnoses are determined for the children born between 1997 and 2002 who are already in the system.

It is important to note that a substantial gender difference exists between males and females with autism. Eight out of 10 persons with autism in the system by December 2002 were males (See pg. 19, Table 7). Therefore, the estimated prevalence of autism for all autism birth cohorts is substantially higher for males compared to females.

The birth year prevalence rates shown in Figure 3 are not corrected for factors including but not limited to persons with autism who may have moved to or out of California in a given year, incorrectly diagnosed or undiagnosed cases of autism, or persons with autism in California who are not enrolled in the voluntary regional center system. Essentially, Figure 3 estimates the number persons identified with autism per 10,000 births in a given year as an uncorrected proportion of total California births for each year between 1970 and 1997. Figure 3 shows that the increase in the number of California births alone between 1970 and 1997 cannot account for the increasing prevalence of persons with autism in the population.

Figure 4 - Uncorrected Birth-Year Cohort Prevalence for Six Annual Populations from 1997 through 2002 for Autism (Codes 1 & 2)

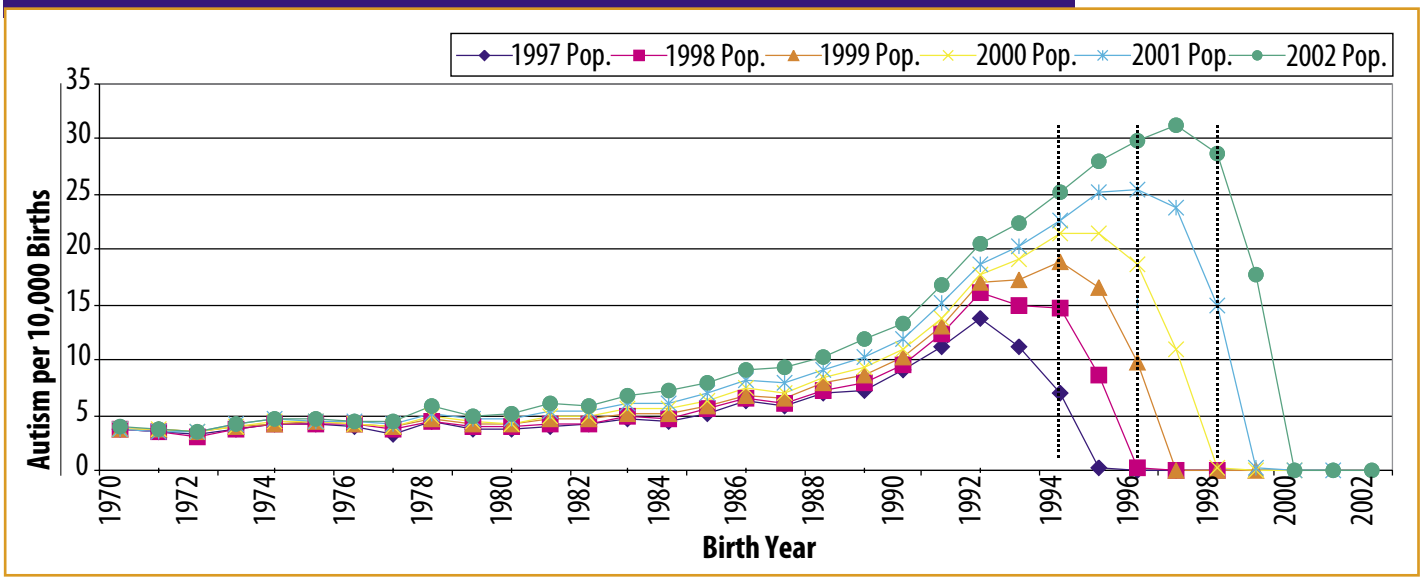


Figure 4 shows uncorrected prevalence rates for the autism (Codes 1 & 2) population as of December in six different years beginning with 1997 and ending in 2002. As of December 2002, estimated prevalence reached a high at 31.2 per 10,000 for birth year 1997. A "birth-year cohort" is the group of persons born in California in a specific calendar year who are diagnosed with autism. Uncorrected birth-year cohort prevalence rates were calculated for each of the six years by dividing the number of persons with autism born in a given year by the number of California births in that year. Rates are not corrected by the same variables described in Figure 3 that could hypothetically change the rate for a given year, i.e., migration in and out of California in a given year, incorrectly diagnosed or undiagnosed cases, or persons with autism in California who are not enrolled in the voluntary regional center system.

As of December 2002, estimated prevalence reached a high at 31.2 per 10,000 for birth year 1997.

Figure 4 shows two important findings:

1. First, that in a given birth year, for example, for persons born in 1994, the estimated prevalence for that birth year continues to increase as time passes. Figure 4 shows that the estimated prevalence in birth year 1994 for the data collection year 1998, i.e., for children who were 4 years old when the data were collected, is 14.6 per 10,000 births compared to an estimated prevalence of 25.3 in that same birth year for data collection year 2002. Figure 4 shows that the prevalence rate continues to rise within the same birth year because children with autism up to 10 years of age or older continue to be identified and enrolled in the regional center system.
2. Secondly, it is clear from the way each population curve continues to "build" for a given birth year and then drop off for more recent birth years that it takes from two to seven years or longer for older children who have autism to enter the system, and that children under three years of age lag in being diagnosed. Figure 4 suggests it is likely that the regional center system will continue to enroll persons with autism (Codes 1 & 2) for a given birth year and that prevalence for each birth year will continue to rise until all persons in that birth year are identified.

