

AUTISTIC SPECTRUM DISORDERS

Changes in the California Caseload
An Update: June 1987 – June 2007



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**Autistic Spectrum Disorders
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Executive Summary

Autistic Spectrum Disorders (ASD) profoundly affect how people perceive the world around them, and can interfere with how someone communicates and socializes with others. Children who have the neurodevelopmental disorders associated with ASD generally show little interest in other people and fail to learn from their natural environments as successfully as other children. Although some children with ASD can develop typical or advanced skills, the majority exhibit a wide range of behavioral, cognitive, and emotional challenges. This lifelong condition presents medical, psychological, behavioral, and educational challenges that require costly interventions and services.

Once considered rare, ASD now is more prevalent than Type I diabetes (Centers for Disease Control, 2005), Down syndrome (National Center for Birth Defects, 2005), or childhood cancer (United States Cancer Statistics Workgroup, 2005). People who have autism now outnumber people with cerebral palsy, and are soon projected to exceed those diagnosed with epilepsy. ASD rates continue growing in California, nationally, and internationally. In fact, recent investigations report a prevalence of 1 out of every 152 children is diagnosed with ASD (Centers for Disease Control, 2007). Given this dramatic increase, ASD has commanded the attention of parents, practitioners, educators, researchers, and policy makers who search for causes and solutions.

For the purpose of this report, the term “autism” refers only to the condition characterized by the California Department of Developmental Services (DDS) as “autistic disorder.” “Autistic disorder” is a specific classification in the Diagnostic Statistical Manual (DSM) IV TR (American Psychiatric Press, 2000). Unless specifically noted, the numbers and data presented in this report relating to “autism” do not include counts of persons with other disorders on the autism spectrum, noted below. From June 1987 through June 2007, California experienced a twelve-fold increase in individuals with autism being served by DDS.

The term Autistic Spectrum Disorder (ASD)¹ is used to refer to this larger group. Each of the disorders in on the spectrum has unique symptoms that vary in severity and scope. ASD includes Autistic Disorder, Asperger’s Disorder, Rett’s Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD, NOS), and Childhood Disintegrative Disorder. Together, these conditions have grown to represent more than 20 percent of the total caseload served by DDS.

Currently there are more than 38,000 people in California receiving services for ASD, growth that has averaged 13.4 percent annually since 2002. Based on current projections, regional centers and developmental centers will be serving more than 50,000 people with ASD by September 2009. If the trend continues, DDS may serve as many as 70,000 people with ASD by June 2012.

The biggest population boom is concentrated in young people. Over the last 20 years, the median age of people receiving services for autism with DDS has dropped from 19

¹ Autistic Spectrum Disorder consists of Autistic Disorder, Asperger’s Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Rett’s Disorder, and Childhood Disintegrative Disorder.

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to 10.75 years old. As of June 2007, more than one-third of all cases involved someone aged 9 or younger and 82 percent were 19 or younger. As the median age of this population decreases, the duration of services increases because state law mandates that services be provided for life for anyone who is eligible. A significant issue for this population is the increasing need for out-of-home residential services as these children reach late adolescence. Currently, approximately 6,000 adults with a diagnosis of autism receive services from DDS. In the next five years, more than four thousand teenagers with autism will be reaching adulthood. By 2018, the number of adults with autism being served by DDS will triple, to more than 19,000.

Great variability exists among the regional centers in the proportion of their caseloads attributed to autism. Regional centers in Los Angeles County serve a higher percentage of individuals with autism on their caseloads. All ethnicities comprise the autism spectrum with individuals self-identified as whites and Hispanics representing the largest groups. In general, ethnicity closely parallels the ethnic breakdown of the entire state population.

A notable shift in this population, in terms of cognitive ability, has occurred. Over the past two decades, there was a 40 percent increase in the number of individuals diagnosed with autism who were not also diagnosed with mental retardation. Presently just 36 percent of people with autism being served by DDS also have a diagnosis of mental retardation.

Local, state, national, and international attention focuses increasingly on the expanding numbers in the ASD community in the United States and abroad.

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Preface

California's regional center system consists of 21 nonprofit and independent agencies that contract with DDS to provide services to people with developmental disabilities. This system, created in 1969, serves professionally diagnosed individuals with mental retardation, autism, epilepsy, cerebral palsy and conditions similar to mental retardation.² Currently, investigators estimate that 75 to 80 percent of the total population of persons in California with autism is enrolled in the DDS service delivery system (Croen, Grether, Hoogstrate, & Selvin, 2002).

As the ASD caseload has grown in California, so has the demand for objective data. DDS data, which measure the population of individuals with ASD served by the regional center system is the largest longitudinal study of its kind in the country. It is the subject of frequent requests from national researchers, advocates, families, regional centers, allied agencies, the California Legislature, and others.

This report updates the previous Autism report (California DDS, 2003) which found notable rises in the number Californians with ASD. This trend continues. From 1987 to 2007, the number of people with ASD grew 1,148 percent, significant when compared to increases of 73 percent for cerebral palsy, 66 percent for epilepsy, and 95 percent for mental retardation. During this same period, California's general population grew 27 percent (State of California, 2007). The objective of this report is to provide current data about this population.

Note to Readers:

The information presented in this report is purely descriptive and should not be used to draw scientifically valid conclusions about the incidence or prevalence of ASD in California. Numbers of people 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, hand entry, and possible error, by case workers of large amounts of information onto state forms. Finally, it is important to note that entry into and exit from California's developmental services system is voluntary. This may further alter the data presented herein relative to the actual population of persons with ASD in California.

²Although part of the Autistic Spectrum Disorder, persons diagnosed with Pervasive Developmental Disorder, Not Otherwise Specified (PDD, NOS) and Asperger's Disorder are not eligible for regional center services unless they possess impairments constituting 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.

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Introduction

ASD consists of a continuum or spectrum of complex neurodevelopmental disorders with a serious lifelong impact on individuals from all ethnic and socioeconomic backgrounds (Minschew, 2007; Pessah, 2006; Grandjean & Landigan, 2006; London & Etzel, 2000). Both genetic and environmental factors appear to contribute to the development of ASD (Herbert, 2006; Hertz-Picciotto, Croen, Hansen, Jones, Van de Water, & Pessah, 2006; London & Etzel, 2000). ASD includes five disorders: Autistic Disorder, PDD, NOS, Asperger's Disorder, Retts Disorder, and Childhood Disintegrative Disorder. Common manifestations include challenges in communication, imaginative play, and socializing with others. Preoccupation with unusual interests and a restricted/repetitive pattern of interests and/or behaviors are typical. Routines, inflexibility, and difficulty with new situations characterize many individuals. Intellectual disabilities are common.

Great variation characterizes the cognitive and language skills of individuals with autism. For instance, about 20 to 25 percent of children with ASD demonstrate normal to superior functioning in at least one of the major cognitive domains: verbal and nonverbal (California DDS, 2002). Some individuals show more limited abilities and struggle with speech and communication and other domains (Sigman & McGovern, 2005). Some who are nonverbal convey needs through other forms of communication. Rates of co-occurring intellectual delay or mental retardation vary from 40 to 62 percent in one study (Centers for Disease Control and Prevention, 2007) to 70 percent in another investigation (Fombonne, 2003) to 70 percent to 80 percent in other reviews (Shea & Mesibov, 2005).

Approximately 90 percent of parents of children with ASD recognize abnormality by 24 months of age (De Giacomo & Fombonne, 1998). Sometimes, parents report that their children seem to be developing typically and then lose skills. Researchers document that 20 to 30 percent of children who have been diagnosed with ASD experienced a regression in development, with onset between age 18 to 24 months, after a period of apparently normal development (Hertz-Picciotto et al, 2006; Rogers, 2002). The condition involves both the neurological and physical aspects of the individual, with varying rates of medical complications occurring with this condition (Amaral, 2007; Herbert, 2005; Herbert, 2006). Volkmar (2006) reports a range of 5 to 33 percent of individuals with autism having co-existing medical problems while others report rates up to 17 percent. Immune system dysfunction is often involved (Fombonne, 2003; Amaral, 2007; Herbert, 2006). About 20 to 33 percent of individuals with ASD experience seizures (Shea & Mesibov, 2005). Seizures are present by adolescence in about 30 percent of children with ASD (Hertz-Picciotto et al, 2006).

Not only does ASD directly impact the individuals identified with this condition, family members are impacted as well. Research findings suggest that parents of children with ASD experience higher levels of anxiety and other emotional problems and lower levels of family functioning than do parents of children without autism and/or parents of children with other disabilities (Orsmund, Lin, & Seltzer, 2007; Baker,

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2007). In addition, families of persons with ASD are more likely to include siblings with disabilities, than are families of children without disabilities, or families with other types of disabilities (Orsmond, Lin, & Seltzer, 2007).

Background

In 1999, DDS reported substantial increases in the numbers of people with autism receiving services from California's 21 regional centers statewide. The first 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. The second report, entitled *Autistic Spectrum Disorders Changes in the California Caseload: An Update*, included counts of people with ASD previously reported, i.e. from 1987 to 1998, and up through 2002. The present document reports findings for the number of people with ASD being served by California's regional centers and developmental centers from 1987 through June 2007.

In parallel with rates in California, other states and other countries report substantial increases in the number of new cases. For instance, in a survey of 32 empirical studies from 13 countries, the combined rate of all pervasive developmental disorders occurred at 60 to 70 per 10,000 (Fombonne, 2003). Bertrand and colleagues (2001) documented a prevalence of all ASD combined as 67 individuals per 10,000. In a review of 40 studies, prevalence estimates of 7.1 per 10,000 for autism and 20 per 10,000 for all ASDs were reported (Williams et al 2006). Blanchard and associates (2006) reported a rate of about 1 per 200 children (50 per 10,000) as having autism. Most recently, in 2007 the Centers for Disease Control reported a rate of all ASDs to be 6.6 per 1,000 individuals (CDC, 2007). The findings on higher prevalence rates of autism, and the broader ASD spectrum including PDD, NOS and Asperger's Disorder, stir much discussion among researchers, epidemiologists, and others in the autism field. (Baird et al, 2006; Davis & Schwartz, 2007; Rutter, 2005; Wing and Porter, 2002).

