

Department of Developmental Services

Fact Book Seventh Edition



Prepared by DDS Information Services Division
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Department of Developmental Services
1600 Ninth Street, Room 220
Sacramento, CA 95814

Preface

The Fact Book presents pertinent data about the individuals served by the Department of Developmental Services (DDS), including an overview of services and trends in California. We hope you find this information useful in better understanding California's developmental services system and the persons served.

DDS is responsible for administering the Lanterman Developmental Disabilities Services Act and the Early Intervention Services Act. These laws ensure the coordination and provision of services and supports to enable persons with developmental disabilities to lead more independent, productive and integrated lives. In addition, these laws ensure the delivery of appropriate services to infants and toddlers at risk of having developmental disabilities and their families. DDS carries out its responsibilities through 21 community-based, non-profit corporations known as "regional centers" (RC) and State-operated facilities, including five State developmental centers (SDC) and two smaller facilities. For purposes of this publication, the two smaller facilities will be included in numbers reported for SDCs.

A "developmental disability" is a condition that originates before an individual reaches age 18; continues, or can be expected to continue indefinitely; and constitutes a substantial impairment in three or more areas of major life activity.¹ Developmental disabilities include mental retardation, epilepsy, cerebral palsy, autism, and disabling conditions closely related to mental retardation or requiring treatment similar to that required by people with mental retardation. The service delivery system, which offers personalized supports, includes individuals with developmental disabilities, their families and/or legal representatives, advocacy and professional organizations, the State Council on Developmental Disabilities, direct service providers, SDCs, RCs, and DDS.

The following pages offer a look at the demographics and characteristics of persons served by DDS. The Fact Book and other information is available on the DDS home page at www.dds.ca.gov. Questions may be directed to the DDS Data Request Line at (916) 651-7435. Information in this publication was derived from data reported electronically to DDS Headquarters and compiled by the Data Extraction Unit.

¹Areas of major life activity include self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Substantial impairment reflects the person's need for a combination of special, interdisciplinary, or generic support services.

Cover Art: The mural "Life Along the Sacramento" was commissioned by the Department of Rehabilitation for the California Environmental Protection Agency (Cal/EPA). The ceramics tile work of art was designed and created by adults with developmental disabilities at Southside Art Center (SSAC) in Sacramento, California. SSAC is a nonprofit organization serving individuals with developmental disabilities through art, personal development and community integration programs. Cover art used by permission of Cal/EPA.

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Whom DDS Serves

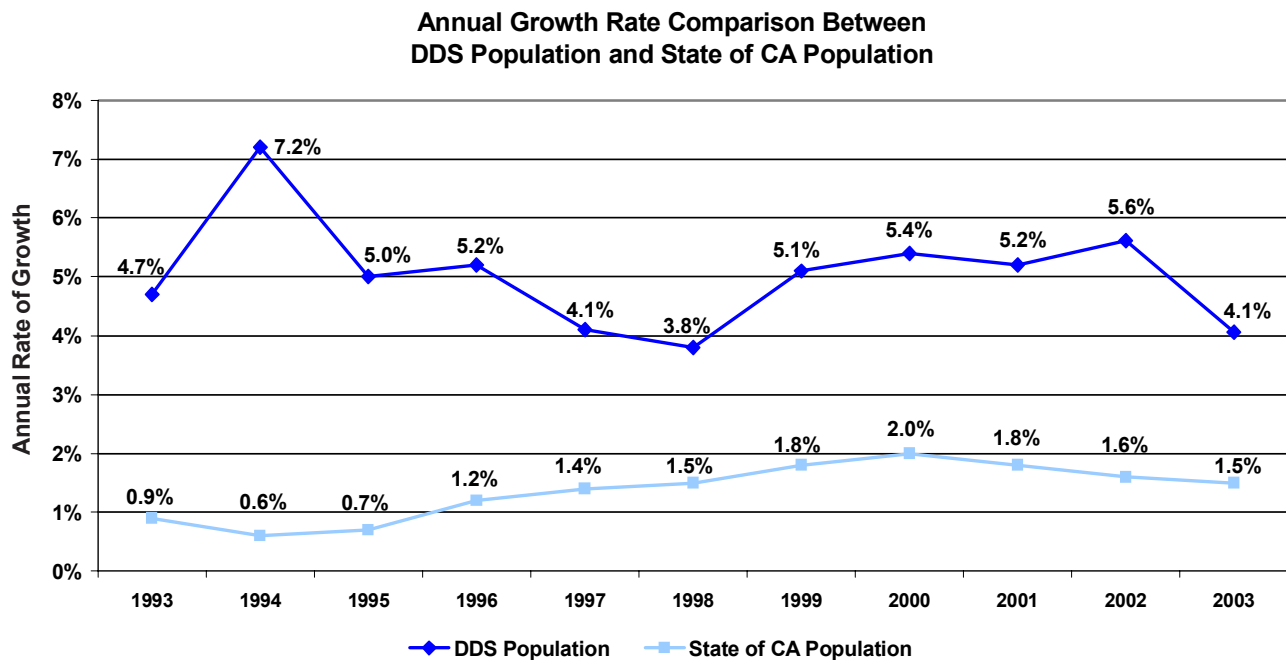


"Celebrating California" - A collaborative ceramics tile piece designed and created by adults with developmental disabilities at Southside Art Center in Sacramento, CA. This art work is on display at LaBou at 1100 O Street in Sacramento. Copy of art used by permission of LaBou Bakery and Cafe.

Caseload

The number of persons served by DDS increased 71.1 percent from January 1993 through December 2003. According to Department of Finance estimates, California's general population grew 16.0 percent between January 1993 and January 2004. About 0.54 percent of California's population was being served by DDS in January 2004.

While the total DDS population (i.e., persons with status codes 1, 2 and 8 on the Client Master File (CMF))² and the general population in California both increased in numbers each year during the period displayed below, the annual rate of growth differed significantly in these two populations.



From January 1993 through December 2003, the number of individuals served by DDS in the community (i.e., persons with status codes 1 and 2) increased 78.3 percent. During this same period, the State developmental center (SDC) population (i.e., persons with status code 8) decreased 46.7 percent.

²The source of the data depicted in the Caseload charts is the [Client Master File \(CMF\)](#). Information on a person is initially entered into the CMF at the time of application for RC services. The CMF is the primary source for demographic, case status and service coordinator information. The definitions of active status codes are as follows:

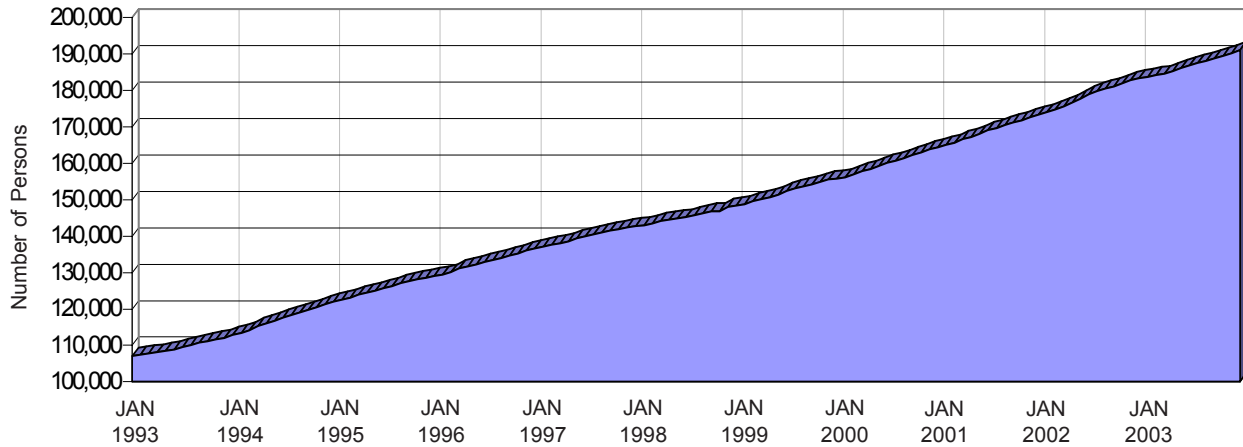
Status Code 1: Children birth to age three who are at risk of having a developmental disability or who have a developmental delay but have not been diagnosed as having a developmental disability. Persons with a status code 1 qualify for early intervention and prevention services.

Status Code 2: Persons diagnosed as having a developmental disability and being served in the community (not in an SDC).

Status Code 8: Persons diagnosed as having a developmental disability and being served in an SDC.

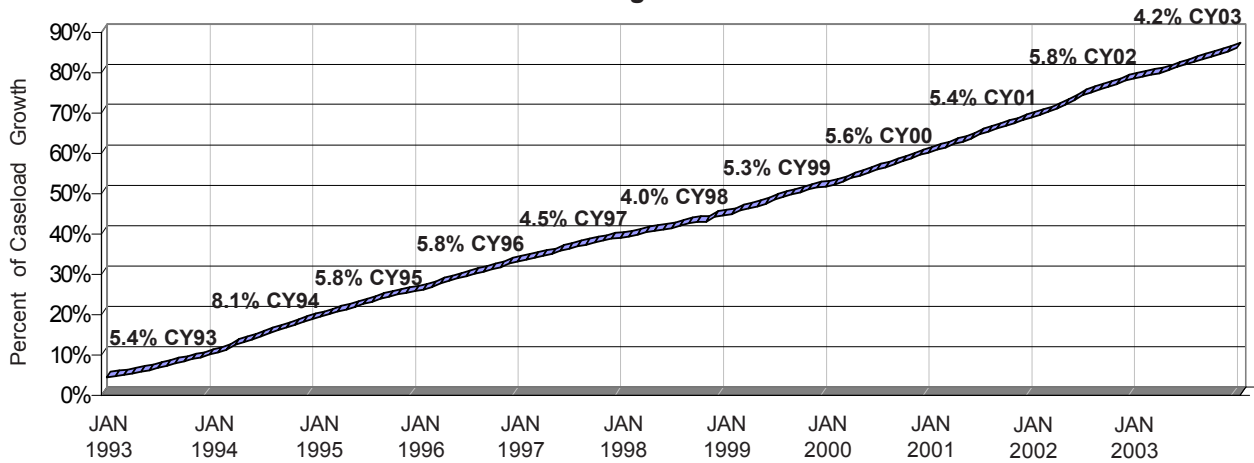
Community Caseload

Caseload Growth*
1/93 through 12/03



*Persons with status codes 1 and 2.

Cumulative Percent of Caseload Growth*
with Annual Percent Changes Noted
1/93 through 12/03

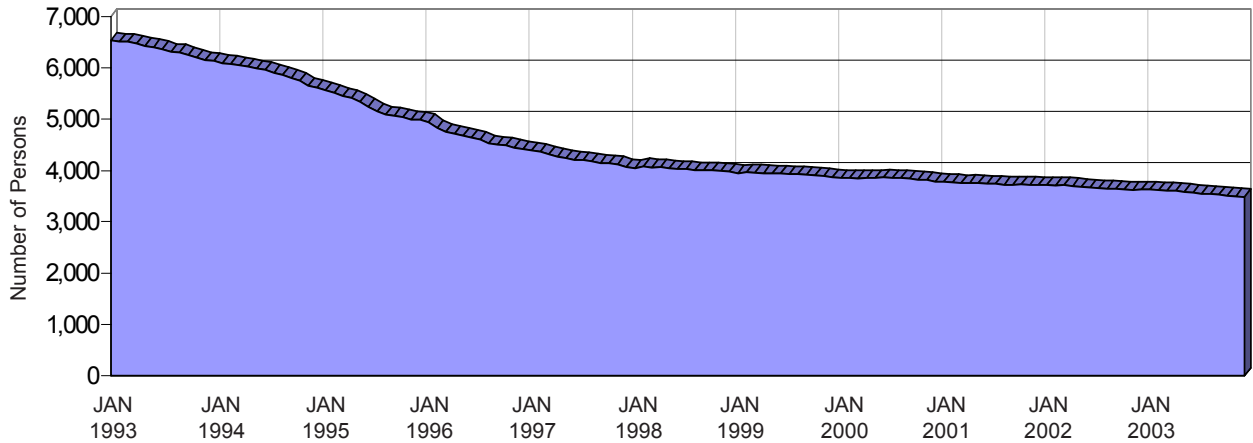


*Persons with status codes 1 and 2.

Note: In graph above, CY means Calendar Year.