Figure 5 - Percent Change By Type of Autism and Other PDD Diagnoses

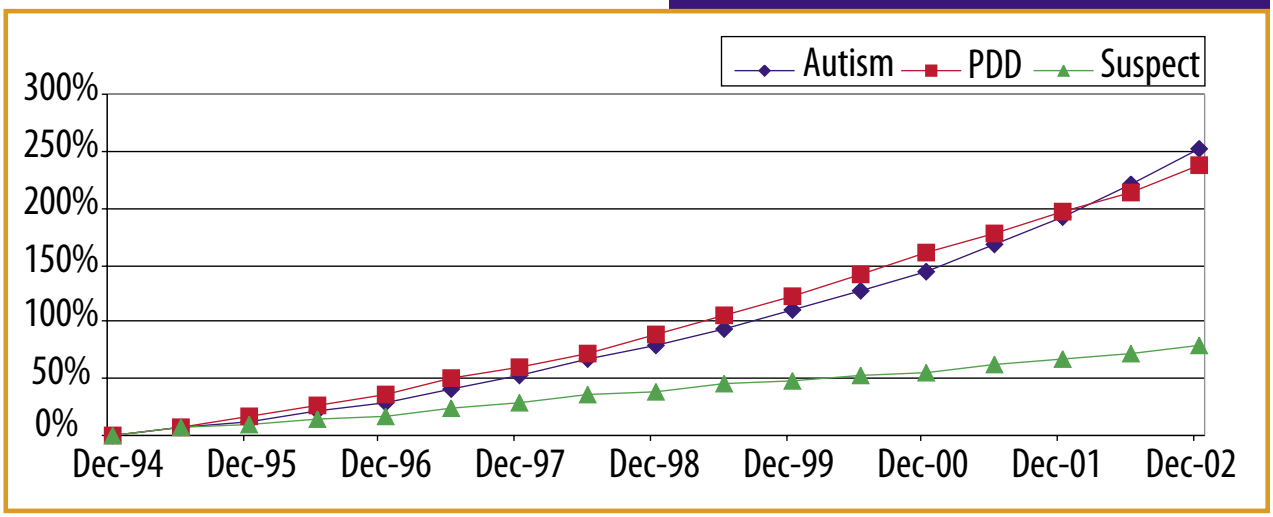
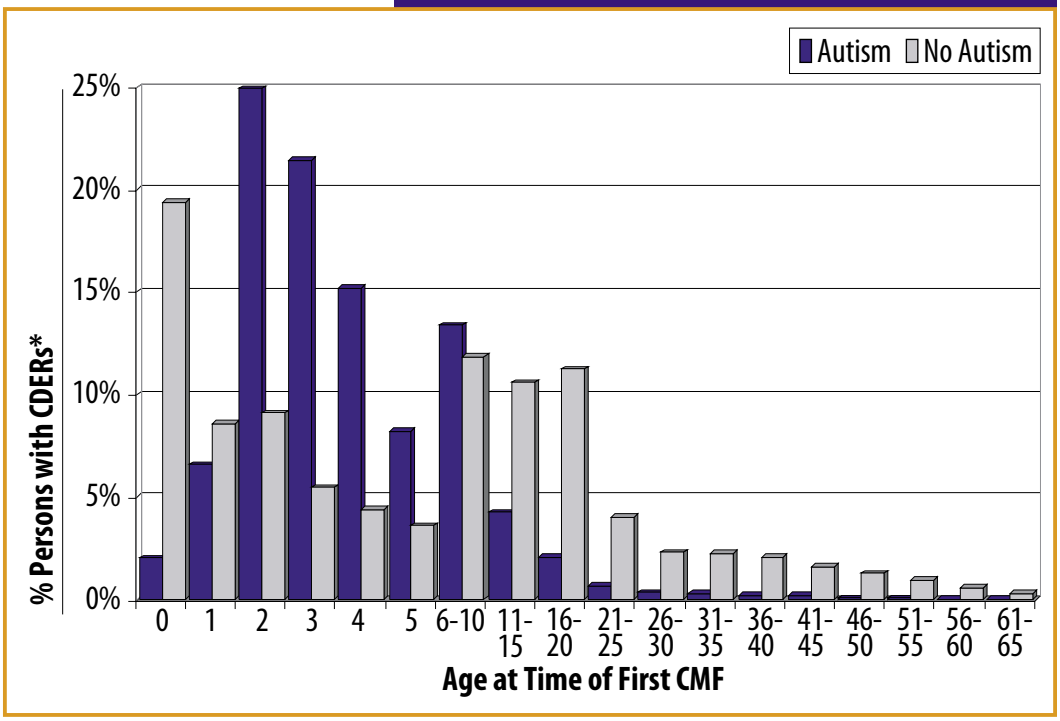


Figure 5 shows the cumulative percent change for autism, the Other PDDs and autism suspected, not diagnosed (Code 9) from 1994 through 2002. Figure 5 begins with the entire number of persons in each diagnostic category as of the end of 1994 and shows the cumulative percent change every six months through 2002. There was a 253 cumulative percent increase in the number of persons with autistic disorder (CDER Codes 1 & 2) from December 1994 through December 2002. The Other PDDs increased 238 percent whereas autism suspected, not diagnosed increased 79 percent during the same time period. The cumulative increase in the Other PDDs was similar to increases in autism Codes 1 & 2 up to the end of the year 2001. Figure 5 shows that in the early part of year 2002, percent increases in the Other PDDs began to decline relative to autistic disorder. By December 2002, there were 2,036 persons in the system with Other PDD diagnosis. Autism suspected, not diagnosed (Code 9) increased in a linear trend during the same time period, but at a substantially lower rate. By December 2002, there were 2,119 persons classified autism suspected, not diagnosed (Code 9).

Figure 6 - Comparison of Age at Time of First Client Master File Between Persons With Autism (Codes 1 & 2) and Persons Without Autism



When a person requests services from the regional center, a demographic record on the Client Master File (CMF) is created. The date of that record for each individual with a CDER was used to estimate the age of each individual at the time of intake. The individual's diagnosis may not be recorded on the CDER until after the person's first CMF record is created.

Figure 6 compares the age of persons with Autism (Codes 1 & 2) and those who did not have Autism (Codes 1 & 2). Figure 6 shows two distinct patterns for age at intake. Persons without autism were far more likely than persons with autism to enter the system before age two (28.0% vs. 8.6%). However, for ages two through five combined, the percent of persons with autism entering the system far exceeded the percentage of persons without autism (69.8% vs. 22.6%). After the age group 16 thru 20 years, less than one percent of persons with autism entered the system in any subsequent age group. No persons with autism entered the system after age 60. By contrast, at least one percent or more of persons without autism entered the system in all age groups until the 51 thru 55 years age group. Note that only persons who had their first CMF between January 1, 1993 and December 31, 2002 were included in this analysis.