Items to Consider in Reviewing this Report

The numbers presented in this report originate from the Client Development Evaluation Report (CDER), an instrument used to collect diagnostic and evaluation information on people with developmental disabilities during their Individual Program Plan (IPP) meetings. A new IPP, and thus updated CDER, is required at least once every three years. The CDER also should be updated when there is a significant change in the person's physical or mental capabilities. The CDER documents diagnostic elements and the functional level for the majority of persons age three and above. The count of persons reported for a given year was taken from the total number of CDERs on the electronic file at the end of the year reported.

Regional centers vary in their CDER documentation protocols in terms of who confirms and reviews each individual's diagnosis, who enters and updates information on the CDER, and how the data are reported.

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The term ASD is commonly used by clinicians and others to include autism and related disorders. Both nationally and within California, there is not total agreement on which diagnoses should be included as part of the spectrum. As stated in the DDS document, *Autism Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment (California DDS, 2002)*, “controversy continues to surround the ‘spectrum’ concept, primarily due to the questions remaining as to whether disorders within the autistic spectrum are, in fact, continuous” (p. 147). Some entities include up to five disorders: Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Asperger’s Disorder, Rett’s Disorder, and Childhood Disintegrative Disorder. The term “Pervasive Developmental Disorder” is used in the DSM to classify diagnoses considered to be in the autism spectrum.

California continues to work to improve consistency in diagnosis and reporting. In 2002, DDS, in collaboration with regional centers and numerous experts in the field, published, *Autism Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment* for this purpose (California DDS, 2002). Additionally, DDS has become partners with the University of California Medical Schools to provide training to community practitioners. Finally, regional center specialty groups of psychologists, physicians, and clinical directors meet regularly and discuss diagnostic criteria. However, there currently is no mechanism in place that rigorously evaluates inter-rater reliability or diagnostic consistency across regional centers. Therefore, this possible variance in diagnoses and recording must be considered when reviewing the CDER data.

Most of the data presented in this report include counts of people reported on the CDER as having autism only, and *generally* do not include counts of people with other disorders on the spectrum (Asperger’s Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, and PDD, NOS). DDS can not accurately delineate the CDER population into ASD subgroups. Please see the section below for more information. Any interpretation of this data must take into account the CDER data limitations and constraints.

CDER Definitions of Autism

The numbers presented in this report were taken from the CDER instrument and corresponding CDER Manual, dated from March 1986, used by DDS to document diagnostic and functional level of development for the majority of person’s 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-R (APA, 1994) classification of Autistic Disorder (DSM IV-R 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

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for regional center services. 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 that only 75 to 80 percent of the total population of persons in California with autism is enrolled in the developmental service system (Croen et al, 2002).

The DSM IV-R classification of Pervasive Developmental Disorders includes four additional disorders: Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder and PDD, NOS. For individuals diagnosed with one of these four conditions, and who meet regional center eligibility criteria as substantially handicapped, 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 PDD 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-R 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.

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 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

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 intervention program known as Early Start. Individual services are provided by each of the regional centers. Infants and toddlers may meet eligibility criteria for early intervention services provided they have one or more developmental delays or an established risk of known etiology with a high probability of delayed development. Alternatively, infants and toddlers may meet eligibility criteria if they show high risk of substantial developmental disability due to a combination of risk factors.

In 1992, DDS began recording demographic data for children enrolled in the Early Start Program. Data describing these children are reported on the Early Start Profile. Until they turn three years old, the majority of children in the Early Start Program do not have a documented diagnosis. Those individuals with a documented diagnosis are included in this report where applicable.

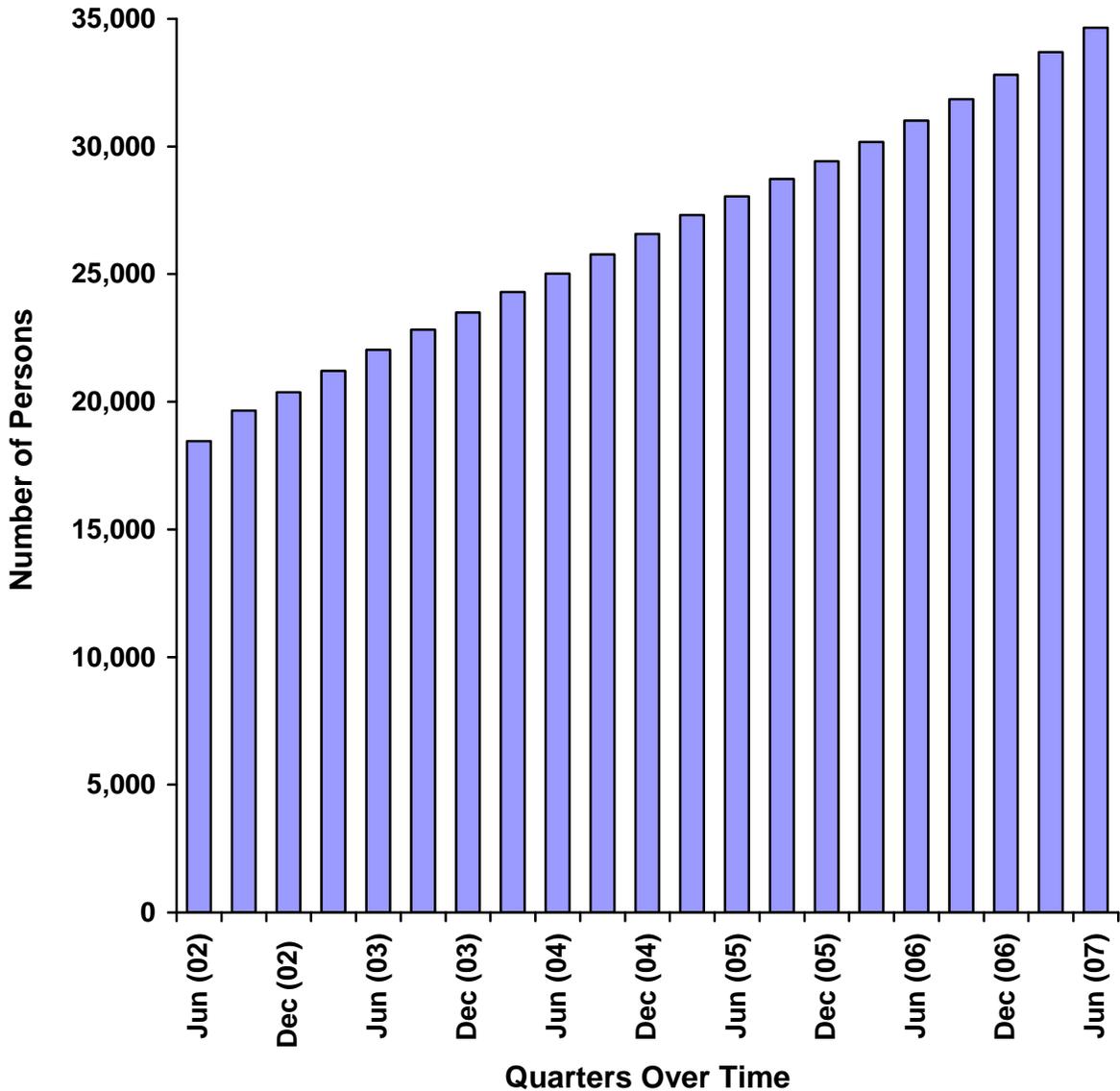
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Findings

Caseload Changes

For the five-year period from June 2002 to June 2007, net growth of 14,279 individuals (70 percent increase) occurred in the autism caseload. This rise follows the pattern reported in previous reports. Quarterly growth has averaged three percent over this span. By the end of June 2007, 34,656 individuals with autism were receiving regional center and developmental center services. Quarterly increases of persons with autism (Codes 1 and 2) for the past five years are shown in Figure 1.

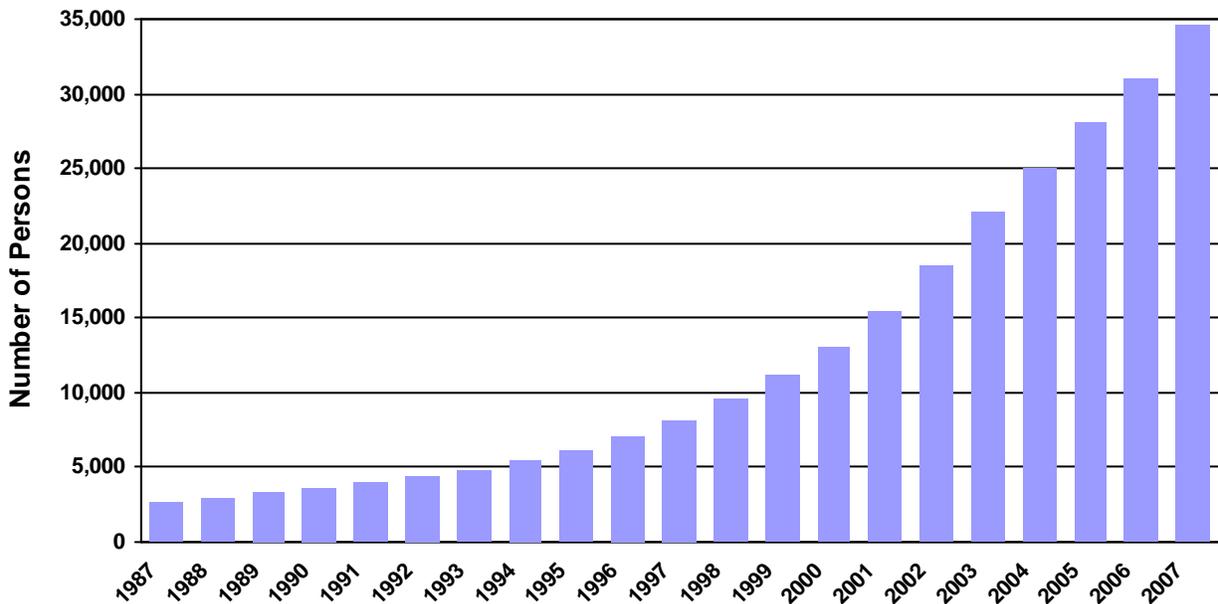
**Figure 1: Quarterly Frequencies of Persons with Autism
June 2002 - June 2007
(Codes 1&2)**



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Figure 2 displays the growth in autism from June 1987 through June 2007, for persons with autism (Codes 1 and 2). As can be seen, there have been continuous increases over that time, and accelerated growth in the past 11 years. The annual growth percentage increases range from 3.1 percent to nearly 20 percent, with annual growth averaging 13.2 percent. The largest percentage increases occurred between 1997 and 2002. Overall, a four-fold increase has occurred in the number of people with autism being served by the regional centers and developmental centers since 1997. There was a 12-fold jump in the number of people with autism over the past two decades.