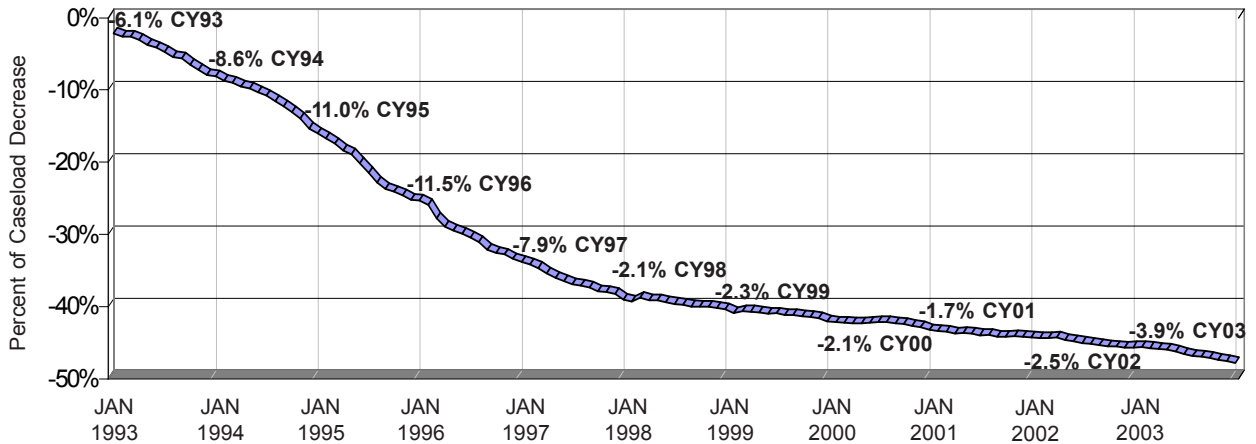
State Developmental Center Residents

Decline in Number of Residents*
1/93 through 12/03



*Persons with status code 8.

Cumulative Percent in SDC Residence*
with Annual Percent Changes Noted
1/93 through 12/03



*Persons with status code 8.

Note: In graph above, CY means Calendar Year.

Demographics of Persons Served by DDS

In the pages that follow, demographic information is provided on gender, age, residence types and ethnicity of persons with status codes 1, 2, and 8 as of December 2003. To obtain a more complete picture of the demographic changes in the population served by DDS since December 1993, please refer to prior editions of the Fact Book (available at www.dds.ca.gov/factsstats/factbook.cfm).

The trend in the gender distribution of persons served by DDS continued in 2003 with males increasing in numbers relative to females. In December 1993, 56.4 percent of persons served were male versus 43.6 percent female. In December 2003, the gap widened to 59.8 percent male versus 40.2 percent female.

Age distribution trends for persons served by DDS also continued. With 56.6 percent of the population under 22 years of age in December 2003 as compared to 49.4 percent in this age group in December 1993, the DDS population is becoming increasingly younger.

Changes in the residence types of the population are also worth noting. While 62.6 percent of persons resided in the home of a parent or guardian in December 1993, 71 percent had this residence type in December 2003. During this same period, decreases continued in the proportion of persons living in community care settings (19.9 to 13.6 percent³) and developmental centers (5.1 to 1.8 percent).

The predominant trend in the ethnic makeup of the population continued in 2003. Hispanics are the fastest growing segment of the DDS population increasing from 23.9 percent in December 1993 to 31.1 percent in December 2003. Over this same period, the white segment of the population decreased from 51.5 percent to 43.1 percent.

Definitions of Residence Types

Own Home-Parent: Home of a family member or guardian.

Community Care: Settings such as a Community Care Facilities (CCF), Foster Homes for Children, and FHA Family Homes for Adults.

ILS/SLS: Independent Living Setting (ILS) or Supported Living Setting (SLS).

SNF/ICF: Skilled Nursing Facility (SNF) or Intermediate Care Facility (ICF). ICF includes ICF/Developmentally Disabled (ICF/DD), ICF/Developmentally Disabled-Habilitation (ICF/DD-H), and ICF/Developmentally Disabled-Nursing (ICF/DD-N).

Developmental Center: State developmental center (SDC) operated by DDS.

Other: Settings such as hospitals, community treatment facilities, rehabilitation centers, psychiatric treatment centers, correctional institutions, and other settings in the community.

³The "Other" residence type category is newly added to this Fact Book. Prior Fact Book editions grouped persons currently counted in the "Other" residence type category in the "Community Care" category. Under the prior grouping, the percentage change in the number of persons residing in "Community Care" from December 1993 to December 2003 would have been 19.9 to 14.2 percent.

Demographics of Persons Served by DDS

Persons with Status Codes 1, 2 and 8

Based on Client Master File as of December 2003

Gender	Number of Persons	Percentage of Total
Female	78,170	40.2%
Male	116,284	59.8%
Total	194,454	100.0%

Age	Number of Persons	Percentage of Total
Birth - 2 Yrs.	21,424	11.0%
3 - 13 Yrs.	56,681	29.1%
14 - 21 Yrs.	32,024	16.5%
22 - 31 Yrs.	27,144	14.0%
32 - 41 Yrs.	23,079	11.9%
42 - 51 Yrs.	19,648	10.1%
52 - 61 Yrs.	9,899	5.1%
62 Yrs. & Older	4,555	2.3%
Total	194,454	100.0%

Residence Type	Number of Persons	Percentage of Total
Own Home-Parent	138,141	71.0%
Community Care	26,376	13.6%
ILS/SLS	16,583	8.5%
SNF/ICF	8,728	4.5%
Developmental Center	3,467	1.8%
Other	1,159	0.6%
Total	194,454	100.0%

ILS/SLS: Independent Living Settings/Supported Living Settings.

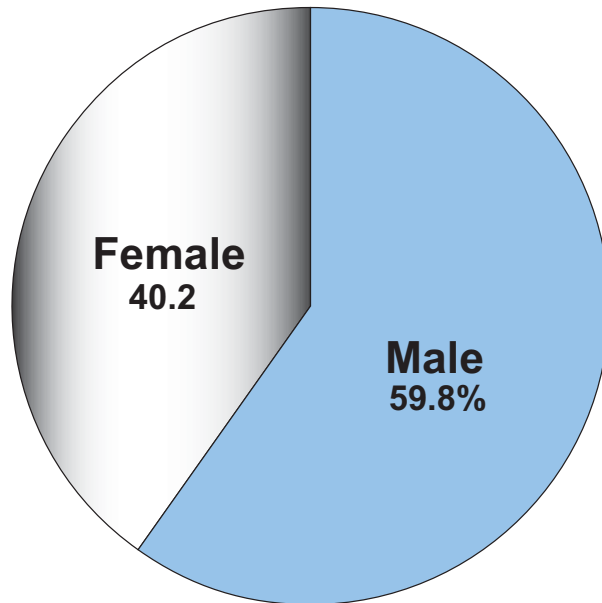
SNF/ICF: Skilled Nursing Facility/Intermediate Care Facility.

ICF includes ICF/DD, DD-H, and DD-N.

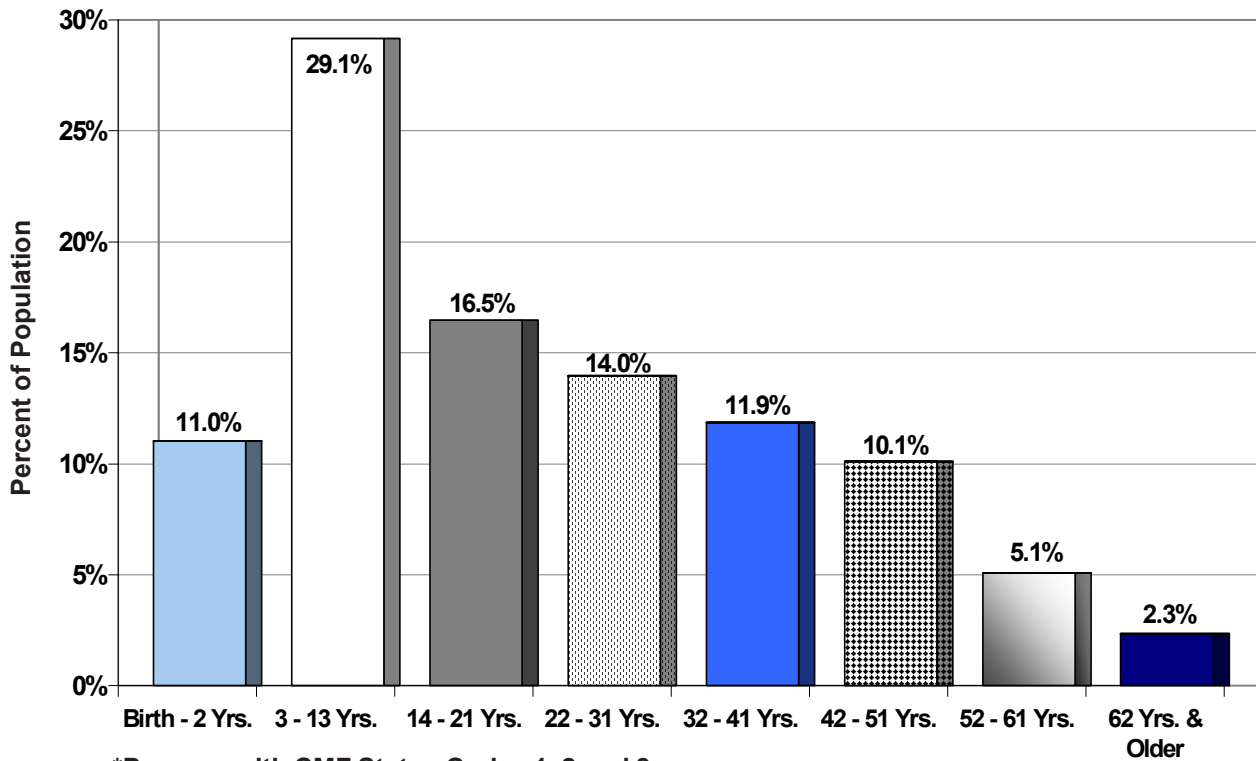
Ethnicity	Number of Persons	Percentage of Total
White	83,867	43.1%
Hispanic	60,471	31.1%
Black	20,150	10.4%
Asian	10,284	5.3%
Filipino	3,728	1.9%
Native American	779	0.4%
Pacific Islander	423	0.2%
Other	14,752	7.6%
Total	194,454	100.0%

Note: The source of the data depicted in the "Demographics of Persons Served by DDS" tables and charts is the Client Master File (CMF). Please refer to page 1 for the definitions of the CMF and status codes.