Age Distribution

Figure 7 shows a shift toward younger persons with autism (Codes 1 & 2) between 1987 and 2002. In 1987, the autism population served by regional centers totaled 2,778 persons. The highest percentage of persons in 1987 was in the 20 to 24 year age-range. By the end of 2002, when the autism population totaled 20,377 persons, the greatest number of persons (4,282) shifted to children in the 5 to 9 year age range. By 2002, 70 percent of all persons with autism in the regional center system were under 15 years of age, compared to 35 percent in 1987.

Figure 7 - Age Distribution for All Persons with Autism (Codes 1 & 2) in 1987 and 2002

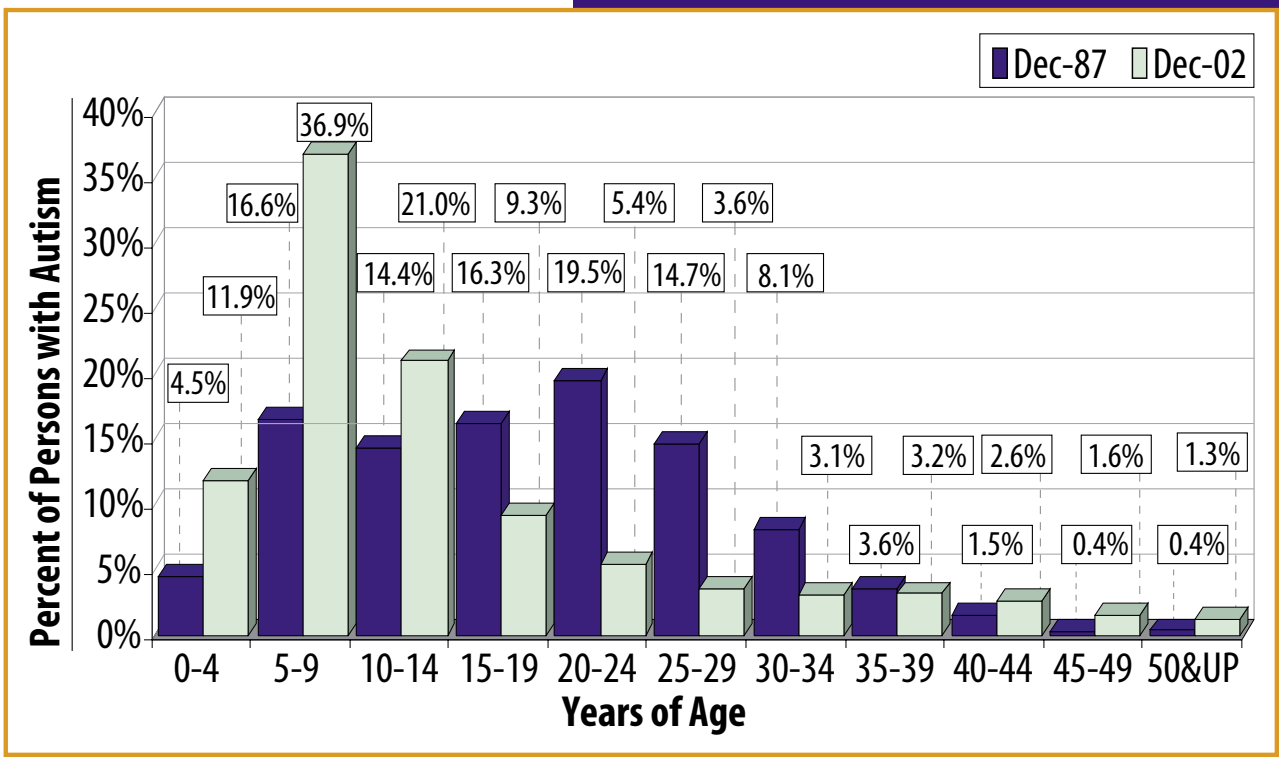


Table 4 - Number of Persons in Each Age Group with Autism (Codes 1 & 2) by December 1987 and December 2002

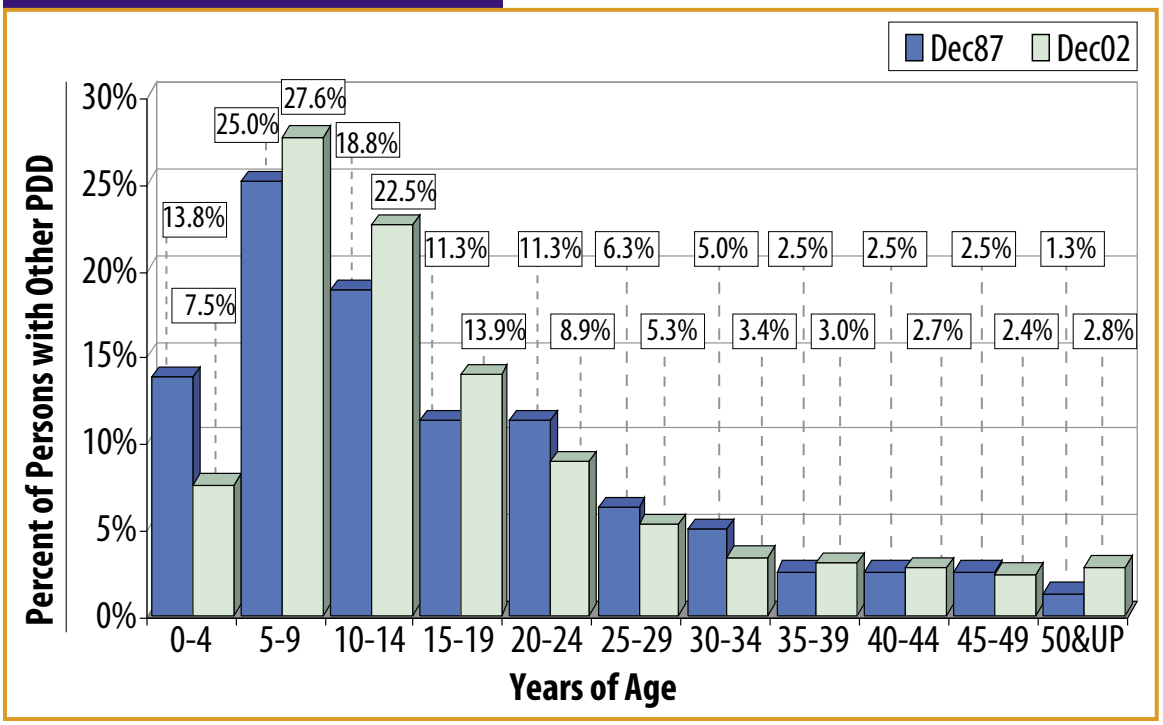
Age Group	0 to 4	5 to 9	10 to 14	15 to 19	20 to 24	25 to 29	30 to 34	35 to 39	40 to 44	45 to 49	50 & UP	Total
Numbers for 1987	125	460	399	453	543	407	226	100	43	10	12	2,778
Numbers for 2002	2,421	7,518	4,282	1,887	1,108	729	641	658	536	329	268	20,377