Figure 2: Annual Frequencies of Persons with Autism from June 1987 - June 2007



In late 1993, DDS began reporting quarterly data for its entire population of people with developmental disabilities. Beginning in September 2002, DDS began posting the Quarterly Client Characteristics Report (QCCR) on its website at www.dds.ca.gov. at the end of the second week in January, April, July, and October of each year.

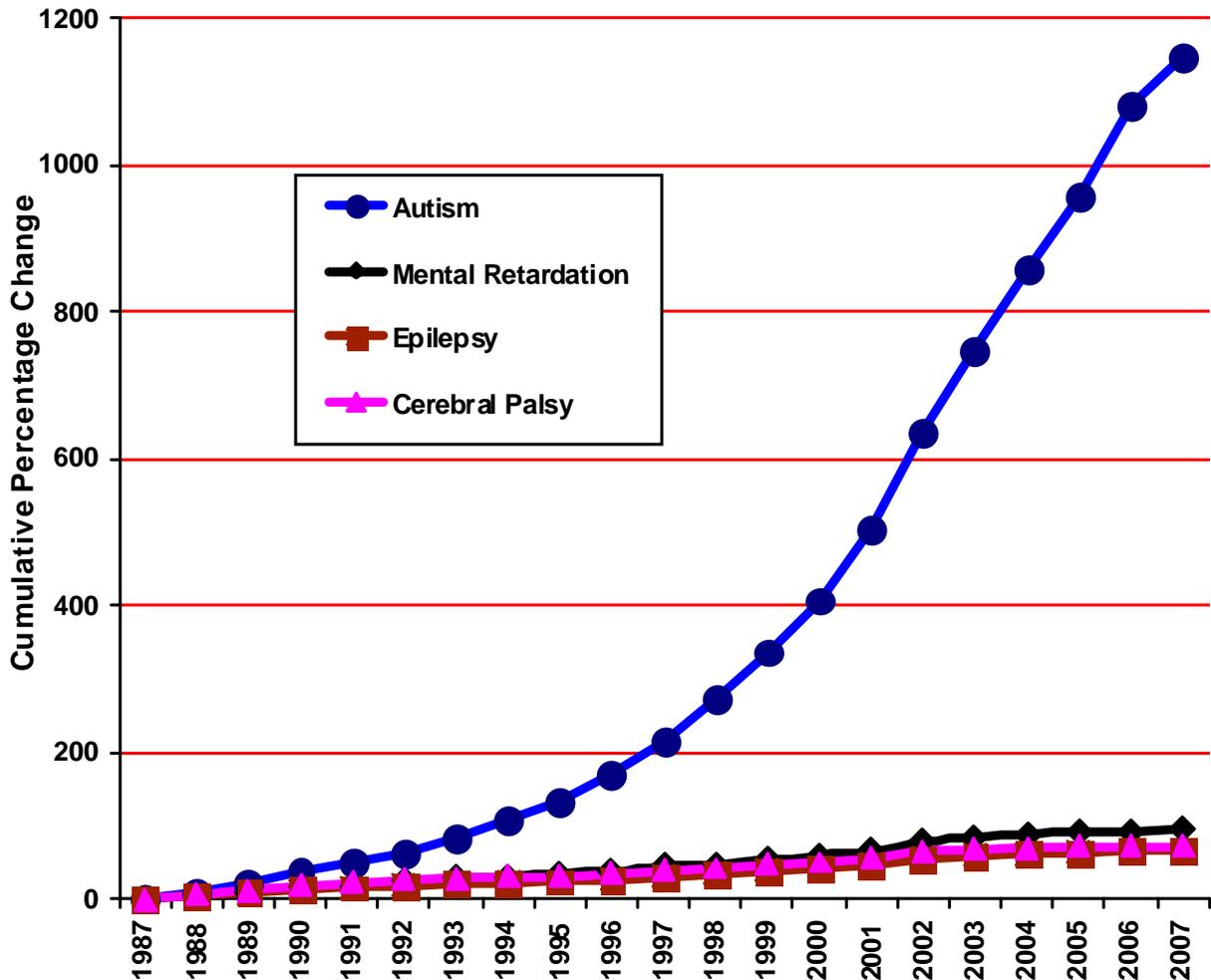
Autism rates show gains that exceed population increases. For instance, between 1990 and 2000, the population of California rose 13.8 percent (USA Counties and Census, 2000). However, during this same time period, the population of individuals with autism being served by DDS increased 359 percent. Thus, the number of persons with autism being served by regional centers rose 26 times faster than that of the general California population.

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Changes in Developmental Disability

Figure 3 displays the percentage change over time for the four primary diagnostic categories in state law. This depiction highlights several long-term trends over 20 years, as well as the more recent fluctuations observed in the past five years. It is apparent that mental retardation doubled over two decades, while epilepsy grew by about two-thirds. Cerebral palsy grew by about three-quarters in frequency over 20 years. Most significantly, autism continues to stand out as the disorder displaying large growth spurts. In just the past five years, autism grew nine times more than mental retardation, epilepsy, and cerebral palsy combined. Autism increased over 1,100 percent over two decades while the total number of individuals in the DDS system increased 136 percent. People with autism now outnumber people with cerebral palsy in the DDS system, and most likely will soon surpass epilepsy.

Figure 3: Cumulative Percentage Change of Autism, Cerebral Palsy, Epilepsy, and Mental Retardation over Two Decades

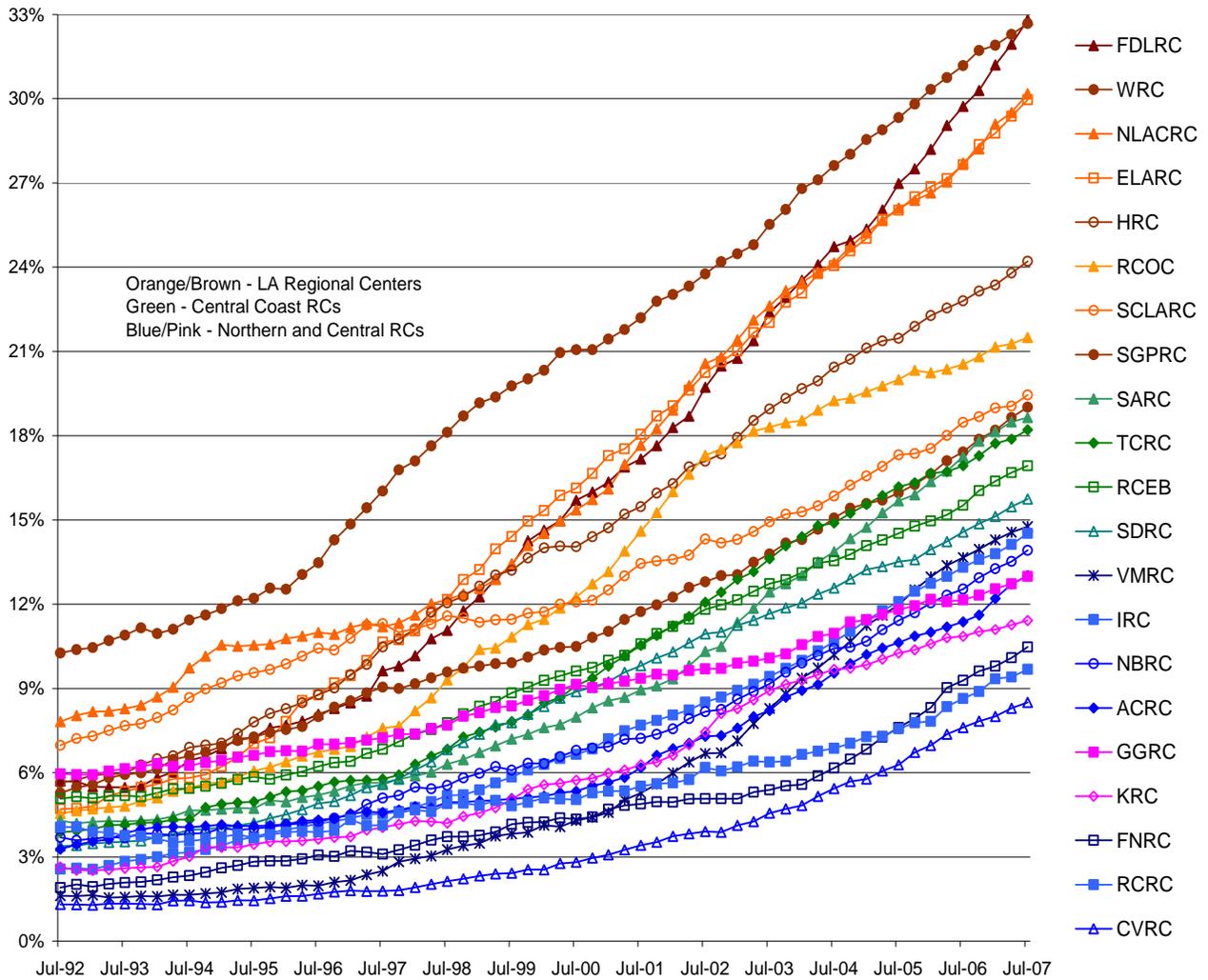


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Autism as Percentage of Caseload

Figure 4 details the percentage of persons identified with autism as a function of total caseload. As can be seen, growth and total percentage vary greatly across the state's regional centers. The highest areas consist of two regional centers in the Los Angeles area, with the highest at 33 percent (Westside and Frank D. Lanterman Regional Centers). The northern and central California regional centers fall near the bottom in prevalence data, with the lowest at only eight percent (Central Valley Regional Center).