Gender of Individuals Served by DDS*

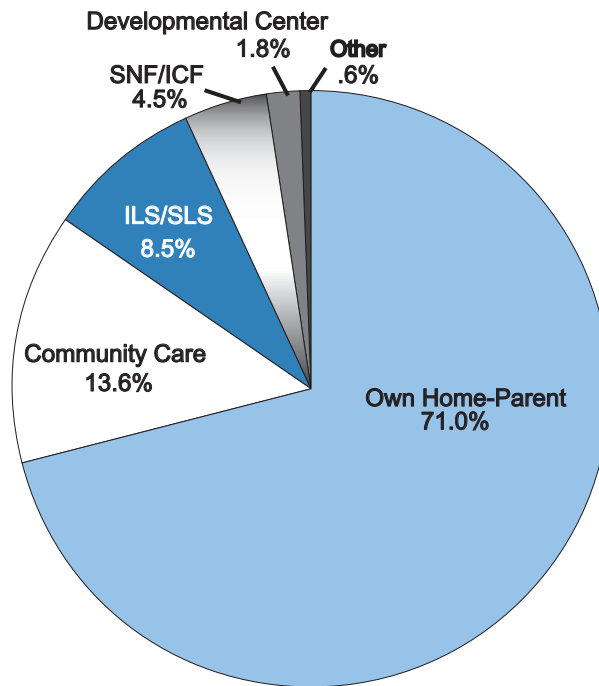


Age of Individuals Served by DDS*

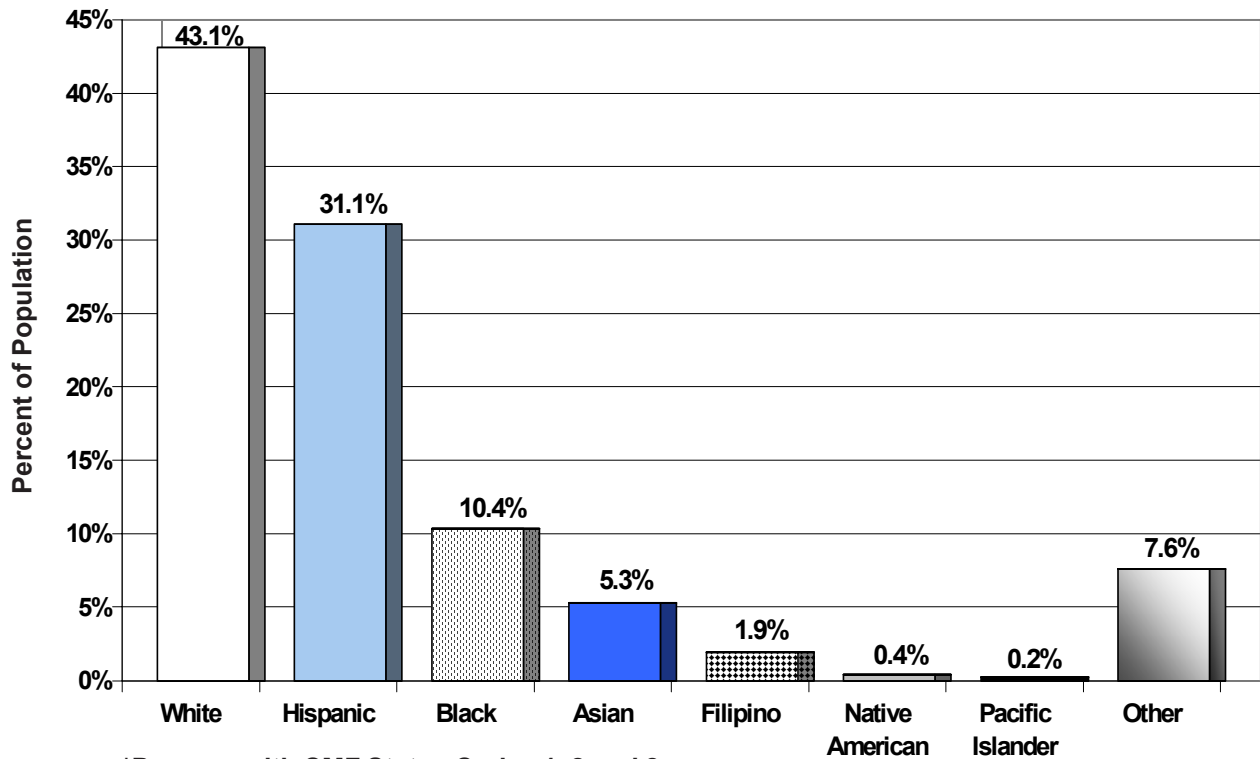


*Persons with CMF Status Codes 1, 2 and 8

Residence of Individuals Served by DDS*



Ethnicity of Individuals Served by DDS*



*Persons with CMF Status Codes 1, 2 and 8

Residence Types of Persons with Developmental Disabilities by Age Group in December 1998 and December 2003

During the period from December 1998 through December 2003, the percentage of persons served by DDS in both the “Birth through 17” and “18 and Older” age groups increased for those residing in the home of a parent, guardian or conservator (labeled “Own Home-Parent” in the tables below) and decreased for those residing in community care settings and developmental centers. These changes are consistent with the high priority the Lanterman Act places on providing opportunities for children with developmental disabilities to live with families and for people of all ages to live in home-like environments.

The percentage of persons 18 years of age and older residing in independent and supported living settings also increased between December 1998 and December 2003. This change also follows the Lanterman Act’s direction to provide “opportunities for individuals with developmental disabilities to be integrated into the mainstream of life in their home communities, including supported living and other appropriate community living arrangements.”

Individuals Ages Birth through 17				
Residence Type	as of Dec. 1998		as of Dec. 2003	
	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
Own Home-Parent	62,785	90.4%	88,788	93.6%
Community Care	5,457	7.9%	5,027	5.3%
SNF/ICF	744	1.1%	599	0.6%
Developmental Center	138	0.2%	68	0.1%
ILS/SLS	22	0.0%	3	0.0%
Other	277	0.4%	368	0.4%
Total	69,423	100.0%	94,853	100.0%

Individuals Ages 18 and Older				
Residence Type	as of Dec. 1998		as of Dec. 2003	
	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
Own Home-Parent	38,209	46.4%	49,353	49.6%
Community Care	19,610	23.8%	21,349	21.4%
ILS/SLS	12,985	15.8%	16,580	16.6%
SNF/ICF	7,407	9.0%	8,129	8.2%
Developmental Center	3,811	4.6%	3,399	3.4%
Other	328	0.4%	791	0.8%
Total	82,350	100.0%	99,601	100.0%

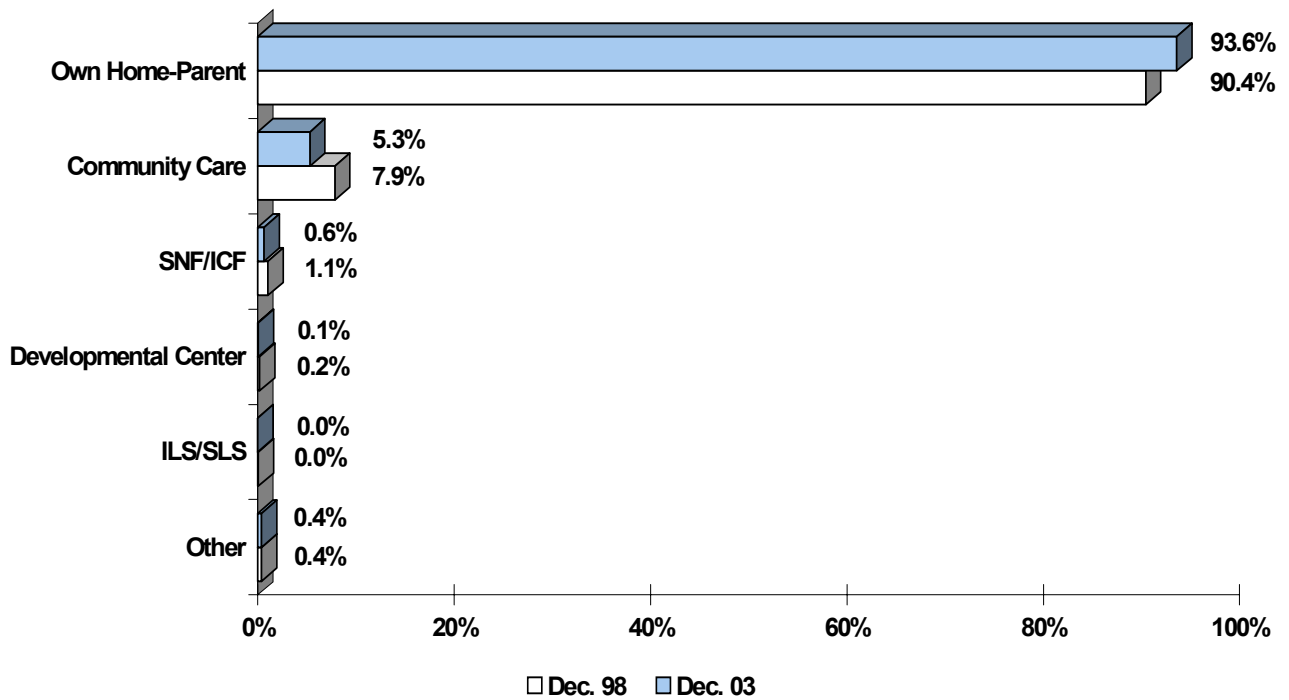
Note: The tables above include only persons with status codes 1, 2 and 8.

ILS/SLS: Independent Living Settings/Supported Living Settings.

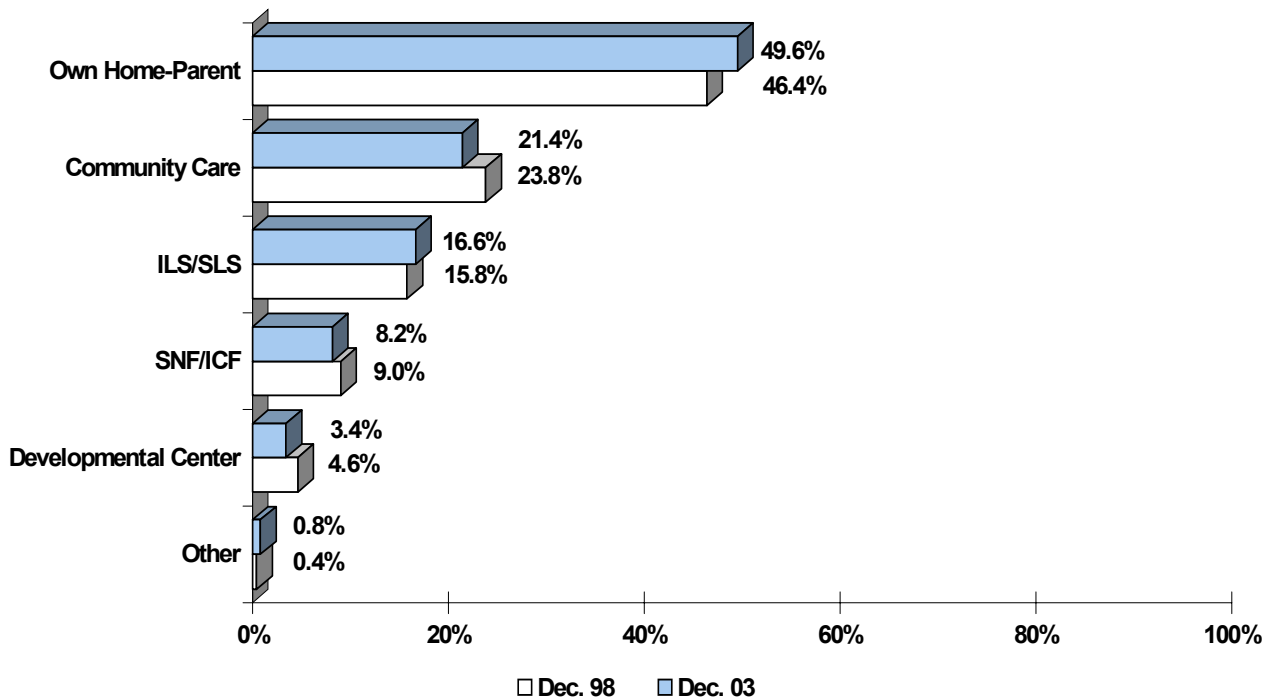
SNF/ICF: Skilled Nursing Facility/Intermediate Care Facility.

ICF includes ICF/DD, DD-H and DD-N.

Individuals Ages Birth Through 17*



Individuals Ages 18 and Older*



*Persons with CMF Status Codes 1, 2 and 8

Age of Persons at Time of Intake Into Developmental Services System and Demographics of Persons Engaged in the Intake and Assessment Process

The age of individuals at the time of intake (based on the first CMF date) was analyzed for persons who entered the developmental services system during the ten-year period of January 1994 through December 2003. The following patterns were found:

- 56 percent of persons entering the developmental services system were under three years of age. 66 percent were five years of age or younger.
- Entries into the developmental services system declined during the typical school ages but increased as individuals “aged out” of the school system at around age 18.
- Another peak in the number of persons entering the developmental services system was found as individuals reached their mid 30s. A possible explanation for this increase is that parents, guardians or conservators may be less able to continue providing the same level of support as they and their adult children grow older.

Information relating to the gender and age of persons engaged in the intake and assessment process in December 2003 is provided on the next page.⁴ Comparisons across the years may indicate changes are occurring in the gender and age distribution of persons involved in the intake and assessment process. However, because the numbers for each year are based on only one point in time, a more complete study would be required to draw conclusions.

In December 1993, the percent of males to females engaged in intake was far closer (59% male to 41% female) than the percent found in December 2003 (65.2% male to 34.8% female). In age distribution, the largest differences for persons engaged in intake in December 1993 compared to December 2003 was in the age ranges of 3 through 13 years and 22 through 41 years. Persons ages 3 through 13 years represented 30.9 percent of the intake population in December 1993 versus 38.8 percent in December 2003. Individuals in the 22 through 41 age range composed 10.5 percent of the intake population in December 1993 compared to 5.5 percent in December 2003.

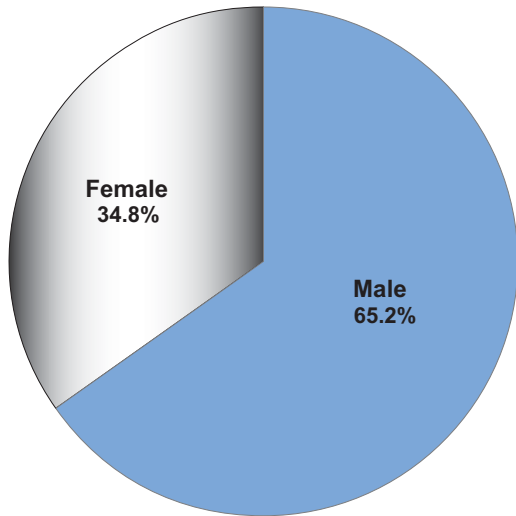
Of the 6,547 persons who received intake and assessment services in December 2003, 51.6 percent were determined eligible to receive services and given a “high risk infant” status (code 1) or an active status (codes 2 or 8) on the CMF as of July 2, 2004.