Table 4 shows the numbers of persons represented in Figure 7 for each age group of persons with autism (Codes 1 & 2) as of December 1987 and December 2002. For December 2002, adding the number of persons in the five age groups from birth through 24 years indicates that 84 percent of the entire autism population (Codes 1 & 2) was born after 1977.

Age Distribution Of Other PDDs

Figure 8 shows the age distribution for individuals diagnosed with one of the Other PDDs in December 1987 and December 2002. This figure shows that 58 percent of the Other PDD population both in 1987 and 2002 are in the age range birth to 14 years. Figure 8 shows in 2002 that the highest percentage of persons diagnosed with one of the Other PDDs was in the 5 to 9 years age range with the second highest percentage in the 10 to 14-age range. The count for Other PDDs used in this figure was determined by searching all diagnostic fields on the CDER when autism Code 1 or 2 was not recorded. The slightly higher count (2,293) of persons with Other PDDs in this figure (compared with 2,036 in Figure 5) resulted from dropping Code 9 as an exclusion code in the count of Other PDDs.

Figure 8 - Age Distribution for Persons With PDD Codes But Not Autism (Codes 1 & 2)

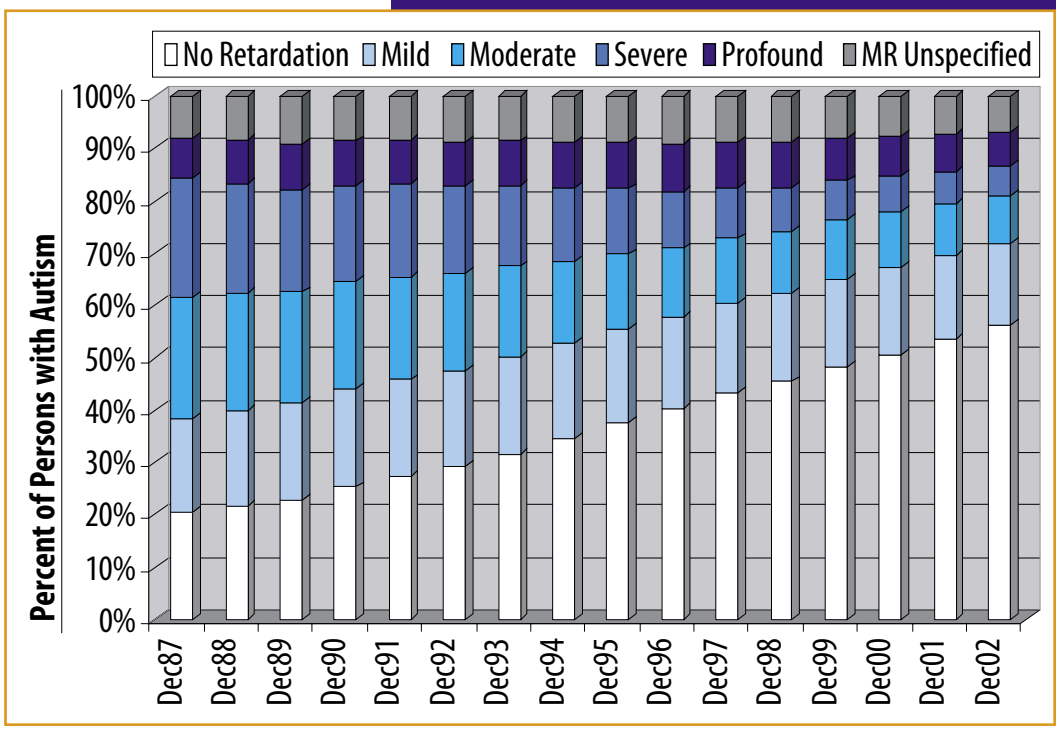


Cognitive Level

Professionals including behavioral vendors, special educators and regional center clinical staff who interact with children with autism after receiving intervention services report increased cognitive and adaptive gains in a proportion of cases. These anecdotal reports suggest that the proportion of higher functioning children within the autism population is on the rise. The question is whether or not proportionately fewer children with autism (Codes 1 & 2) and Other PDDs have coexisting cognitive deficits compared to children in the past.