Figure 4: Autism as a Proportion of Regional Center Caseload 1992-2007



LEGEND: RC = Regional Center
 FDLRC = Frank D Lanterman RC
 WRC = Westside RC
 NLARC = North Los Angeles RC
 ELARC = Eastern Los Angeles RC
 HRC = Harbor RC
 RCOC = RC of Orange County
 SCLARC = South Central Los Angeles RC

SG/PRC = San Gabriel/Pomona RC
 SARC = San Andreas RC
 TCRC = Tri-Counties RC
 RCEB = RC of the East Bay
 SDRC = San Diego RC
 VMRC = Valley Mountain RC
 IRC = Inland RC

NBRC = North Bay RC
 ACRC = Alta California RC
 GGRC = Golden Gate RC
 KRC = Kern RC
 FNRC = Far Northern RC
 RCRC = Redwood Coast RC
 CVRC = Central Valley RC

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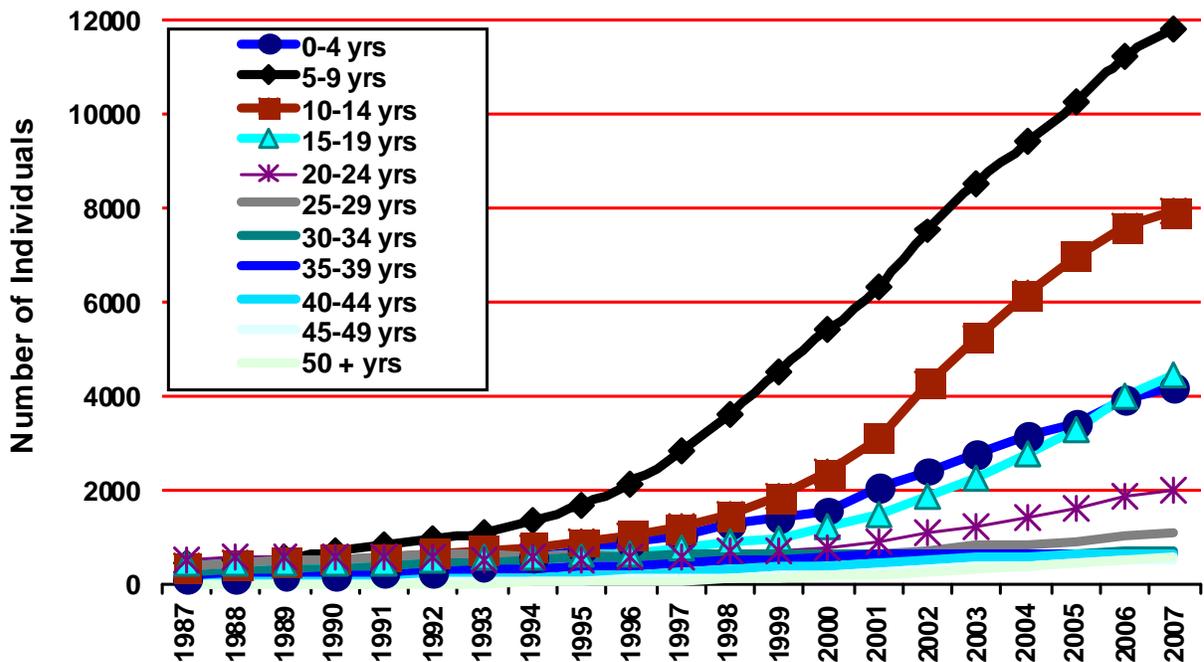
Further examination of regional center caseload data reveals four other patterns. First, all of the regional centers show significant increases in the number of individuals with autism served over the past 15 years. Second, over time, all of the regional centers have added a higher percentage of individuals with autism versus other developmental disabilities to their caseload. Third, the differences in caseload composition of the regional centers have widened over the past 15 years, and especially in the last decade. For instance, in 1992 the range in percentage of caseload attributed to persons with autism was 2 to 10 percent across the 21 agencies. This range climbed to 2 to 16 percent in 1997 and 8 to 33 percent in 2007. Fourth, the southern California regional centers show the steepest climbs in percentages of caseload over this time span, in contrast to the northern and central regional centers which show more modest growth increases.

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Age Distribution

Over time, a pattern emerges with more individuals with autism crossing all age spans. Figure 5 displays the age distribution in detail. The age group showing the most growth consists of children aged 5 to 9 years. The 10 to 14 age group and the 15 to 19 age group also are growing rapidly. The group showing the smallest changes over time consists of those aged 50 and above.

**Figure 5: Age Distribution of Persons with Autism
1987 - 2007**



As of June 2007, the mean age for people with autism being served by the regional centers and developmental centers was 13.6 years of age, with a standard deviation of 11. Therefore, two-thirds of the population of persons classified with autism in the California system fell between the ages of 2.6 years of age and 24.6 years of age.

Specifically, 34 percent of the total number of persons with autism presently fall in the 5 – 9 age group. Twenty-three percent are in the 10 - 14 group followed by 13 percent in 15 – 19 and 12 percent in 0 - 4. Six percent fall in the group of 20 to 24, and 3 percent fall in the age group of 25 to 29. Individuals in the 30 - 34 age group represent 3 percent of those on the spectrum being served by DDS. Those in the 35 – 39 and 40 – 44 age groups each represent two percent. Finally, the remaining three percent consist of people aged 45 and over.

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Diagnostic Stability of Autism

The diagnostic stability of autism observed in Table 1 (below) shows that, in general, little change in this diagnosis occurs once clinicians assign this classification. This DDS finding closely matches that found by other researchers. For instance, Lord and her colleagues (2006) reported diagnostic consistency of 90 percent for ASD between ages 2 and 9 years in a recently published longitudinal study.

In California data spanning the last two decades, 94 percent of the total people with autism kept that diagnosis. Fewer than six percent had their diagnosis of autism changed or left the system after that diagnosis had been initially provided.

Table 1: Detail of Changes in Diagnosis and System Entries and Exits for Persons with Autism from June 1986/1987 – June 2006/2007

Year *	Year Start Population	Dropped Diagnoses	Added Diagnoses	Left System	Entered System	Net Growth	Net Growth %	Year End Population
1986-1987	2,619	-139	162	-168	227	82	3.1 %	2,701
1987-1988	2,701	-65	150	-133	291	243	9.0 %	2,944
1988-1989	2,944	-41	146	-145	358	318	10.8 %	3,262
1989-1990	3,262	-38	152	-154	407	367	11.3 %	3,629
1990-1991	3,629	-33	120	-162	472	397	10.9 %	4,026
1991-1992	4,026	-43	119	-142	486	420	10.4 %	4,446
1992-1993	4,446	-28	80	-162	489	379	8.5 %	4,825
1993-1994	4,825	-23	140	-256	760	621	12.9 %	5,446
1994-1995	5,446	-28	115	-338	984	733	13.5 %	6,179
1995-1996	6,179	-31	113	-358	1,102	826	13.4 %	7,005
1996-1997	7,005	-30	130	-392	1,466	1,174	16.8 %	8,179
1997-1998	8,179	-44	221	-479	1,710	1,408	17.2 %	9,587
1998-1999	9,587	-40	231	-545	2,000	1,646	17.2 %	11,233
1999-2000	11,233	-46	284	-615	2,198	1,821	16.2 %	13,054
2000-2001	13,054	-53	329	-547	2,658	2,387	18.3 %	15,441
2001-2002	15,441	-59	372	-580	3,286	3,019	19.6 %	18,460
2002-2003	18,460	-54	429	-687	3,892	3,580	19.4 %	22,040
2003-2004	22,040	-60	443	-887	3,484	2,980	13.5 %	25,020
2004-2005	25,020	-53	384	-1,097	3,792	3,026	12.1 %	28,046
2005-2006	28,046	-95	378	-1,556	4,239	2,966	10.6 %	31,012
2006-2007	31,012	-107	378	-1,440	4,813	3,644	11.8 %	34,656
21 Year Total		-1,110	4,876	-10,843	39,114	32,037		

* July 1 through July 1

Key

Dropped Diagnoses - Diagnoses changed during year from autism to other diagnoses.

Added Diagnoses - Diagnoses changed during year from other diagnoses to autism.

Left System - Exited service through out-migration, death, etc.

Entered System - Entered service system as autistic from Early Start or referral.

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Ethnicity

The June 2007 ethnic profile of people with autism being served by DDS, compared with the ethnic profile of all people served by DDS, and the ethnic profile of California at large, is displayed in Table 2, below. The largest demographic of people with autism served by DDS continues to be those who identify themselves as White.

Table 2 also shows the parallel breakdown in ethnicities for all people in the developmental disability service system. The percentages for autism closely match the percentages for all individuals served by DDS. All ethnicities fall within four percentage points of each other in the two populations compared.