⁴Prior editions of the Fact Book offer similar information for other years.

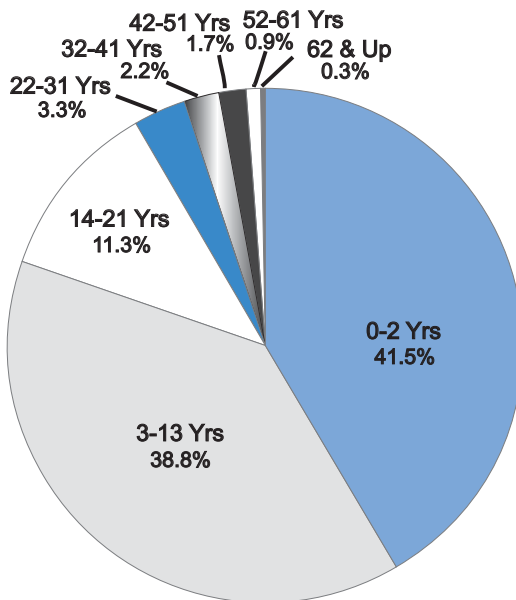
Demographics of Persons Engaged in the Intake and Assessment Process

Persons with Status Code 0

Based on Client Master File as of December 2003



Gender	Number of Percentage	
	Persons	of Total
Male	4,269	65.2%
Female	2,278	34.8%
Total	6,547	100.0%



Age	Number of Percentage	
	Persons	of Total
Birth to 2 Yrs	2,715	41.5%
03 to 13 Yrs	2,540	38.8%
14 to 21 Yrs	743	11.3%
22 to 31 Yrs	217	3.3%
32 to 41 Yrs	144	2.2%
42 to 51 Yrs	110	1.7%
52 to 61 Yrs	57	0.9%
62 and Older	21	0.3%
Total	6,547	100.0%

Note: The source of the data depicted in the "Demographics of Persons Engaged in the Intake and Assessment Process" tables and charts is the CMF. Please refer to definition on page 1.

Characteristics of Persons with CDERs⁵ on File as of December 2003

DDS collects data on the characteristics of the persons it serves. In the tables and charts that follow, information on four of the major types of developmental disabilities of persons served by DDS are presented for December 2003. Similar data have been reported for other years in prior editions of the Fact Book.

The composition of the population by type of developmental disability shows some significant shifts from December 1993 to December 2003. For example, only 11.6 percent of the population served had “No Mental Retardation” recorded on their CDERs in December 1993. But by December 2003, the percent with “No Mental Retardation” had grown to 21.1 percent. During this same time period, the percentage of persons reported to have “Moderate”, “Severe” or “Profound Retardation” continued to decline from a collective 45.4 percent to 33.5 percent. The percent of the population with epilepsy and the percent with cerebral palsy also declined over this period from 26 to 21.4 percent for epilepsy and from 24.4 to 19.8 percent for cerebral palsy. The only developmental disability type that showed an overall increase as a percentage of the population was autism, which grew from 4.8 percent in December 1993 to 13.8 percent in December 2003.⁶

The accumulated growth rates spanning December 1994 through December 2003 for the four major types of developmental disabilities are compared on page 16. In addition, the graph on page 17 displays information on the combinations of developmental disabilities that persons served by DDS have.

⁵Only persons with a Client Development Evaluation Report (CDER) on file are included in the “Characteristics of Persons” article, tables and graphs. The CDER file contains diagnostic and evaluation data including developmental, cognitive, behavioral and medical information that is recorded when a person is given a client development evaluation. All persons diagnosed with a developmental disability who have active status in the DDS system should have a CDER on file. For children under three years of age, a different, age-appropriate assessment tool called the Early Start Report is used instead of the CDER.

⁶For detailed analyses regarding persons with autism who are served by DDS, please refer to the 2003 DDS Autism Report available on-line at www.dds.ca.gov/autism.

Mental Retardation		
Level of Mental Retardation	Number of Persons	% of Total
Not MR	36,022	21.1%
Mild	67,146	39.3%
Moderate	30,818	18.0%
Severe	14,977	8.8%
Profound	11,523	6.7%
Unknown	10,414	6.1%
Total	170,900	100.0%

Mental Retardation is characterized by significant limitations both in intellectual functioning (i.e., an IQ of approximately 70 or below) and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. Levels of retardation are reported here as mild, moderate, severe, profound, not MR (i.e., mental retardation is not present), or unknown.

Epilepsy		
Has Epilepsy	Number of Persons	% of Total
No	134,309	78.6%
Yes	36,591	21.4%
Total	170,900	100.0%

Epilepsy is defined as recurrent, unprovoked seizures. Seizures can cause loss of muscle control, tremors, loss of consciousness and other symptoms. A modification of “International Classification of Epileptic Seizures” is employed for describing seizures.

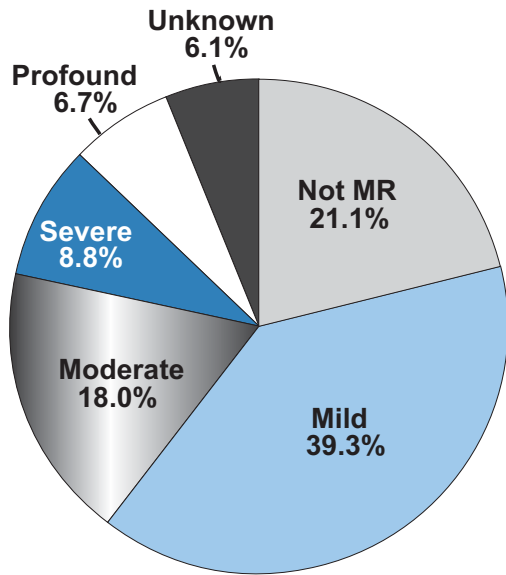
Cerebral Palsy		
Has CP	Number of Persons	% of Total
No	137,087	80.2%
Yes	33,813	19.8%
Total	170,900	100.0%

Cerebral Palsy includes two types of motor dysfunction: (1) nonprogressive lesion or disorder in the brain occurring during intrauterine life or the perinatal period and characterized by paralysis, spasticity, or abnormal control of movement or posture which is manifest prior to two or three years of age, and (2) other significant motor dysfunction appearing prior to age 18.

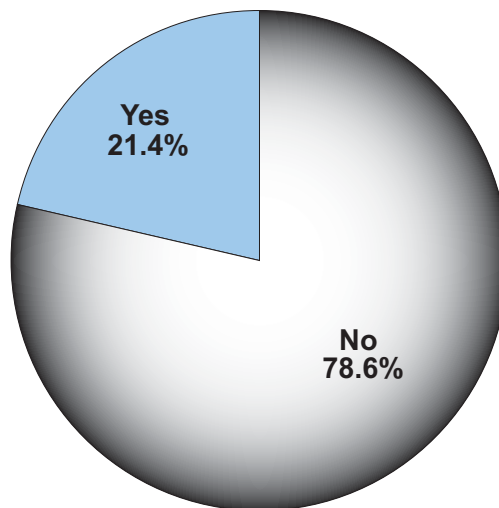
Autism		
Has Autism	Number of Persons	% of Total
No	147,398	86.2%
Yes	23,502	13.8%
Total	170,900	100.0%

Autism is a neurodevelopmental disorder with multiple etiologies defined as a syndrome causing gross and sustained impairment in social interaction and communication with restricted and stereotyped patterns of behavior, interests, and activities that appear prior to the age of three. This item includes only those individuals diagnosed with Autistic Disorder as classified in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).

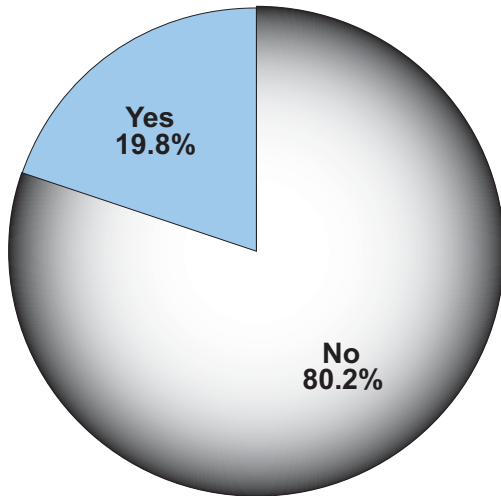
Level of Mental Retardation



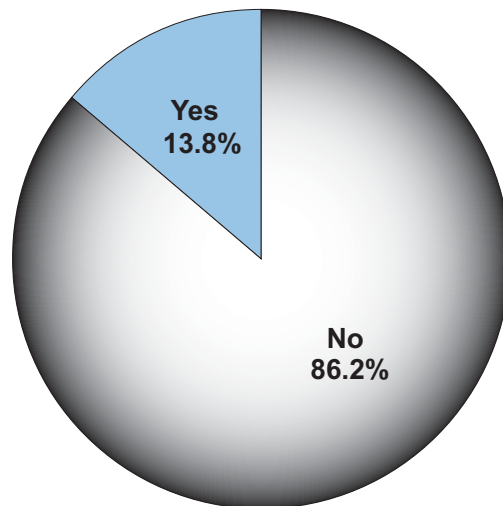
Epilepsy or Seizure Disorder



Cerebral Palsy or Similar
Motor Dysfunctions

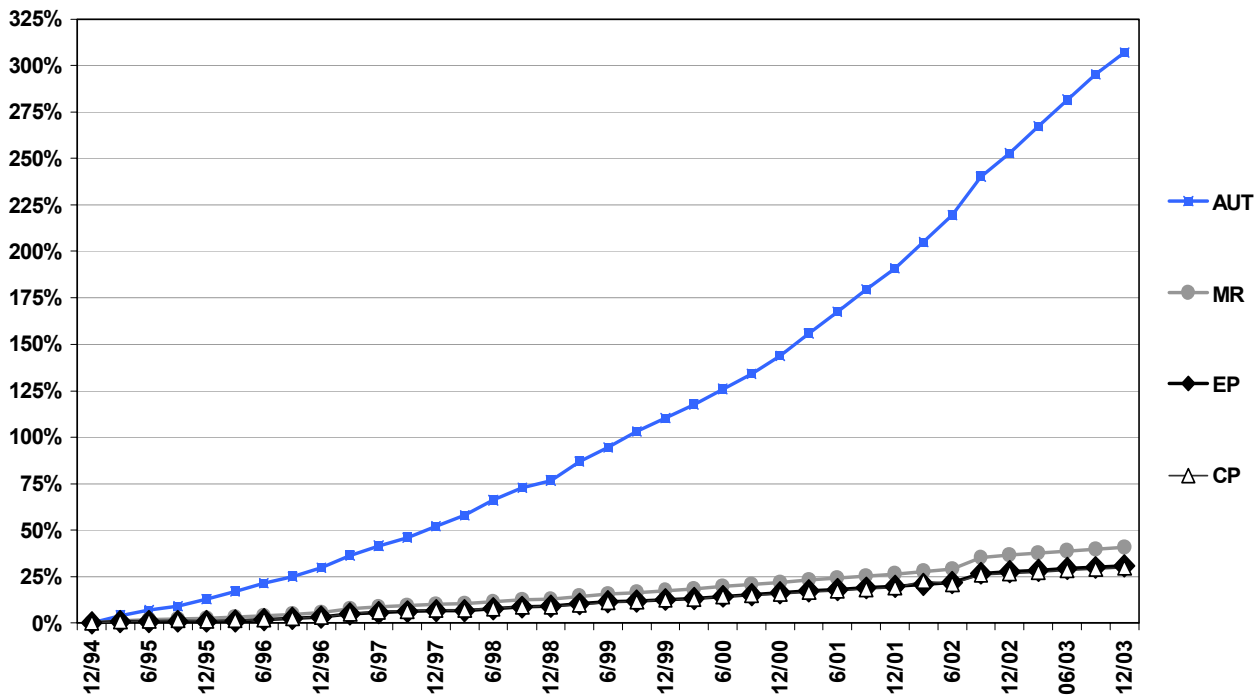


Autism



Trends of Four Major Developmental Disabilities Compared Population Growth from December 1994 through December 2003 Based on CDERs at Quarterly Intervals