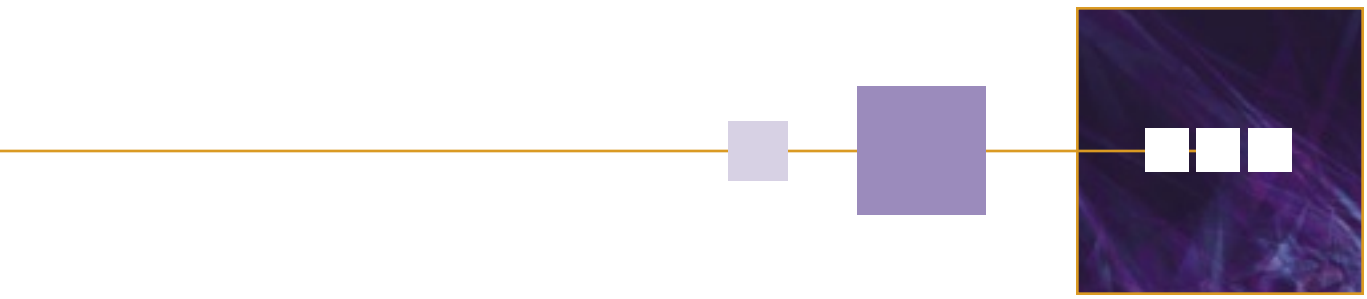
The scientific literature has traditionally reported a strong relationship between autism and mental retardation (MR). Studies have reported that up to 70 percent (National Research Council, 2001) or 80 percent (Rutter, et al, 1994) of persons with autism have IQ scores in the range of MR.

Figure 9 - Level of Cognitive Ability of Persons with Autism (Codes 1 & 2) from December 1987 through December 2002



Level of cognitive ability, i.e., level of MR as a coexisting condition, is recorded on the CDER for persons with autism. Figure 9 shows level of cognitive ability for the entire population of persons with autism from December 1987 through 2002. Figure 9 shows that data recorded annually on the CDER from all 21 regional centers indicate a gradual but steady decline in the proportion of persons with autism who also have MR. There was a shift from 19 percent of the 1987 population recorded as not having MR to 56 percent without MR in the year 2002 population. Figure 9 shows that the proportion of persons with autism and coexisting Mild MR did not change significantly between 1987 and 2002 (ranging from 16 and 18 percent). The greatest yearly proportional changes were reductions in the percent of persons with autism and a coexisting diagnosis of Moderate, Severe or Profound MR and the corresponding increase in the percent of persons with no mental retardation.

The data in Figure 9 cannot be interpreted as scientific proof of a measured reduction in the proportion of autism cases with coexisting MR but the shift in the proportion of cases with moderate, severe and profound MR to no MR is significant, and is worthy of direct scientific investigation. There are a number of uninvestigated reasons that could account for the higher proportion of persons in 2002 with no reported coexisting MR. Speculative factors that could possibly account for the change in the proportion of persons who have autism but who are not intellectually disabled are: failure to record an MR diagnosis on the CDER; increasing eligibility of persons with forms of higher functioning autism; the cumulative and beneficial effects of early intervention programs that focus on skills that contribute to higher IQs; and the possible recognition of a new phenotype(s) of autism.



Residence

Figure 10 - Change in Residence Type From 1987 to 2002 for Persons with Autism (Codes 1 & 2)

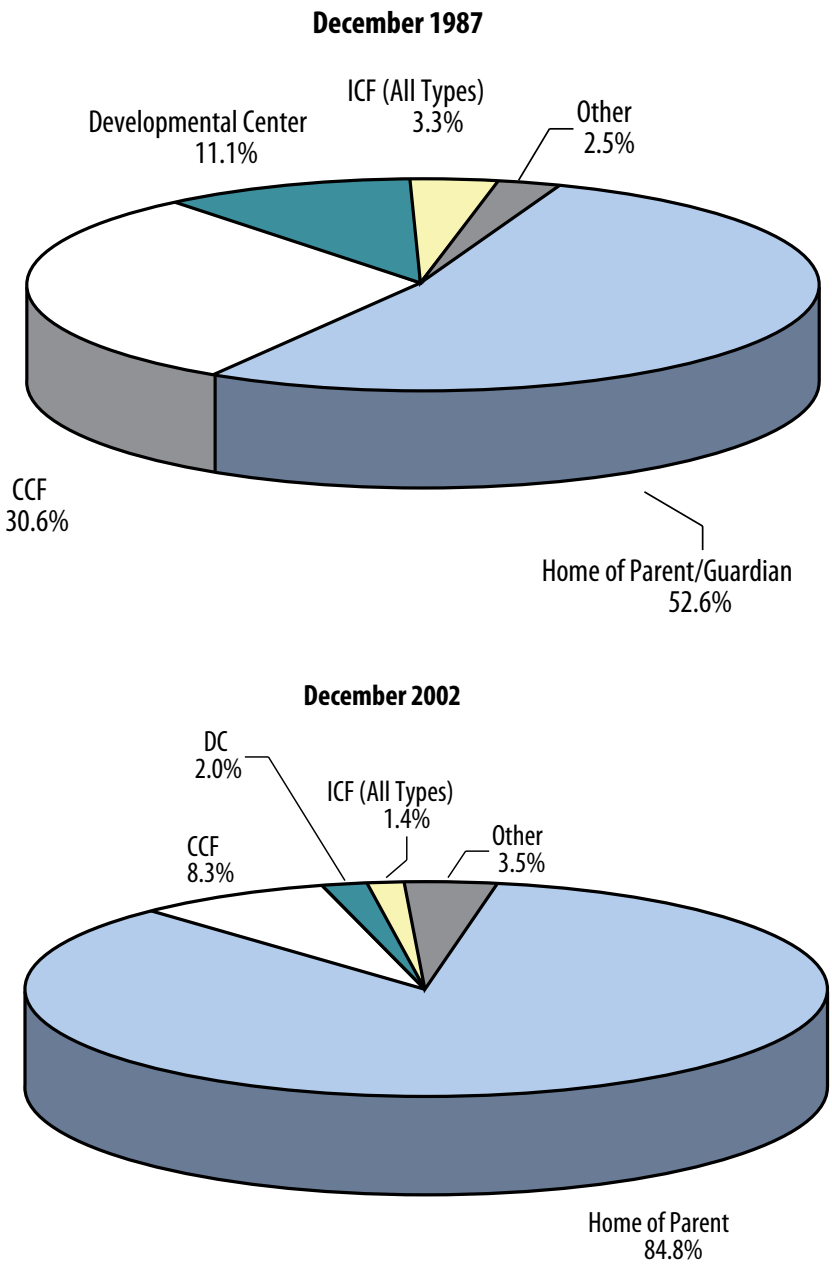


Figure 10 shows the change in the proportion of persons with autism (Codes 1 & 2) living in different types of residences between December 1987 and December 2002. There was a 32 percent increase in the segment or proportion of the autistic population living at home with parent(s) or guardian between 1987 and 2002. Between December 1987 and December 2002, there was a 22 percent decrease in the segment of the autistic population living in Community Care Facilities (CCF).