California's population ethnicity breakdown varies somewhat from the autism breakdown. While caution must be used when examining this comparison as the state ethnicity breakdown varies somewhat from the ethnicity classifications used by DDS, some noteworthy patterns are apparent. People who identify themselves as Hispanic (28%) are under-represented in the autism community compared to the state population as a whole (36%).

Table 2: Ethnicity, by Percentage, for Persons with Autism Served by DDS, All Persons Served by DDS, and Californians

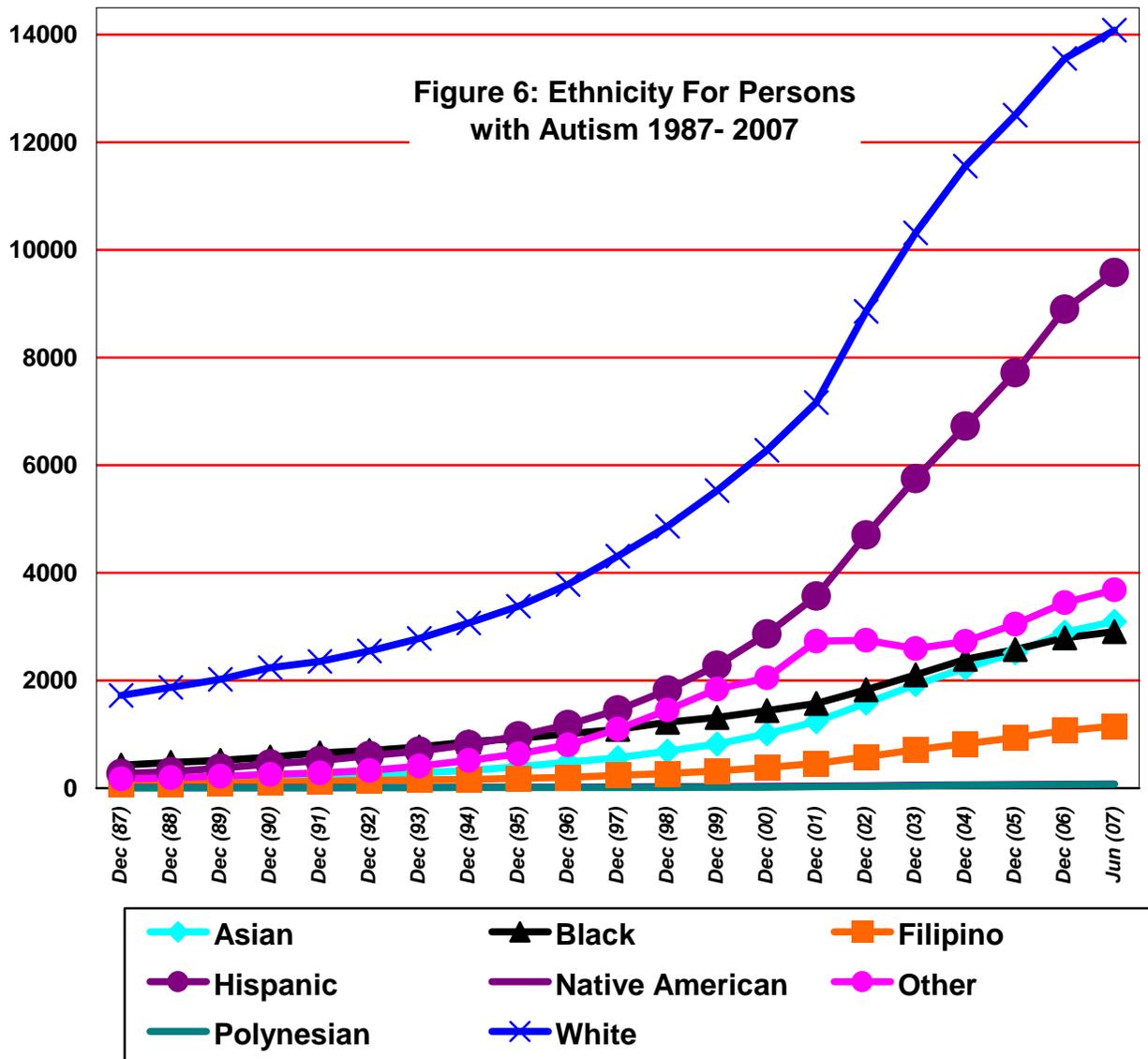
Ethnicity	Autism	All DDS Consumers	Californians*
White	40.1	42.1	43.4
Hispanic	27.7	31.7	35.8
Asian	8.9	5.8	11.7
Black	8.4	10.4	6.0
Filipino	3.3	2.2	Not Available
Native American	0.2	0.4	0.6
Polynesian	0.2	0.2	0.4
Other	10.6	7.1	2.1

*2007 California ethnic population projection, from State of California Department of Finance, Race/Ethnic Population with Age and Sex Detail, 2000-2050, Sacramento, CA, July 2007.

Figure 6 on the next page displays the number of individuals served by DDS with autism by ethnicity going back to 1987. As can be seen, people who identify themselves as White and Hispanic showed the greatest increase in numbers in the past 20 years.

The number of people self-identified as White increased more than eight-fold, while the number of persons self-identified as Hispanic grew by 35 times. Recent increases continue this trend. For instance, the population identifying themselves as White grew 59 percent since December 2002, while the population of people who identify themselves as Hispanic grew 104 percent in that same time period.

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Ethnicity by Regional Center

A graphic depiction of ethnicities at the various regional centers appears in Figure 7. This figure illustrates numerous findings and patterns of distribution. Four are especially noteworthy:

- People who identify themselves as White constitute the highest percentage of the population being served at 17 of the 21 regional centers.
- At four regional centers (Eastern Los Angeles, Frank D. Lanterman, South Central Los Angeles, and San Gabriel/Pomona), individuals who identify themselves as Hispanic constitute the highest overall percentage of those being served.
- Of all of the regional centers, the highest percentage of persons who identify themselves as Black with autism are found in South Central Los Angeles Regional Center (32.3 percent).

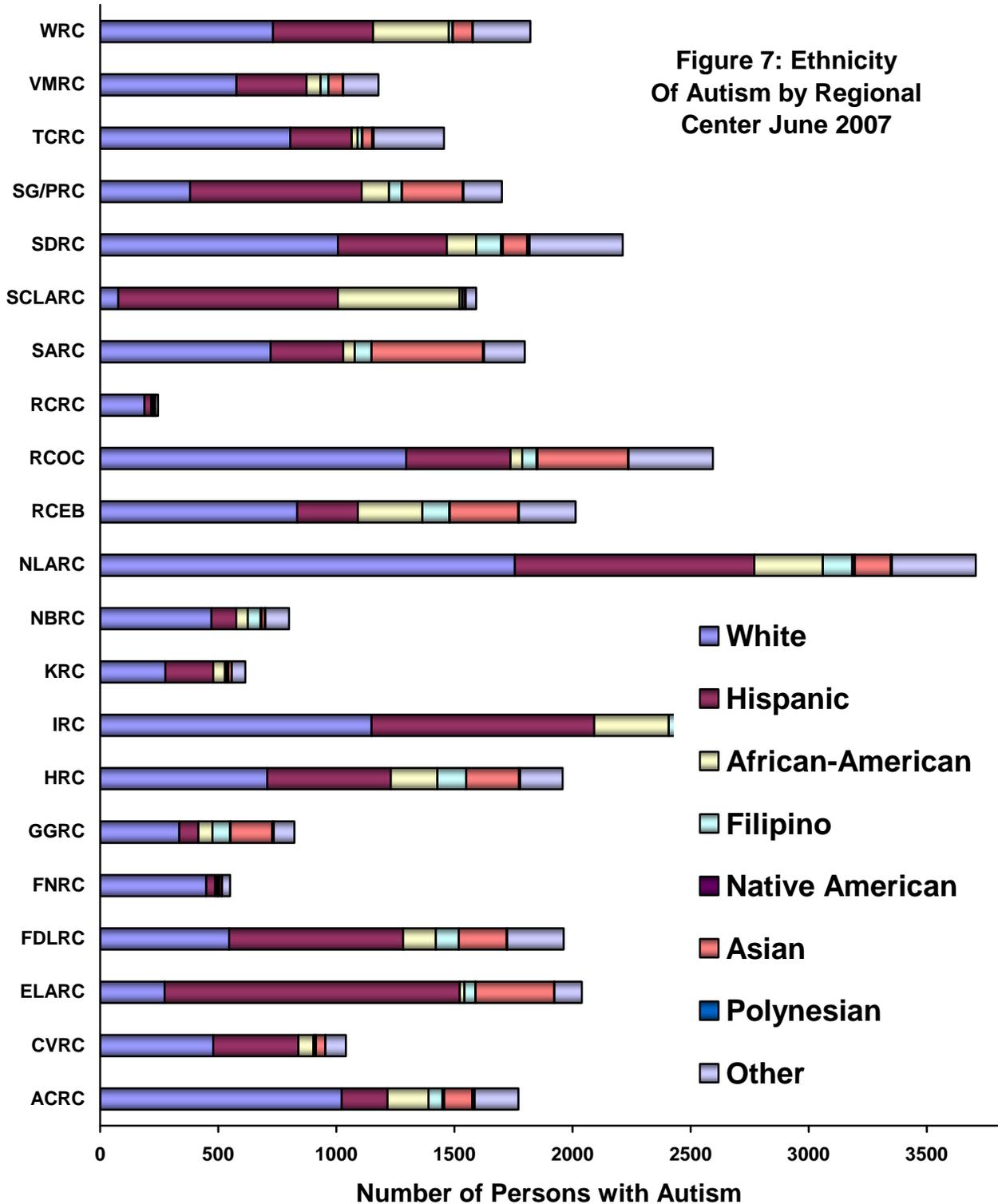
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- Eastern Los Angeles and San Andreas Regional Centers serve the greatest number of individuals who identify themselves as Asian.