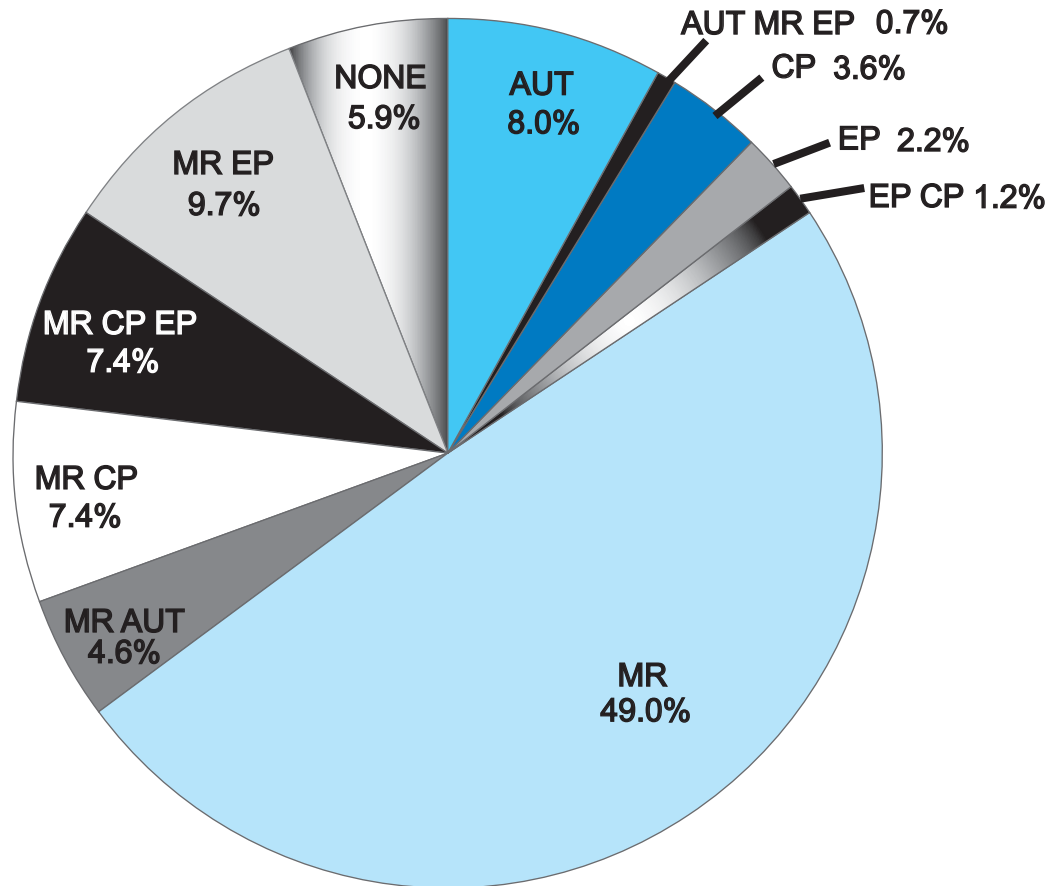
An examination of growth in the population served by DDS (defined here as persons who have a CDER on file) for each of the four primary types of developmental disabilities over a nine-year period, from December 1994 through December 2003, reveals a significant rate of growth for those with autism compared to the other three types of developmental disabilities. While the total number of persons with current CDERs increased 56 percent (109,359 to 170,900), the number of persons with autism recorded on their CDERs grew 307 percent (5,775 to 23,502) from December 1994 through December 2003. During this same period, the other types of developmental disabilities showed the following growth: 1) mental retardation, 41 percent (95,773 to 134,878 persons); 2) epilepsy, 31 percent (27,972 to 36,591 persons); and 3) cerebral palsy, 30 percent (26,087 to 33,813 persons). As shown on the next page, individuals may have more than one type of developmental disability.



MR = Mental Retardation; AUT = Autism; EP = Epilepsy/Seizure Disorder; CP = Cerebral Palsy

Note: Population numbers for each type of developmental disability identified above should not be added together, because there is duplication of persons across categories.

Information on Developmental Disability Combinations
Based on December 2003 CDER



Note: The four major types of developmental disabilities have been abbreviated in the chart above as follows--Autism (AUT), Cerebral Palsy (CP), Epilepsy/Seizure Disorder (EP), and Mental Retardation (MR). The chart segment labeled "None" represents the fifth category of developmental disability defined as a disabling condition closely related to mental retardation that requires similar treatment. Five developmental disability combinations were omitted from the chart above because the percent of people who fell in these categories was so small. The combinations and percents are as follows--AUT/EP=0.2%, AUT/MR/CP=0.1%, AUT/CP=0.0%, AUT/EP/CP=0.0% and AUT/MR/EP/CP=0.1%.

What People Receive



“Deserving the Best” - James Ervin, Artist*

*The poster entitled “Deserving the Best” by artist James Ervin won second place in the California State Council on Developmental Disabilities’ (SCDD) 2003 Poster Art Contest. James Ervin grew up in Los Angeles and Sacramento in a family of artists. Although James cannot read or write, he has become an accomplished artist, producing a wide range of art works from abstracts to Native American paintings. He relates, “Art became my communication. My paintings tell my story. Art became my life and life became my art. Art is my key to freedom, success, peace and harmony, it is my strength.”

Mr. Ervin’s art legacy continues at Porterville Developmental Center (PDC), his former place of residence, in the art murals painted by James on buildings at PDC and in the artistic accomplishments of the people James mentored at PDC. James currently resides in the Sacramento area and continues his art training at American River College. He also works on art projects at New Visions Gallery and volunteers his time and talents teaching art to children and others through his “Healing World of Arts” program. The artist requests that persons interested in obtaining additional information regarding his art works or program contact DDS.

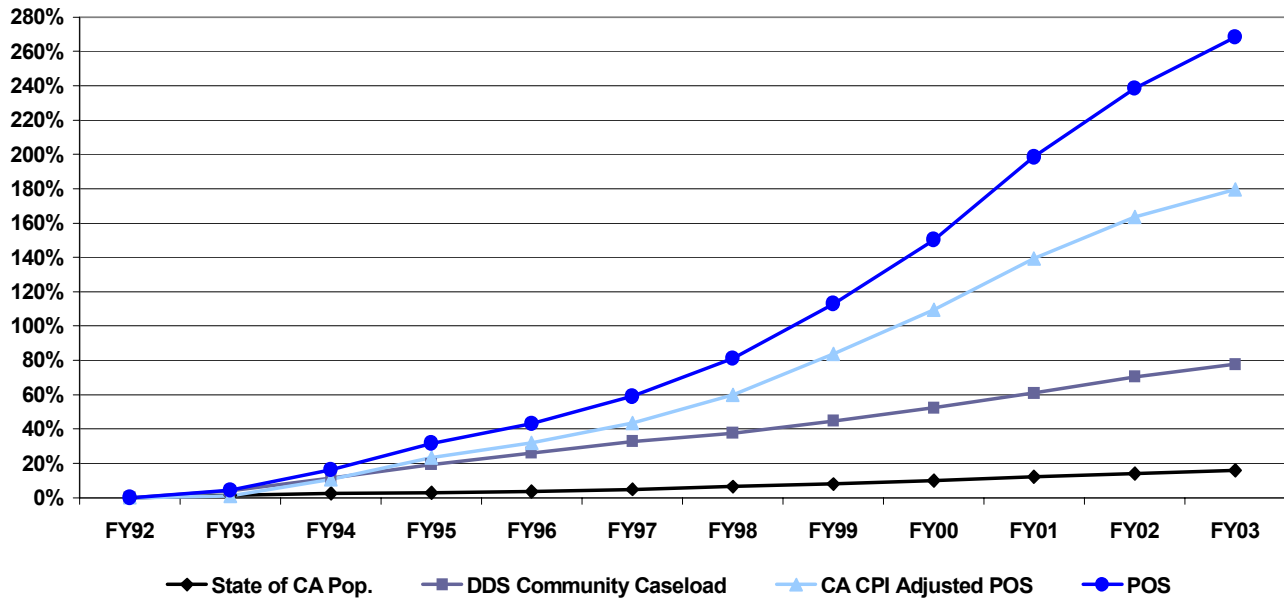
Permission to use the artist’s biographical information was given by James Ervin, and permission to use the copy of his art work was given by James Ervin and SCDD. SCDD promotes and celebrates the inclusion of individuals with disabilities in all aspects of daily life — at work, in school, and throughout the community.

For more information on SCDD, you can visit their Web site at www.scdd.ca.gov.

POS Growth Compared to DDS Caseload and State of California Population Growth - Fiscal Years (FY) 1991/92 through 2002/03

The cumulative rate of growth for Purchase of Service (POS) expenditures over the period of FY 1991/92 through FY 2002/03 totaled 268 percent. The cumulative growth rate of POS dollars adjusted by the California Consumer Price Index⁷ totaled roughly 180 percent. By comparison, the DDS community caseload (persons with status codes 1 and 2 on the CMF in June of each FY) grew 78 percent over this period. The State of California population from January 1992 through January 2003 grew 16 percent (based on Dept. of Finance estimates).

Comparison of Cumulative Growth in POS, CA CPI Adjusted POS, DDS Community Caseload, and State of California Population
Fiscal Years 1991/92 Through 2002/03



Fiscal Year	State of CA Pop (DOF Jan. Estimates)		DDS Caseload (CMF Status 1 & 2)		CA CPI Adjusted POS		POS Expenditures	
	Number of Persons	Cumulative Growth	Number of Persons	Cumulative Growth	Dollars	Cumulative Growth	Dollars	Cumulative Growth
1991/92	30,723,000	0	105,076	0	\$344,686,170	0	\$493,590,596	0
1992/93	31,150,000	1.39%	109,117	3.85%	\$348,381,687	1.07%	\$514,908,133	4.32%
1993/94	31,418,000	2.26%	117,149	11.49%	\$381,335,704	10.63%	\$573,528,899	16.20%
1994/95	31,617,000	2.91%	125,312	19.26%	\$424,824,925	23.25%	\$649,982,136	31.68%
1995/96	31,837,000	3.63%	132,411	26.01%	\$455,156,656	32.05%	\$706,403,130	43.12%
1996/97	32,207,000	4.83%	139,321	32.59%	\$494,120,749	43.35%	\$784,663,750	58.97%
1997/98	32,657,000	6.29%	144,619	37.63%	\$551,546,585	60.01%	\$893,505,467	81.02%
1998/99	33,140,000	7.87%	151,926	44.59%	\$633,328,227	83.74%	\$1,051,324,857	113.00%
1999/00	33,753,000	9.86%	160,091	52.36%	\$721,704,353	109.38%	\$1,235,557,853	150.32%
2000/01	34,431,000	12.07%	169,022	60.86%	\$824,783,704	139.29%	\$1,473,063,696	198.44%
2001/02	35,049,000	14.08%	179,028	70.38%	\$908,363,836	163.53%	\$1,670,481,094	238.43%
2002/03	35,612,000	15.91%	186,763	77.74%	\$963,424,747	179.51%	\$1,817,982,498	268.32%

⁷The source of the California CPI index is the California Department of Finance (DOF). DOF calculates the index using a formula developed by the California Department of Industrial Relations.