Table 5 - Residence Type By Age Group for Autism (Codes 1 & 2) in 1987 and 2002

Comparison of Age Group by Residence Type for Persons with Autism (Codes 1 & 2) in December 1987

Residence Type	0 - 14 Yrs		15 - 29 Yrs		30 - 44 Yrs		45 Yrs & Up		Total Autism by Res. Type	
Home of Parent	801	81.40%	594	42.34%	61	16.53%	5	22.73%	1,461	52.59%
CCF	149	15.14%	554	39.49%	137	37.13%	9	40.91%	849	30.56%
DC	10	1.02%	154	10.98%	138	37.40%	5	22.73%	307	11.05%
ICF (All Types)	9	0.91%	62	4.42%	19	5.15%	2	9.09%	92	3.31%
Other	15	1.52%	39	2.78%	14	3.79%	1	4.55%	69	2.48%
Total Autism by Age	984	100.00%	1,403	100.00%	369	100.00%	22	100.00%	2,778	100.00%

Comparison of Age Group by Residence Type for Persons with Autism (Codes 1 & 2) in December 2002

Residence Type	0 - 14 Yrs		15 - 29 Yrs		30 - 44 Yrs		45 Yrs & Up		Total Autism by Res. Type	
Home of Parent	13,847	97.37%	2,758	74.06%	586	31.93%	90	15.08%	17,281	84.81%
CCF	196	1.38%	612	16.43%	657	35.80%	217	36.35%	1,682	8.25%
DC	1	0.01%	58	1.56%	183	9.97%	158	26.47%	400	1.96%
ICF (All Types)	20	0.14%	97	2.60%	119	6.49%	57	9.55%	293	1.44%
Other	157	1.10%	199	5.34%	290	15.80%	75	12.56%	721	3.54%
Total Autism by Age	14,221	100.00%	3,724	100.00%	1,835	100.00%	597	100.00%	20,377	100.00%

Table 5 shows the number of persons with autism (Codes 1 & 2) in each type of residence for each age group in 1987 and in 2002. Table 5 allows a comparison between the number of persons in a specific residence type by age group in 1987 and 2002. One implication of Table 5 is that in 2002, 13,847 children under age 15 were living at home (68 percent of the total 20,377 persons with autism (Codes 1 & 2) in the entire system). The eventual movement of this group into other supported residences will significantly increase out-of-home residential costs. A substantial proportion of children currently living at home will likely require, by age of adolescence and certainly as young adults, some form of out-of-home placement. For example, in 2002 Table 5 shows that for persons with autism in the "15-29 years" age group, 74 percent resided in the home of parent in 2002 compared to 97 percent of persons with autism in the "0-14 years" age group. Comparing the proportion of individuals living in the other residence types to Home of Parent residence type shows that the relative percent increases for persons living in other residence types starts with the 15-29 age group and continues in older age groups. As age increases, more individuals, as expected, move away from the home of parent and require more supports and more expensive out of home placements.

Ethnicity

Table 6 shows relative shifts among ethnic groups in the number and percentage of persons with autism between 1987 and 2002. Relative to the entire population of persons with autism, Asians and Hispanics increased the most in the 15-year interval between 1987 and 2002. Relative to the entire autism population in 2002, the Asian and Hispanic proportion more than doubled compared to 1987. Increased efforts on the part of regional centers over the past 15 years to reach specific ethnic groups may have contributed in part to the proportional increase in Asians and Hispanics with autism entering the system.

Table 6 - Ethnicity Comparison of Persons with Autism (Codes 1 & 2) in December 1987 and December 2002

Ethnicity	December 1987		December 2002	
Asian	103	3.71%	1,577	7.74%
Blk/African Amer.	427	15.37%	1,829	8.98%
Filipino	66	2.38%	580	2.85%
Hispanic	270	9.72%	4,705	23.09%
Native Amer.	10	0.36%	44	0.22%
Polynesian	6	0.22%	35	0.17%
White	1,725	62.01%	8,857	43.47%
Other	171	6.16%	2,750	13.50%
Total Population with CDERs	2,778	100.00%	20,377	100.00%

Note: References to "Persons" and "Population" include only individuals with CDERs.

Gender

Table 7 shows percent changes in gender proportion between 1987 and 2002. In the 15-year comparison, there was a five percent proportional increase in males with autism compared to females. The figures shown in Table 7 are generally consistent with published reports of a gender bias for males diagnosed with autism.

Table 7 - Gender of persons with Autism (Codes 1 & 2) in December 1987 and December 2002

	Dec. 1987	% of Total	Dec. 2002	% of Total
Male	2,140	77.03%	16,675	81.83%
Female	638	22.97%	3,702	18.17%
Total Population with Autism	2,778	100.00%	20,377	100.00%

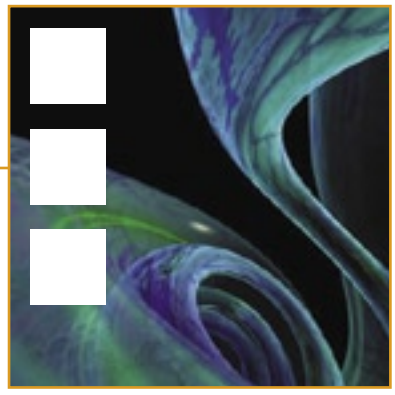
Note: References to "Persons" and "Population" include only individuals with CDERs.

Conclusions

The Department's 1999 Report on Changes in the Population of Persons with Autism and Pervasive Developmental Disorders in California's Developmental Services System reached two general conclusions: (1) the number of persons entering the system with autism had increased dramatically between1987 and 1998 relative to the other developmental disabilities; and (2) the accelerated rate that has been sustained over this period would likely continue in future years. This Update Report, based on four additional years of data, suggests that the number of persons with autism entering the system continues to increase dramatically. In fact, the rate first documented in the 1999 Report has accelerated in the last four years. Autism is and will most probably continue to be the fastest growing disability served by the regional center system.