The graph also demonstrates the great range in relative sizes in autism numbers across the various centers. The regional center with the largest population of people with autism is 15 times larger than the one with the smallest. North Los Angeles regional center serves 3708 persons with autism (10.7 percent), while Redwood Coast regional center serves 245 persons with autism (0.7 percent).

The highest percentage of populations served tends to be the southern California regional centers. In fact, the regional centers in the Los Angeles area serve 48 percent of the total persons in the State identified with autism. Smaller percentages tend to occur in more rurally located centers. The San Francisco Bay Area regional centers serve 10.5 percent of the State's autism caseload. These data reflect the great diversity of persons diagnosed with this complex disorder.

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LEGEND: RC = Regional Center
 FDLRC = Frank D Lanterman RC
 WRC = Westside RC
 NLARC = North Los Angeles RC
 ELARC = Eastern Los Angeles RC
 HRC = Harbor RC
 RCOC = RC of Orange County
 SCLARC = South Central Los Angeles RC

SG/PRC = San Gabriel/Pomona RC
 SARC = San Andreas RC
 TCRC = Tri-Counties RC
 RCEB = RC of the East Bay
 SDRC = San Diego RC
 VMRC = Valley Mountain RC
 IRC = Inland RC

NBRC = North Bay RC
 ACRC = Alta California RC
 GGRC = Golden Gate RC
 KRC = Kern RC
 FNRC = Far Northern RC
 RCRC = Redwood Coast RC
 CVRC = Central Valley RC

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Gender Ratio

The ratio of males to females with autism in the DDS system is 4.6 to 1. This pattern occurred for all ethnicities and for all types of residence status. The preponderance of males with autism compared to females occurred across all regional centers and in all counties in California. This finding is consistent across the scientific literature. For instance, in his review of over 30 studies, Fombonne in 2003 found that the mean gender ratio of boys to girls was 4.3 to 1. Volkmar (2006) reported a ratio of 3.5 to 1, while the CDC (2007) reported a ratio for ASD ranging from 3.4 to 1 to 6.5 to 1 across 14 states studied.

This gender ratio has shown a steady increase over the past 20 years. The rate rose from 3.4 to 1 in 1987 to 4.6 to 1 in 2007.

Cognitive Level

Figure 8 illustrates changing cognitive patterns over the last twenty years. Over this time span, the percentage of people identified with autism who also have a diagnosis of mental retardation has declined. Rates of people with autism who also had some degree of mental retardation dropped by over half, from 79.6 percent in 1987 to 35.6 percent in June 2007. Lower percentages of people with moderate, profound, and severe levels of mental retardation are being diagnosed with autism over time, while the percentage of individuals with mild mental retardation has remained about the same (16.4 percent).

Although this finding contradicts previous national prevalence rates of 70 to 80 percent of people with autism having mental retardation (ASD Best Practice Guidelines, 2002; DSM IV-R TR, 2000), this California data trend parallels the recent literature. For instance, Bertrand (2001) found that 49 percent of the people with ASD in her study also had mental retardation. Fombonne (2003) found that 30 percent of people in his studies reviewed had “mild to moderate intellectual impairment,” while 40 percent had “severe to profound level of mental retardation.” Chakrabarti and Fombonne (2001) reported a downward trend for the rate of mental retardation with ASD.

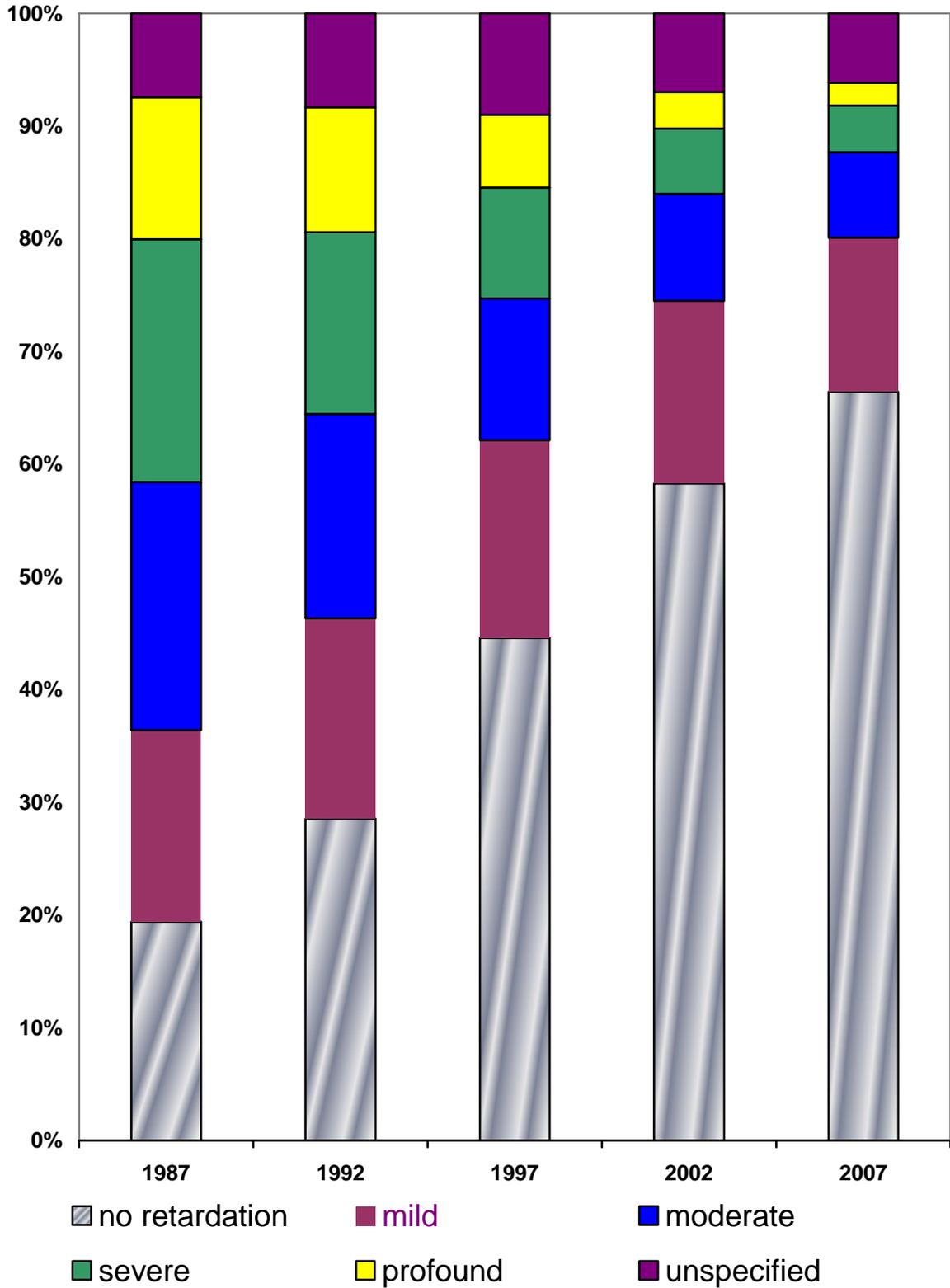
Interestingly, the ratio of males to females with autism varies by level of mental retardation (Table 3 and Figure 8).

Table 3: Gender Ratio by Level of Mental Retardation for Autism

Mental Retardation Level	Ratio of Males to Females
No mental retardation	5.2 to 1
Mild	4.4 to 1
Moderate	3.5 to 1
Severe	3.0 to 1
Profound	2.4 to 1

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Figure 8: Cognitive Changes 1987 - 2007