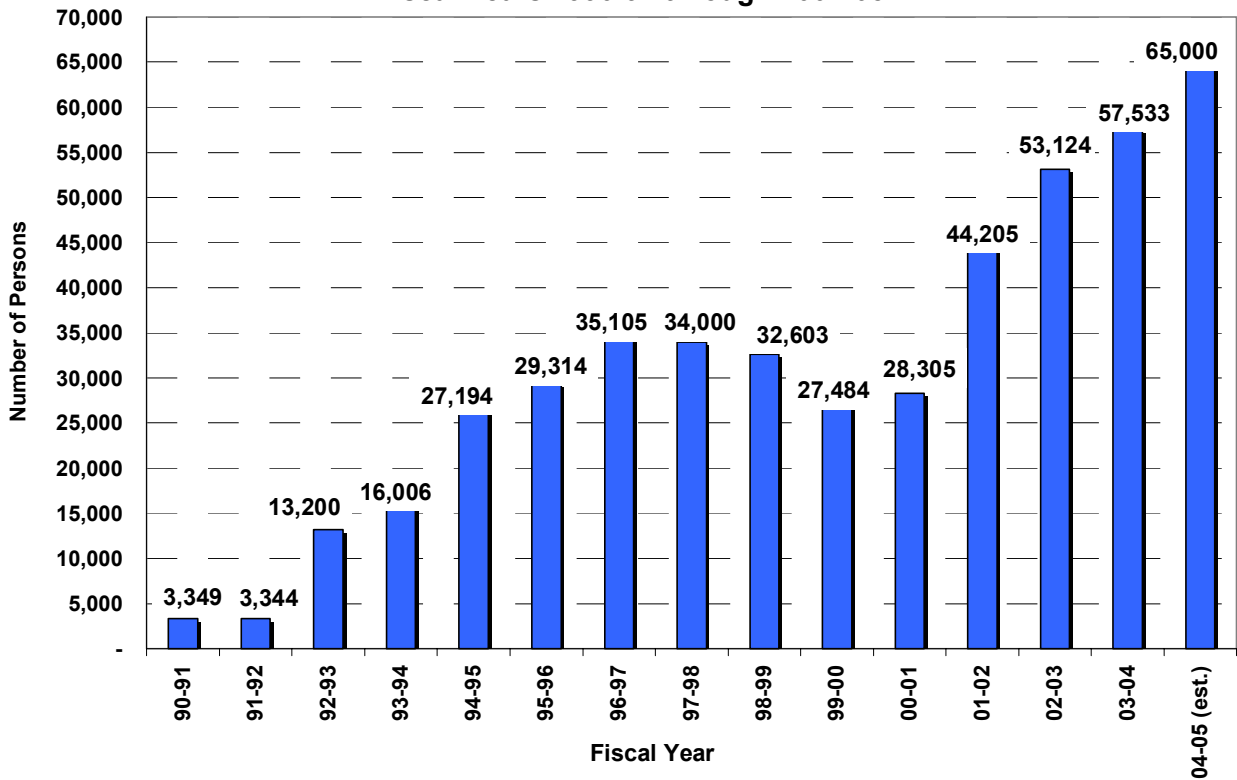
Federal Funding Supporting Community-based Services

DDS relies on a variety of federal funding, in combination with State General funds, to support the community service delivery system. The major federal funding sources include the following:

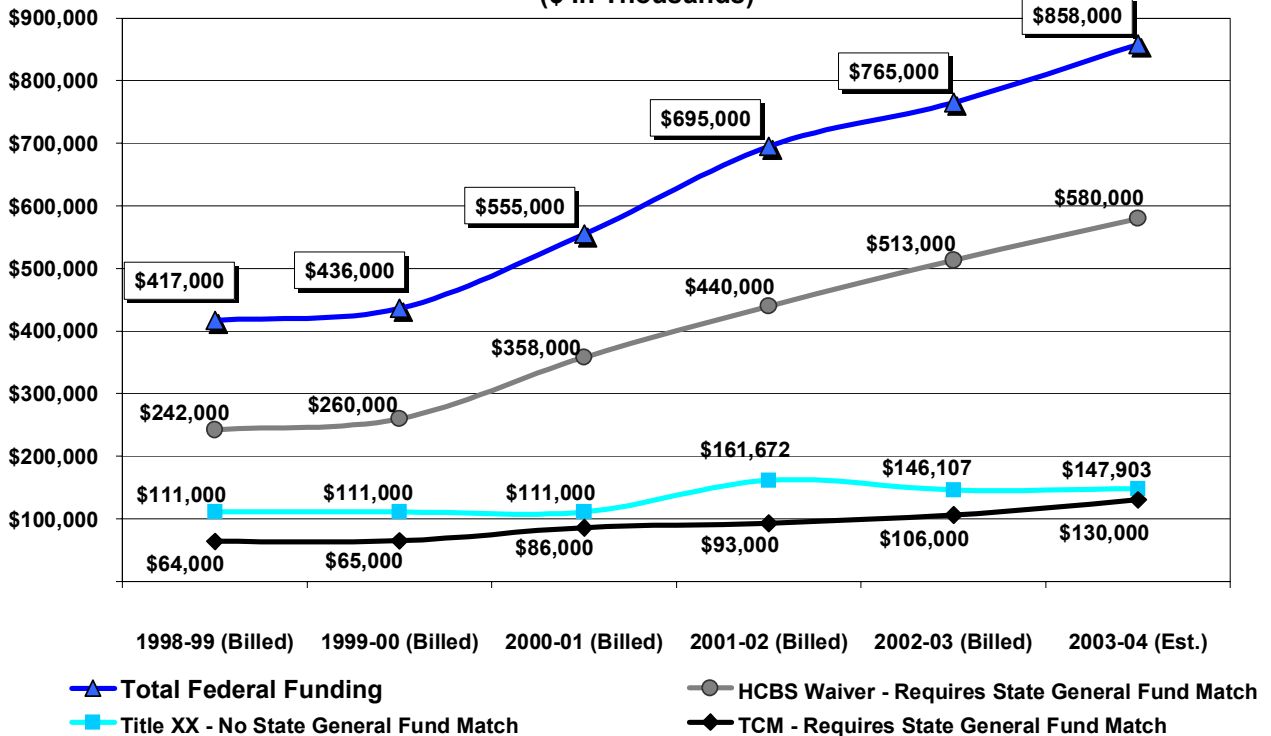
- Home and Community-based Services (HCBS) Waiver: This program funds residential, day program, and other services to eligible individuals who, without these services, would require the level-of-care provided in an intermediate care facility.
- Title XX Block Grant: These funds are for preventing/remedying neglect, abuse or exploitation, and for preventing/reducing inappropriate institutional care by providing community-based, home-care based, or other forms of less intensive care.
- Targeted Case Management (TCM): This funding supports case management services provided by regional centers to eligible consumers. “Case management” for purposes of claiming TCM funding is defined by the federal government as those services that assist the consumer in gaining access to needed medical, social, educational, and other services.

California's HCBS Waiver for individuals with developmental disabilities is the largest, in terms of enrollment, Waiver of its kind in the nation. The enrollment cap for this Waiver remained stable through the mid-1980's until the early 1990's when it began to grow. The “Growth in HCBS Waiver Enrollment” chart shows the growth beginning in the early 1990's through the projected enrollment figures for fiscal year 2004-05. In addition, this chart shows the impact of the freeze that the Federal government imposed in 1998 on California's Waiver enrollment. The second chart shows the federal funding for the community service delivery system by individual funding source and total federal funding for fiscal years 1998-99 through 2003-04. DDS continues to pursue all additional federal funds to which it may be entitled to support community services to individuals served through the regional center system.

Growth in HCBS Waiver Enrollment Fiscal Years 1990-91 through 2004-05



Increases in Federal Financial Participation for Regional Centers by Funding Source and Total from Fiscal Year 1998-99 through 2003-04 (\$ In Thousands)



Purchase of Service Expenditures by Budget Category Fiscal Year 2001/02 and Fiscal Year 2002/03 Compared

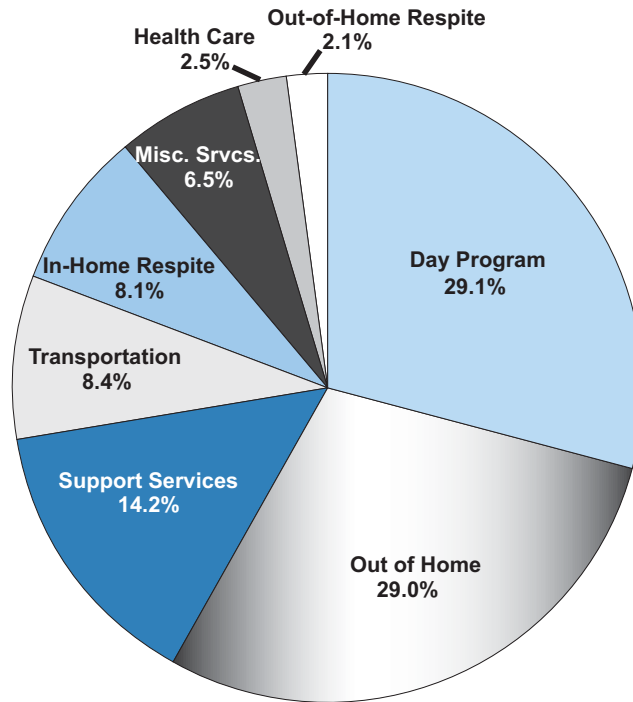
POS budget categories include Out-of-Home, Day Programs, Transportation, and Other Services. Included in each category are the following services: “Out-of-Home”--care, supervision and training for individuals in community care facilities; “Day Programs”--community-based training, e.g., behavior management, self-help/self-care skills, community integration, and infant development programs; “Transportation” --transportation provided by transportation companies, residential facilities, day programs, public transportation, family members, friends or ambulances. “Other Services” are broken into five sub-categories, namely Health Care, In-Home Respite, Out-of-Home Respite, Support Services, and Miscellaneous Services. “Support Services” includes community integration training, adaptive skills training, community activities support, supplemental residential, day services or program support, behavior management consulting, and supported living services. “Miscellaneous Services” includes the services of tutors, special education teachers, recreational therapists, counselors, infant development specialists, and speech pathologists.

In FY 2002/03, expenditures for these services totaled more than 1.8 billion dollars. In total dollars spent, each category increased from FY 2001/02 to 2002/03. However, certain budget categories decreased in terms of their relative share of total POS dollars between these years, while others increased. Of all budget categories, Support Services increased the most, from 12.4 percent in FY 2001/02 to 14.2 percent of total POS in FY 2002/03. The budget category with the largest decrease was Day Program, which declined from 30 percent in FY 2001/02 to 29.1 percent of total POS dollars in FY 2002/03.

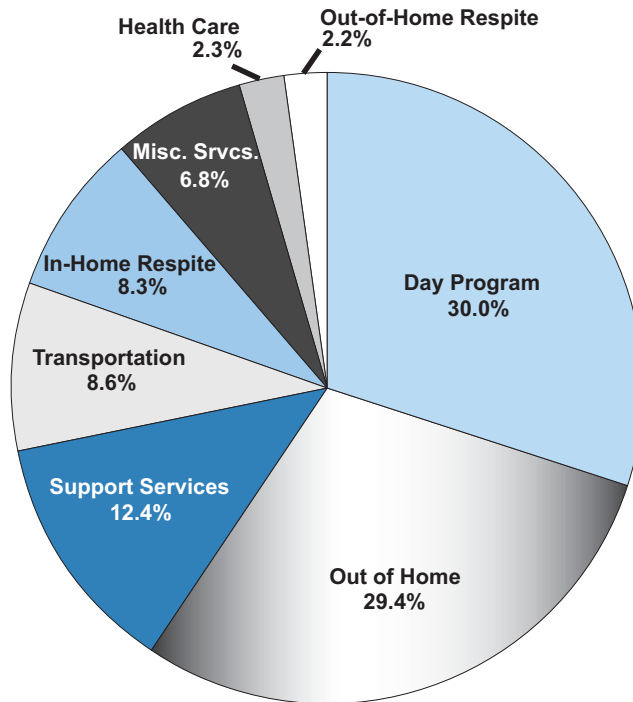
Budget Category	Fiscal Year 2001/02		Fiscal Year 2002/03	
	POS Dollars	% of Total	POS Dollars	% of Total
Day Program	\$501,202,009	30.0%	\$529,555,728	29.1%
Out-of-Home	491,273,101	29.4%	526,403,170	29.0%
Support Services	206,416,198	12.4%	258,298,487	14.2%
Transportation	143,654,841	8.6%	152,050,535	8.4%
In-Home Respite	139,370,908	8.3%	147,878,320	8.1%
Misc. Services	113,584,147	6.8%	118,800,887	6.5%
Health Care	38,657,861	2.3%	45,912,905	2.5%
Out-of-Home Respite	36,322,030	2.2%	39,082,467	2.1%
Total	\$1,670,481,094	100.0%	\$1,817,982,498	100.0%

Note: Regional centers can submit purchase of service claims to DDS years after the services have been delivered. Dollar amounts are recorded in the POS file according to when the services were rendered, not when the claims were received. As such, the POS dollar amounts reflected for prior years continue to change as additional vendor billings are received for services delivered during previous years. The POS file at DDS HQ is updated monthly. While all of the POS-related articles in this Fact Book edition are based on the POS file as updated in July 2004, dollar amounts reported for prior years may not agree with the dollar amounts reported for the same years in previous editions of the Fact Book.

Fiscal Year 2002/03 POS Dollars



Fiscal Year 2001/02 POS Dollars



POS Expenditure Changes Fiscal Years 1998/99 through 2002/03

While every service category increased in terms of total POS dollars spent in FY 2002/03 compared to 1998/99, the growth in dollars in terms of the percentage change in dollars over the period varied considerably from one service category to the next. "Activity Center" under Adult Day Programs had the least amount of growth (under three percent) from FY 1998/99 to FY 2002/03. Another service category with little growth between these years (roughly five percent) was "Mobility Training".