In addition, based on ongoing research into the fundamental nature of autism, the relationship of autism to the other pervasive developmental disorders has been recognized and redefined as a spectrum of related disorders with an associated range of handicapping conditions. As a consequence of the change in the way persons diagnosed with autistic features are evaluated, some persons diagnosed with one of the Other PDDs are entering the system. This trend toward an increasing number of persons diagnosed with one of the Other PDDs being served by regional centers is likely to continue as well.

During the last four years, and with ongoing support under the Department's ASD Initiative, formal epidemiological studies commissioned by the California Legislature confirmed with empirical evidence the common perception that there are many more children with autism in California today than in the past. Research that addresses the cause(s) of this increased prevalence and the complex issues related to the etiology of autism are underway.



Appendix A

Autistic Spectrum Disorder" and "Pervasive Developmental Disorder"

In the 1970s, Lorna Wing and Judith Gould developed the concept of a range of disorders with a triad of impairments in common–social interaction, communication and imagination (Wing & Gould, 1979). This range of impairments became the foundation of the autistic spectrum concept. Although Allen (1988) coined the term "autistic spectrum disorder," Wing and Gould were using the terms "autistic spectrum" and "autistic continuum" interchangeably at the same time (Wing, 1988); they eventually settled on "autistic spectrum". There is still controversy surrounding the "spectrum" concept, primarily due to the questions remaining as to whether disorders within the autistic spectrum are, in fact, continuous. Volkmar and Cohen (1991) pointed out that the assumption that all of the conditions on the so-called "spectrum" represent some variant of autism remains a hypothesis and is not an established fact. Wing was also careful to suggest that phenotypic profiles along the "autistic spectrum" vary widely and cannot be construed as continuous (Wing, 1988).

One of the first published references to use the term "autistic spectrum" occurred in 1984 (Damasio, 1984). Lorna Wing and Tony Attwood (1987) were the first to describe the concept of an autistic spectrum in detail. Earlier, the DSM-III (1980) introduced the term "pervasive developmental disorder" as a descriptor for a class of disorders that included autism. The DSM-III, Revised (American Psychiatric Association, 1987) preserved the term "pervasive developmental disorder," as did the International Classification of Diseases, 10th edition (World Health Organization, 1993). In 1991, Volkmar et al. published a debate concerning the relative appropriateness of the two terms, "pervasive developmental disorder" and "autistic spectrum disorder."

The arguments for using "autistic spectrum disorder" instead of "pervasive developmental disorder" as the official term included several important ideas. Clinicians in favor of using "autistic spectrum disorder" (Wing, 1991; Gillberg, 1991) pointed out that the word "pervasive" was unclear at best, and in the worst case, misleading. The word "pervasive" implied that autism and the other related disorders affected all aspects of development. In questioning the use of "pervasive," several authors were quick to point out that unevenness of development is the hallmark of autism and related disorders, and that some persons with autism have typical ability in selected areas. Therefore, the term "pervasive" appeared to be appropriate only in those cases of autism where severe to profound mental retardation was present. Because some individuals with autism function with significantly higher intellectual and adaptive competence, the term "pervasive" appeared to be a misleading descriptor, i.e., impairment was not pervasive in all aspects of their condition.

The advocates for maintaining "pervasive developmental disorder" as the descriptive label argued that the term "pervasive" was intended "to imply the scope of disturbance as it applies to functioning domains in contrast to the global impairment which characterizes other developmental disorders and the centrality of cognitive problems in 'primary' mental retardation" (Volkmar, 1991). For example, an individual with autistic disorder with an IQ in the normal range may have significant difficulty with the application of skills to everyday situations, which culminates in significant adaptive impairment across domains. Volkmar (1991) argued that use of the term "pervasive" fully appreciates the fact that "disturbances within autism and associated conditions are felt throughout the individual's life and these difficulties pervade and affect virtually every area of activity and development." Advocates for use of "pervasive developmental disorder" pointed out that terms like "autistic spectrum disorder" encourage the assumption that there is an underlying continuity among the variations of autism. However, use of the term "pervasive" implies that all abilities are affected to a similar degree. There may be confusion regarding the terms "pervasive" and "global," which are not synonymous, that may be difficult to circumvent. Nevertheless, the hallmark of autism is the relative discrepancy between abilities and skills, regardless of the degree of impairment.

As a result, "autistic spectrum disorder" (ASD) has become the clinical term that most closely captures the relationships among autistic disorder and other closely related disabilities that share many of the core characteristics. Use of the term "autistic spectrum disorder" or "ASD" in these Guidelines is limited to exactly the same conditions specified under pervasive developmental disorder in the DSM-IV. Those conditions include the following diagnoses and classifications: (1) autistic disorder, (2) Asperger's disorder, (3) Rett's disorder, (4) childhood disintegrative disorder and (5) PDD-NOS. The final category is reserved for individuals who do not meet full criteria for autistic disorder and/or demonstrate equivocal symptomatology that may not be impaired to the same degree as that found in autistic disorder.