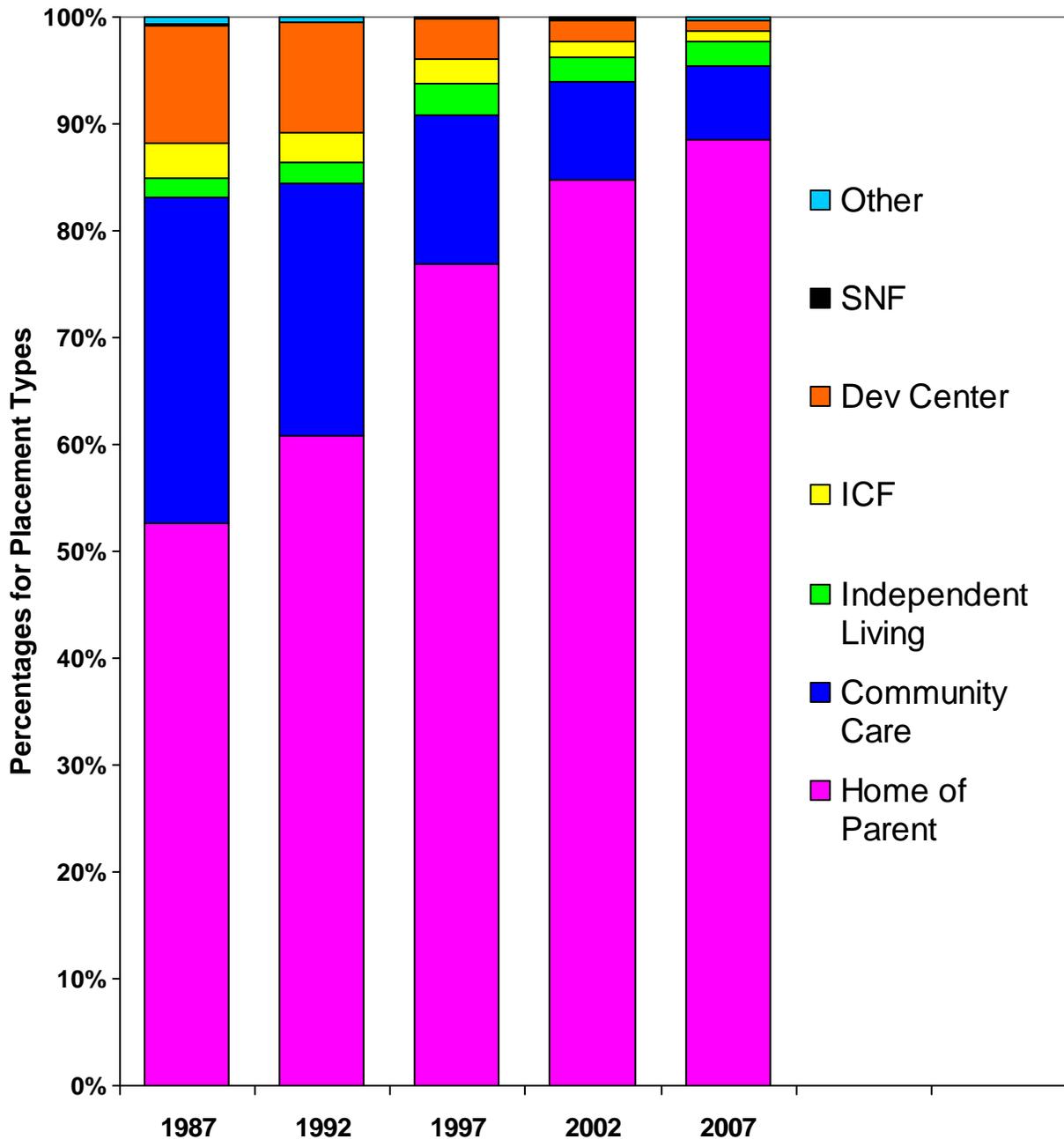


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Residence

In 2007, 89 percent of people with autism lived at home compared to just 53 percent in 1987. In 1987, 31 percent of people identified with autism lived in licensed community residential facilities and this rate has gradually dropped to seven percent in 2007. Similarly, the number of people with autism who are living at developmental centers dropped from 11 percent in 1987 to 1 percent in 2007. The graphic for breakdown for placement type is shown in Figure 9.

**Figure 9: Placement Type for Persons with Autism
1987-2007**



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The level of care of people with autism is closely tied to cognitive delay, as observed in Table 4. Individuals with autism who have more severe cognitive delays tend to reside in licensed community residential facilities, Intermediate Care Facilities (ICFs), and developmental centers. Sixty percent of people with autism and severe or profound mental retardation live in community care, developmental centers, or ICFs. Those with lesser cognitive delays are more likely to reside in the home of a parent/guardian or independent or supported living settings. Table 4 shows that 95.8 percent of people with autism and either mild or no mental retardation live at home or in independent living.

Table 4: Placement Type Composition for Individuals with Autism as Function of Mental Retardation

RESIDENCE TYPE	NO MENTAL RETARDATION	MILD	MOD	SEVERE	PROFOUND	UNK	GRAND TOTAL
Community Care	444	403	531	485	242	100	2,205
Developmental Center	2	19	35	95	201	2	354
Home of Parent/Guardian	21,902	4,110	1,884	675	115	1,987	30,673
ICF	26	35	64	107	104	9	345
Indep/Supported Living	470	123	72	52	18	19	754
Other	172	44	38	18	8	22	302
Skilled Nursing Facility	6	2	5	6	3	1	23

Table 5 displays residence status broken down by age. In general, children and teenagers under age 20 live almost exclusively at home with a parent or guardian (97.2%). The biggest age group living at home, representing almost 34 percent of the total autism caseload is persons in the age group of 5-9. In contrast, adults aged 20 and over tend to reside in a variety of settings, from home (49.5%), community care (27%), independent/supported living (11.8%), developmental centers (5.5%), ICF (4.8%), SNF (0.4%), or other (0.9%). It is noteworthy that the percentage living at home steadily drops after age 9. On the other hand, community care placements, developmental center placements, and ICF and SNF options in general are more prevalent among older adults.

Table 5: Residence Status for individuals with Autism Broken Down by Age Group

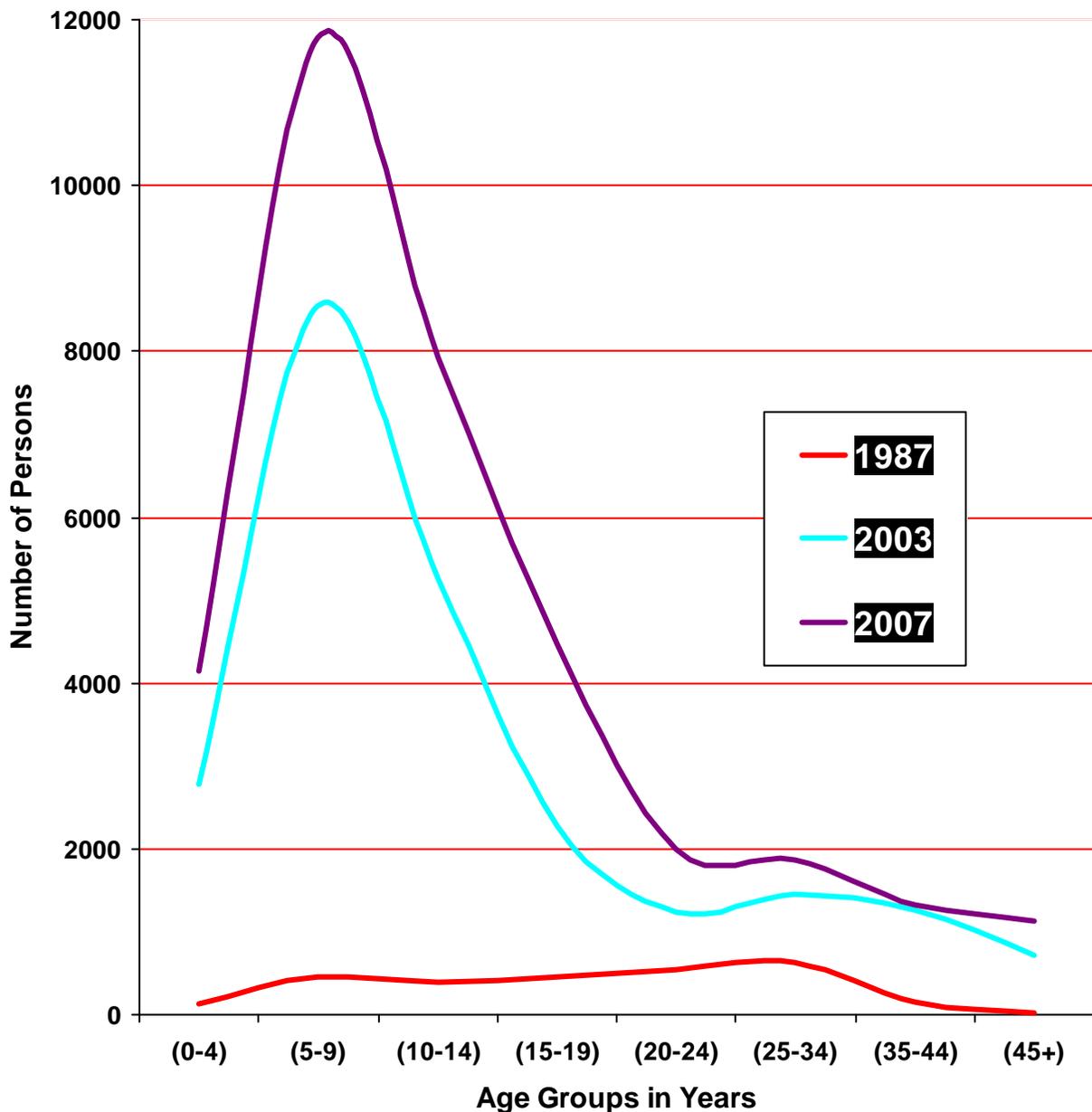
RESID. TYPE	0-4	5-9	10-14	15-19	20-24	25-29	30-34	35-39	40-44	45-9	50+
Com. Care	1	28	172	297	301	271	200	234	248	214	239
Dev. Center	0	0	0	6	16	25	34	33	57	75	108
Home	4,135	11,687	7,663	4,062	1,517	656	362	215	209	91	76
ICF	1	2	9	29	47	37	37	38	44	47	54
Indep. Living	0	0	0	10	100	134	95	108	118	111	78
Other	34	73	68	68	25	13	3	5	5	1	7
SNF	0	0	0	0	1	0	1	3	1	6	11

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Age at Three Points in Time

Figure 10 displays the number of people with autism by age group in 1987, 2003, and 2007. All age groups show significant growth over time, with some groups showing greater increases than others. From 1987 to 2003, the 5-9 age group showed the largest new growth, with an increase of 11,330 persons with autism. The second largest net growth occurred for the 10-14 age group, with an increase of 7,513 persons. The 15-19 age group increased by 4,019 persons, while the 0-4 age group increased by 2,568 persons.

Figure 10: Age Wave of Persons with Autism



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Net growth in the years between 2003 and 2007 parallels that in the years between 1987 and 2003, in that the largest increases in net growth are occurring in the 0-4, 5-9, 10-14, and 15-19 age groups. Between 2003 and 2007, the 5-9 age group showed a net increase of 3,699 children, while the 10-14 age group showed a net increase of 3,169 children, and the 15-19 age group showed a net increase of 2, 415 persons. Children 0-4 showed a net increase of 1,478.

By 2013, more than 4,000 teenagers with autism will become adults, bringing the total number of California adults receiving services for autism through DDS to more than 10,000. By 2015, the over-20 age group will double to more 13,000 people with autism. By 2018, the population of adults with autism will triple in magnitude, to over 19,000 people.