The service category with the highest growth (287 percent) in POS between FY 1998/99 and 2002/03 was "Other Look-Alike Programs" under Adult Day Programs. "Social Recreational Activities" and "Non-Medical Therapy Services" both had large growth rates of 225 percent over this time span. By comparison, total POS expenditures increased 73 percent between FY 1998/99 and 2002/03.

While the expenditure growth rate for a given service category may be large, the difference in actual POS dollars spent may be relatively small. For example, the POS expenditure change for "Non-Medical Therapy Services", which in terms of percentage was one of the highest growth service categories at 225 percent, represented an increase of only \$4.8 million. Conversely, POS expenditures for "Residential Services" that grew 66 percent over this same period represented an increase of over \$205 million.

The relative share of total POS dollars that a service category represents also deserves attention. For example, the combined POS dollar amount in FY 2002/03 for the three service categories with the highest growth rates between FY 1998/99 and 2002/03 (i.e., "Other Look-Alike Programs", "Social Recreational Activities", and "Non-Medical Therapy Services") represented about three percent of the total POS dollars. In contrast, "Residential Services" and "Adult Day Programs", two service categories with expenditure growth rates below the growth rate for total POS dollars during the five year span, together represented over half of all POS dollars spent (28 percent and 26 percent, respectively) in FY 2002/03.

POS Expenditures by Fiscal Year (Dollars in Thousands)

Service Category	FY 98/99	FY 99/00	FY 00/01	FY 01/02	FY 02/03	FY 98/99 to
						FY 02/03 % Change
Residential Services	\$309,331	\$386,173	\$452,053	\$480,449	\$514,518	66.3%
Adult Day Programs	\$324,140	\$353,249	\$405,715	\$442,438	\$480,302	48.2%
Activity Center	\$41,322	\$41,201	\$42,946	\$42,447	\$42,474	2.8%
Adult Development Center	\$158,469	\$174,513	\$200,327	\$213,604	\$225,087	42.0%
Behavior Mgmt. Program	\$68,667	\$76,355	\$89,523	\$99,855	\$107,832	57.0%
Independent Living Program	\$42,840	\$46,279	\$53,386	\$57,952	\$60,764	41.8%
Social Recreation Program	\$2,184	\$2,049	\$2,087	\$2,486	\$2,859	30.9%
Other "Look-Alike" Programs	\$10,659	\$12,852	\$17,446	\$26,094	\$41,288	287.4%
Supported Living & Related Svs.	\$74,233	\$91,628	\$122,542	\$153,808	\$181,015	143.8%
Respite	\$75,782	\$94,282	\$119,440	\$145,816	\$153,598	102.7%
Transportation	\$106,448	\$114,366	\$126,912	\$143,636	\$152,092	42.9%
Infant Program Services	\$45,843	\$53,798	\$65,616	\$75,680	\$84,387	84.1%
Medical Care & Services	\$28,261	\$36,128	\$43,676	\$52,231	\$57,858	104.7%
Behavioral Services	\$20,953	\$23,176	\$28,171	\$39,874	\$49,552	136.5%
Day Care	\$15,259	\$18,824	\$23,972	\$29,561	\$32,805	115.0%
Supplemental Program Support	\$13,677	\$16,976	\$21,171	\$26,265	\$29,184	113.4%
Social/Recreational Activities	\$4,241	\$4,947	\$6,826	\$11,414	\$13,770	224.7%
Medical & Adaptive Equip./Supplies	\$4,189	\$4,364	\$5,337	\$5,919	\$5,140	22.7%
Non-Medical Therapy Services	\$2,136	\$2,852	\$3,411	\$5,547	\$6,931	224.6%
Camps	\$2,295	\$2,671	\$3,286	\$3,844	\$4,409	92.1%
Environmental & Vehicle Mod.	\$547	\$671	\$1,161	\$1,816	\$845	54.5%
Mobility Training	\$598	\$659	\$604	\$599	\$629	5.1%
All Other Services	\$23,391	\$30,792	\$43,170	\$51,584	\$50,948	117.8%
TOTAL	\$1,051,325	\$1,235,558	\$1,473,064	\$1,670,481	\$1,817,982	72.9%

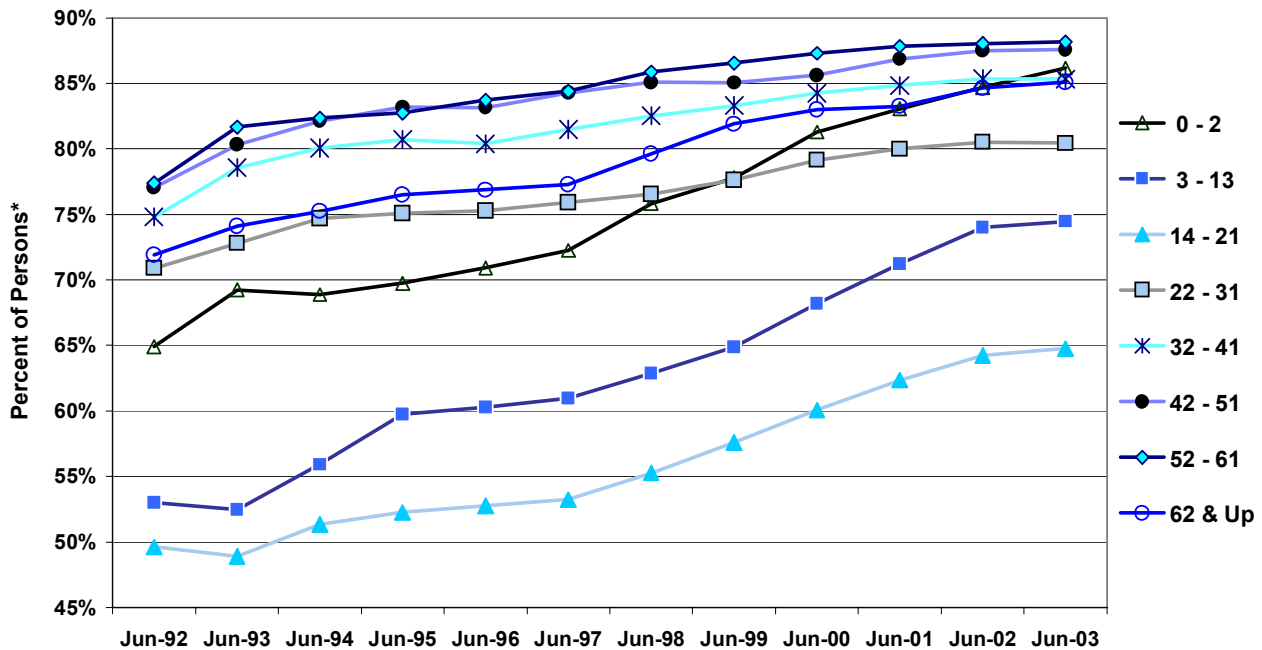
Percent of Persons Receiving RC-funded Services of All Persons Served by DDS in the Community, Fiscal Years 1991/92 through 2002/03

All persons served by DDS receive case management services through their local RC; however, not all persons receive purchased services. RCs are required by law to provide or secure services in the most cost-efficient way possible. They must use all other resources, including those provided by other agencies, before using any RC funds. When alternate sources are not available, the RC purchases services as specified in the person's Individual Program Plan (IPP) or the Individualized Family Service Plan (IFSP).

Of all persons served in the community (CMF status codes 1 or 2), the percent who received RC-funded services increased steadily from FY 1991/92 through 2002/03. About 64 percent of persons served in the community as of June 1992 received RC-funded services during FY 1991/92. By June 2003, 78 percent of the community population received services funded by the RCs during FY 2002/03.

For all age groups of persons served in the community, the percentage receiving RC-funded services increased between FY 2002/03 and FY 1991/92. However, the percentages and growth rates varied widely across age groups. Persons ages "14 - 21" years were the least likely to receive RC-funded services, while persons "52 - 61" years of age were the most likely. Persons "3 - 13" years of age had the highest growth rate in receipt of RC-funded services.

**Of All Persons with Active Status in the Community* Broken Out by Age Group,
the Percent Who Received RC-funded Services**



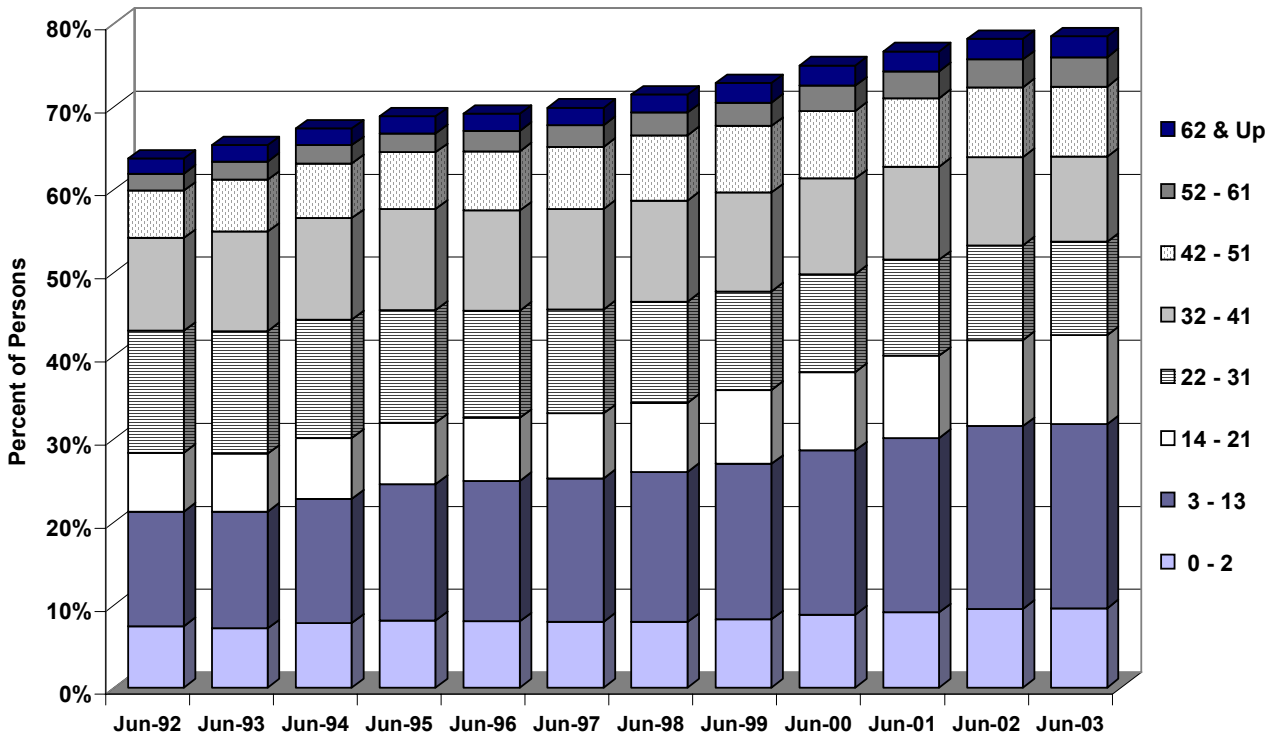
*"Persons with Active Status in the Community" is defined as persons with status codes 1 or 2 on the Client Master File. The data points in the graph above show, for each age group, the percentage who received RC-funded services out of all persons with active status in the community.

Age Distribution of Persons Who Received RC-funded Services, Fiscal Years 1991/92 through 2002/03

While the previous article explored for all persons served in the community by DDS, what percentage received RC-funded services, the subject of this article is the age distribution of the population who received RC-funded services. The top of each bar in the chart below reflects the percent of persons who received RC-funded services out of all individuals served in the community. The sections within each bar represent the distribution by age group of persons who received RC-funded services.

The distribution across age group of persons who receive RC-funded services has shifted over the years from FY 1991/92 through FY 2002/03. In FY 1991/92, persons ages 22 through 31 represented the largest segment of the population receiving RC-funded services. By FY 2002/03, individuals ages 3 through 13 composed the largest segment of RC-funded service recipients. The growth in the “3 through 13” age group’s share of the recipient population correlates with the age group’s growth trend reported in the last article (see chart on page 26).