Appendix B

CLIENT CHARACTERISTICS REPORT DATA

Summary of Autistic Population 1993 to Present

DATE	Total Persons with Autism Codes 1 & 2	Increase from Previous Quarter	Quarterly Percent Change in Autism Codes 1 & 2	Total* Caseload (recorded on CDERs)	Net Increase In Total Caseload from Previous Quarter	Percent Caseload Change
08/27/1993	4,911			105,650		
01/24/1994	5,108	197	4.01%	106,565	915	0.9%
04/14/1994	5,281	173	3.39%	107,367	802	0.8%
07/13/1994	5,323	42	0.80%	107,617	250	0.2%
11/08/1994	5,633	310	5.82%	108,551	934	0.9%
01/12/1995	5,775	142	2.52%	109,359	808	0.7%
04/11/1995	6,009	234	4.05%	110,886	1,527	1.4%
07/12/1995	6,179	170	2.83%	111,928	1,042	0.9%
09/13/1995	6,299	120	1.94%	112,464	536	0.5%
01/12/1996	6,527	228	3.62%	113,047	583	0.5%
04/12/1996	6,757	230	3.52%	114,139	1,092	1.0%
07/15/1996	7,005	248	3.67%	115,214	1,075	0.9%
10/10/1996	7,221	216	3.08%	116,358	1,144	1.0%
01/10/1997	7,487	266	3.68%	117,539	1,181	1.0%
04/09/1997	7,875	388	5.18%	120,141	2,602	2.2%
07/16/1997	8,179	304	3.86%	121,783	1,642	1.4%
10/08/1997	8,431	252	3.08%	122,999	1,216	1.0%
01/08/1998	8,781	350	4.15%	124,024	1,025	0.8%
04/09/1998	9,120	339	3.86%	124,834	810	0.7%
07/08/1998	9,587	467	5.12%	126,487	1,653	1.3%
10/07/1998	9,975	388	4.05%	127,750	1,263	1.0%
01/06/1999	10,206	231	2.32%	128,500	750	0.6%
04/07/1999	10,799	593	5.81%	130,645	2,145	1.7%
07/07/1999	11,233	434	4.02%	132,591	1,946	1.5%
10/07/1999	11,723	490	4.36%	133,888	1,297	1.0%
01/06/2000	12,150	427	3.64%	135,377	1,489	1.1%
04/06/2000	12,566	416	3.42%	136,536	1,159	0.9%
07/01/2000	13,054	488	3.88%	138,700	2,164	1.6%
10/01/2000	13,511	457	3.50%	140,316	1,616	1.2%
01/01/2001	14,077	566	4.19%	142,114	1,798	1.3%
04/03/2001	14,777	700	4.97%	144,040	1,926	1.4%
07/06/2001	15,441	664	4.49%	145,881	1,841	1.3%
10/04/2001	16,146	705	4.57%	147,857	1,976	1.4%
01/03/2002	16,802	656	4.06%	149,806	1,949	1.3%
04/04/2002	17,614	812	4.83%	152,062	2,256	1.5%
07/05/2002	18,460	846	4.80%	154,190	2,128	1.4%
10/09/2002	19,649	1189	6.44%	161,947	7,757	5.0%
01/06/2003	20,377	728	3.71%	163,792	1,845	1.1%

Note: The reader should bear in mind that the increase in numbers for autism or other developmental disabilities from one quarter to the next does not necessarily mean that those persons necessarily entered the regional center system within that quarter. The numbers for each quarter include a significant number of persons who entered the system several quarters, or even a year or more before the reporting quarter. For a number of reasons, some diagnoses may not be recorded on the CDER for months or years after they have entered the regional center system.

References

Allen, D. A. (1988). Autistic spectrum disorders: clinical presentation in preschool children. *Journal of Child Neurology, 3 (Suppl 1)*, 48-56.

American Psychiatric Association. (1980) *Diagnostic and Statistical Manual (3rd ed.)*. Washington, DC

American Psychiatric Association. (1987). *Diagnostic and Statistical Manual of Mental Disorders (3rd ed.)*. Washington, DC: American Psychiatric Association.

American Psychiatric Association. (1994) *Diagnostic and Statistical Manual (4th ed.)*. Washington, DC.

Charman T. (2002) The prevalence of autism spectrum disorders: Recent evidence and future challenges. *European Child Adolescent Psychiatry, Dec;11 (6)*: 249-56.

Croen, L., Grether, J., Hoogstrate, J. & Selvin, S. (2002) The Changing Prevalence of Autism in California. *Journal of Autism and Developmental Disorders, 32, No. 3*, 207 - 215.

Damasio, A. R. (1984). Autism [Editorial]. *Archives of Neurology*, 41, 481.

Gillberg, C. (1991). Outcome in autism and autistic-like conditions. *Journal of the American Academy of Child and Adolescent Psychiatry, 30*, 375-382.

M.I.N.D. Institute. (2002) Report to the Legislature on the Principle Findings from the Epidemiology of Autism in California. Sacramento, CA: University of California, Davis.

Volkmar, F. R. & Cohen, D. J. (1991). Debate and argument: The utility of the term Pervasive Developmental Disorder. *Journal of Child Psychology and Psychiatry, 32*, 1171-1172.

Wing L, Potter D. (2002) The epidemiology of autistic spectrum disorders; is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews, 8(3)*, 151-61.

Wing, L. & Attwood, A. (1987). Syndromes of autism and atypical development. In D. Cohen, A. Donellan & R. Paul (Eds.), *Handbook of Autism and Pervasive Developmental Disorders* (pp. 3-19). New York: John Wiley & Sons.

Wing, L. (1988). The continuum of autistic characteristics. In, E. Schopler & G. Mesibov (Eds.), *Diagnosis and Assessment in Autism* (pp. 1-10). New York, NY: Plenum Press.

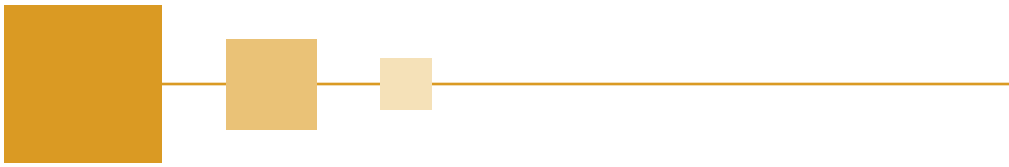
Wing, L. (1991). The relationship between Asperger's syndrome and Kanner's autism. In U. Frith (Ed.), *Autism and Asperger's Syndrome* (pp. 93-121). Cambridge, England: Cambridge University Press.

Wing. L. & Gould J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9*, 11-29.

World Health Organization. (1993). *International Classification of Diseases (10th ed.)*. Geneva, Switzerland: WHO.

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg; N., Boyle,C., Murphy, C. (2003) Prevalence of Autism in a US Metropolitan Area. *Journal of the American Medical Association, 289*, 49-55.

CALIFORNIA DEPARTMENT OF DEVELOPMENTAL SERVICES



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