Increases in the Number of Individuals with ASD

Table 6 displays the number of individuals with ASD being served by DDS, divided into two categories: 1) autism (Autistic Disorder), and 2) ASD other than autism.

Table 6: Individuals with ASD June 2002 – June 2007

Date	Persons with Autism (Autistic Disorder)	Persons with ASD Other than Autistic Disorder	Persons with Autistic Spectrum Disorder	Total DDS Caseload **	Autism Spectrum Disorder Percentage of Total Caseload
Jun 02	18,460	1,894	20,354	154,189	13.20
Sep 02	19,649	1,989	21,638	161,947	13.36
Dec 02	20,377	2,036	22,413	163,792	13.68
Mar 03	21,209	2,104	23,313	165,535	14.08
Jun 03	22,040	2,167	24,207	167,583	14.44
Sep 03	22,826	2,242	25,068	169,257	14.81
Dec 03	23,502	2,309	25,811	170,900	15.10
Mar 04	24,297	2,370	26,667	172,358	15.47
Jun 04	25,020	2,400	27,420	173,709	15.79
Sep 04	25,769	2,451	28,220	174,903	16.13
Dec 04	26,576	2,512	29,088	176,465	16.48
Mar 05	27,312	2,603	29,915	177,749	16.83
Jun 05	28,046	2,673	30,719	178,993	17.16
Sep 05	28,724	2,764	31,488	180,017	17.49
Dec 05	29,424	2,841	32,265	181,191	17.81
Mar 06	30,181	2,951	33,132	182,395	18.16
Jun 06	31,012	3,032	34,044	183,761	18.53
Sep 06	31,853	3,126	34,979	184,873	18.92
Dec 06	32,809	3,240	36,049	186,443	19.34
Mar 07	33,695	3,339	37,034	188,013	19.70
Jun 07	34,656	3,428	38,084	189,684	20.08

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Between 2002 and 2007, the “ASD other than autism” group shows approximately the same increase as the “autism” group (171 versus 168 percent). Studies vary considerably in reporting of the proportion of persons with autism versus other disorders within the spectrum (Bertrand, 2001; Fombonne, 2003). The data in Table 6, above, show that in June of 2007, DDS was serving individuals with ASD at a ratio of 10.1 persons with autism (Autistic Disorder) to 1 person with ASD other than autism (Asperger’s Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Rett’s Disorder, and Childhood Disintegrative Disorder).

As can be seen in Table 7, the age distribution of those with “ASD other than autism” is similar to that of individuals with autism. Of those with autism, the median age was 10 years and 9 months, while the median age for individuals with ASD other than autism, was 14 years. The 5-9 age group contained the most individuals in both the “autism” and “ASD Other than autism” categories. In both groups, the vast majority of individuals are children, with smaller and smaller percentages of adults as age increases.

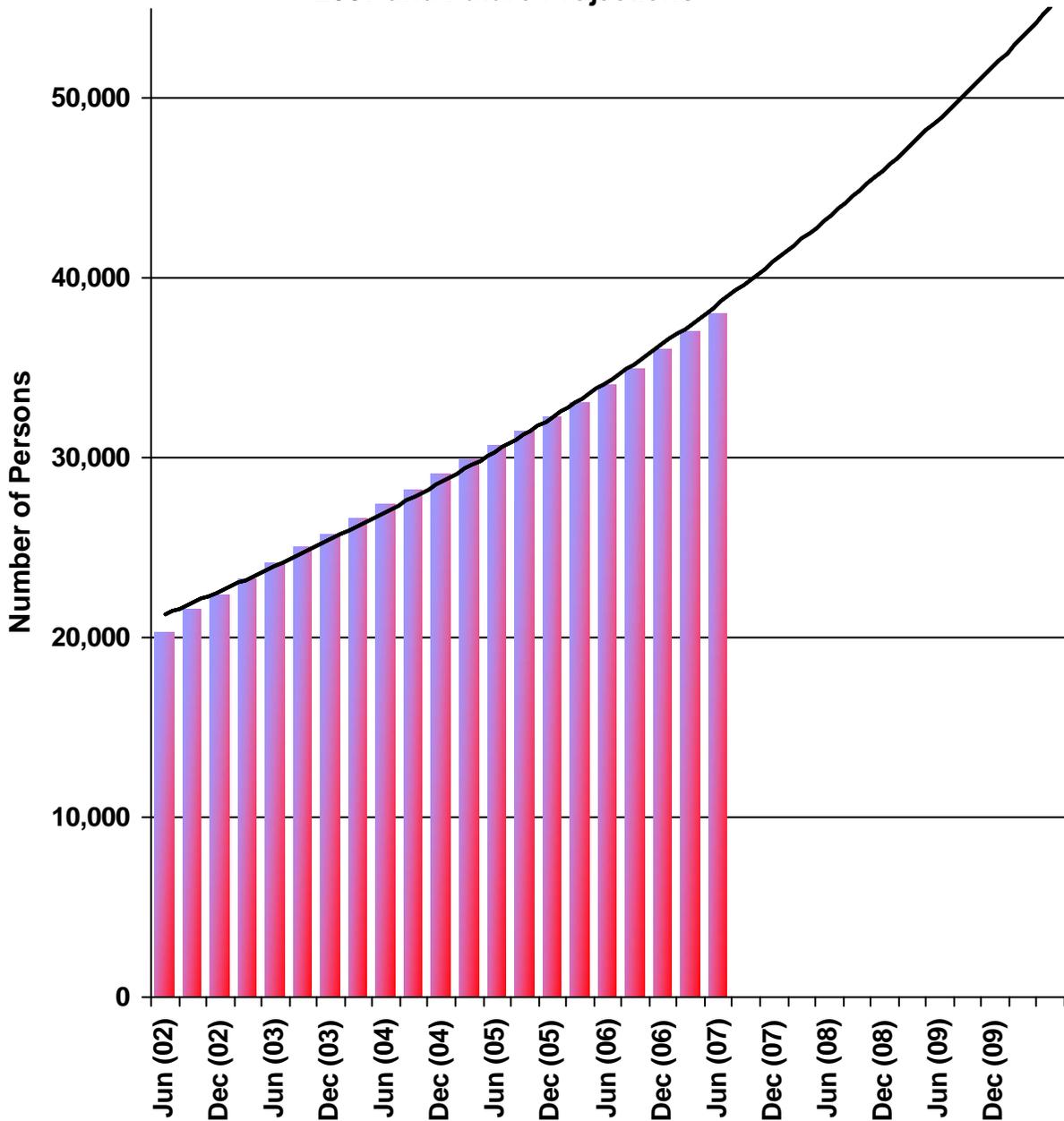
Table 7: Age Statistics and Age Group Percentages for Individuals with Autism and Other PDDs: June 2007

Age Group	Persons with Autism	Persons with ASD Other than Autism
0-4 years	12.0 %	7.7 %
5-9 years	34.0 %	25.5 %
10-14 years	22.8 %	20.7 %
15-19 years	12.9 %	16.6 %
20-24 years	5.8 %	9.9 %
25-29 years	3.3 %	6.5 %
30-34 years	2.1 %	3.2 %
35-39 years	1.8 %	2.4%
40-44 years	2.0 %	2.4%
45-49 years	1.6 %	1.8%
50 + years	1.7 %	3.2 %
Mean of All Ages	13.6	16.8
Median All Ages	10 years 9 months	14 years
Standard Deviation all Ages	11	12.4

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Figure 11 displays the frequency over time of all ASD combined, representing the broadest definition of people with these disorders in the DDS system. Growth averages about 12 percent annually. As of June 2007, there are 38,804 people with ASD served by DDS, representing more than 20 percent of the total DDS caseload. If this growth rate continues, California's 21 regional centers may be serving more than 50,000 people with ASD by September 2009.³ Longer-range projections indicate that there may be more than 60,000 people with ASD receiving services from DDS by March 2011 and 70,000 by June 2012.

Figure 11: Quarterly Frequencies of Persons with ASD: 2002-2007 and Future Projections



³ Projections are based on data June 2002 – June 2007 using an exponential trend line.

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Concluding Comments

This document represents 20 years of longitudinal data about people with ASD who are served by the state's DDS through care coordinated by 21 nonprofit regional centers. During this time in California, unprecedented growth occurred in the number of people with this neurodevelopmental disorder. Currently, nearly 39,000 people in California receive services from DDS for ASD. Many findings emerged during these two decades, including a decline in the average age of people with autism, a sizeable age wave of youth approaching adulthood, an increasing proportion of males who have ASD, and a diagnostic stability over time.

Other notable patterns are visible in the analysis of age, ethnicity, cognitive level, residence status, and geographic location. The majority of people with ASD are children aged 3 to 13, with a 5:1 preponderance of boys to girls.

People who self-identified as Whites (40%) and Hispanics (28%) represent the largest ethnic groups, a proportion that parallels the state's ethnic profile. Many of DDS served people identified with this disorder live in the Los Angeles with intriguing variances in caseload across regional centers.

Only 36 percent have been diagnosed with mental retardation, which represents a reduction of 44 percent in the diagnosis of co-morbid mental retardation over the last two decades. Cognitive level is correlated with residence, with more individuals with cognitive delay living in community care, ICFs, and developmental centers while persons with higher levels of cognitive functioning tend to reside at home or in independent or supported living. Cognitive status shows linkage to gender as well, with a smaller ratio of boys to girls assessed with a lower level of functioning.

The growth of ASD maintains a continuous and gradually accelerating course. In the 12 months from July 1, 2006 to June 30, 2007, growth occurred at approximately 12 percent. Autism continues to be the fastest growing developmental disability in California. As of January 1, 2008, autism constitutes more than 19 percent of DDS caseload, making it one of the most prevalent developmental disabilities served by the state. Projections estimate the total number of people with a disorder on the autism spectrum will surpass 50,000 by September 2009 and reach 70,000 in June 2012.

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