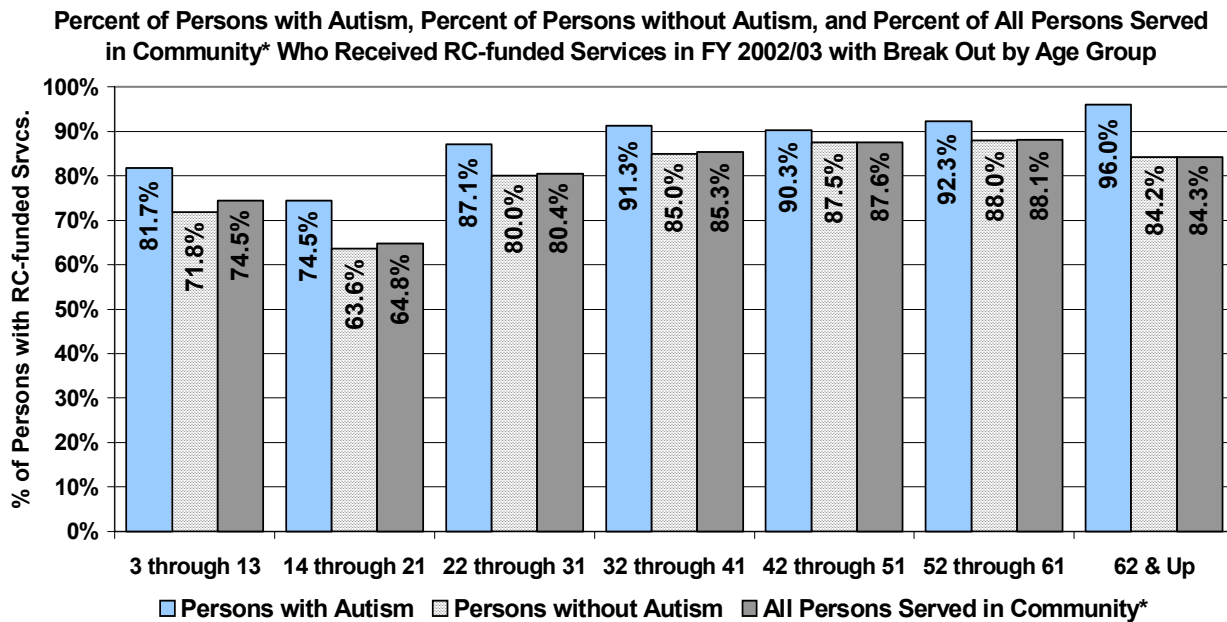
Age Distribution of Persons Who Received RC-funded Services



* Includes only persons with status code 1 or 2 on CMF in June of the respective fiscal year who received RC-funded services.

Persons Who Received RC-funded Services--Comparison Between Persons with Autism and Persons without Autism, with Detail by Age

In FY 2002/03, persons with autism in all age groups were more likely to receive RC-funded (or POS-paid) services than persons without autism. The largest percentage differences between persons with autism and persons without autism receiving RC-funded services were found in the age groups under 22 years and in the age group 62 years and above. In these age groups, the percent for persons with autism was more than ten percent higher than the percent for persons without autism. The smallest difference was in the age group "42 through 51" years where the percent of persons with autism receiving RC-funded services was 2.8 percent greater than the percent for persons without autism.



Number of Persons with Autism Compared to Number of Persons without Autism by Age Group Broken Out by Persons Receiving RC-funded Services Versus Persons in Community*

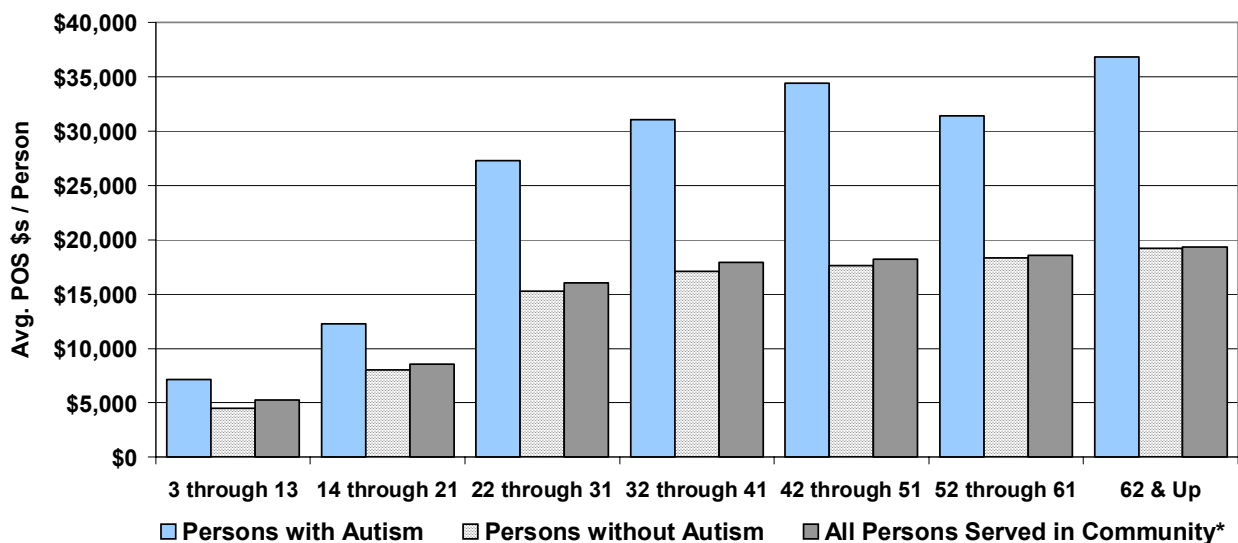
Age Group	Persons with Autism with RC-funded Svcs.	Persons with Autism Served in Community	Persons without Autism with RC-funded Svcs.	Persons without Autism Served in Community
3 through 13 Yrs	12,150	14,865	29,236	40,718
14 through 21 Yrs	2,381	3,197	17,607	27,664
22 through 31 Yrs	1,385	1,590	19,647	24,557
32 through 41 Yrs	1,091	1,195	18,051	21,242
42 through 51 Yrs	540	598	15,182	17,355
52 through 61 Yrs	120	130	7,698	8,746
62 Yrs & Up	24	25	3,452	4,099
TOTAL	17,691	21,600	110,873	144,381

*Only persons with status codes 1 or 2 on the CMF in June 2003 were included in this article. Also, individuals under age three were excluded because children under age three seldom have a CDER, the data source used to identify persons with autism.

Average Per Capita POS Dollars Spent for Persons with Autism Compared to Persons without Autism, with Details by Age

For persons who received services funded by POS dollars in fiscal year 2002/03, the average per capita dollars spent for persons with autism was higher in every age group than the average per capita dollars spent for persons without autism. The largest variance in per capita POS dollars was for the age group “62 Yrs & Up” in which \$17,590 more, on average, was spent on persons with autism than on persons without autism. The smallest difference in per capita POS occurred in the age group of “3 through 13” years, where persons with autism received on average \$2,619 more in RC-funded services than persons without autism.

Comparison of Average Dollars in FY 2002/03 by Age Group for Persons with Autism, Persons without Autism, and All Persons Served in Community*



Age Group	Autism - Dollars	Autism - Persons	Avg \$s per Person
3 through 13	\$86,494,902	12,150	\$7,119
14 through 21	\$29,243,352	2,381	\$12,282
22 through 31	\$37,794,884	1,385	\$27,289
32 through 41	\$33,864,525	1,091	\$31,040
42 through 51	\$18,588,773	540	\$34,424
52 through 61	\$3,772,859	120	\$31,440
62 & Up	\$884,008	24	\$36,834
Autism - All Ages	\$210,643,303	17,691	\$11,907

Age Group	No Autism - Dollars	No Autism - Persons	Avg \$s per Person
3 through 13	\$131,548,667	29,236	\$4,500
14 through 21	\$141,430,490	17,607	\$8,033
22 through 31	\$300,337,825	19,647	\$15,287
32 through 41	\$308,949,278	18,051	\$17,115
42 through 51	\$267,579,617	15,182	\$17,625
52 through 61	\$141,322,101	7,698	\$18,358
62 & Up	\$66,428,714	3,452	\$19,244
No Autism - All Ages	\$1,357,596,692	110,873	\$12,245

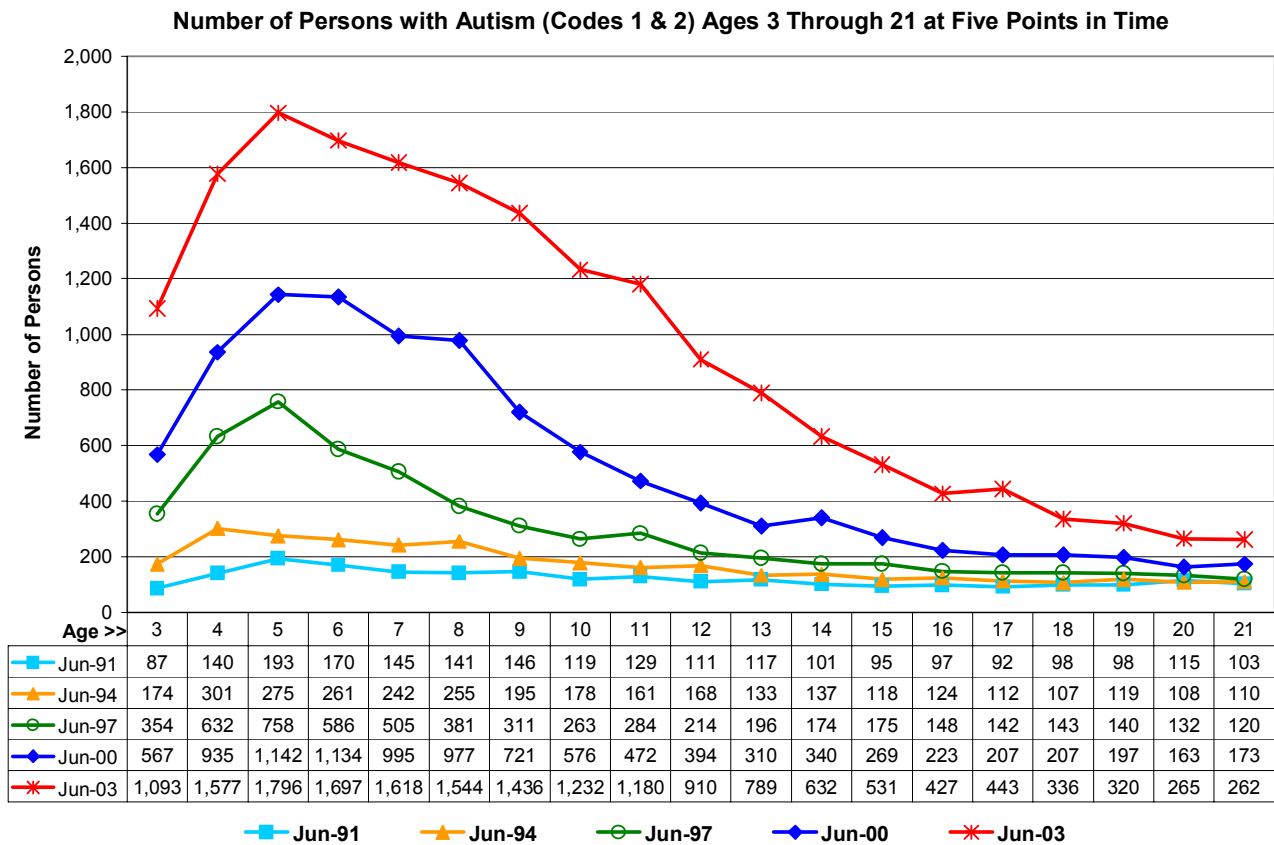
*Only persons with status codes 1 or 2 on the CMF in June 2003 were included in this article. Also, individuals under age three were excluded because children under age three seldom have a CDER, the data source used to identify persons with autism.

Population Trends by Year of Age for Children Ages 3 through 21 with Autism Who Were Served by DDS

As of June 2003, over 82 percent of all persons with autism served by DDS were 3 to 21 years of age, inclusive. As this age group, on average, has lower per capita costs, there is increasing concern regarding the cost implications for future years as this growing segment of the population ages. The chart below shows the distribution by age for children with autism ages 3 through 21 for five points in time. In June 1991, the distribution across these ages was relatively flat. Using June 1991 as the base year, the three ages with the highest cumulative growth rates from June 1991 through June 2003 were ages 3, 4, and 7.

However, the growth percentages found when comparing one point in time to the next shows a different pattern emerging. Between June 1994 and June 1997, the three ages with the largest increases in caseload were ages 4, 5, and 6. The highest caseload growth between June 1997 and June 2000 was for ages 8, 9, and 10. The number of children ages 11, 12, and 13 grew the most between June 2000 and June 2003.

The cost implications as these children grow older are significant. In FY 2002/03, the average cost per child with autism who was 14 through 21 years of age was 73 percent higher than the average cost per child with autism in the 3 through 13 years age group. Average costs for individuals ages 22 through 31 with autism were 283 percent higher than for those 3 through 13 years of age.





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