

Department of Developmental Services

Fact Book Fifth Edition



**Prepared by DDS Information Services Division
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**Department of Developmental Services
1600 Ninth Street, Room 220
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PERSKE

PENCIL PORTRAITS
1971-1990

Drawings by Martha Perske
Introduction by Robert Perske

Abingdon Press
Nashville

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Perske: Pencil Portraits 1971-1990 (Nashville: Abingdon Press, 1998).

Preface

The Fact Book is a collection of pertinent data about persons served by the Department of Developmental Services (DDS). The Fact Book provides an overview of services and trends in California. We hope you find this information useful in better understanding the 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 normal lives. In addition, these laws ensure the delivery of appropriate services to infants and toddlers at risk of having developmental disabilities and to their families. DDS carries out its responsibilities through 21 community-based, non-profit corporations known as “regional centers” (RCs) and State-operated facilities, including five developmental centers and two smaller facilities. For purposes of this publication, the two smaller facilities will be included in numbers reported for State developmental centers (SDCs).

A “developmental disability” (DD) is a condition that originates before an individual reaches age 18; continues, or can be expected to continue indefinitely; and constitutes a substantial impairment. 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 includes individuals with developmental disabilities, their families and/or legal representatives, advocacy and professional organizations, area boards, the State Council on Developmental Disabilities, direct service providers, SDCs, RCs, and the Department.

The following pages offer a look at the demographics and characteristics of persons served by DDS. This fifth edition of the Fact Book also features many new articles. In the section on “Whom DDS Serves,” SDC caseload numbers are displayed by RC and age group (pp. 10-11), and the age composition of the total caseload is compared over time (pp. 12-13). New articles featured in the “What People Receive” section include Purchase of Service (POS) expenditure growth compared to caseload growth (p. 25), POS expenditure changes from 1998/99 through 2000/01 (pp. 26-27), growth in dollars from federal sources compared to total POS (pp. 28-29), and POS expenditure comparisons between persons with autism and the total caseload (pp. 30-31).

The Fact Book and other information concerning the Department of Developmental Services 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 Department’s Data Extraction Unit.

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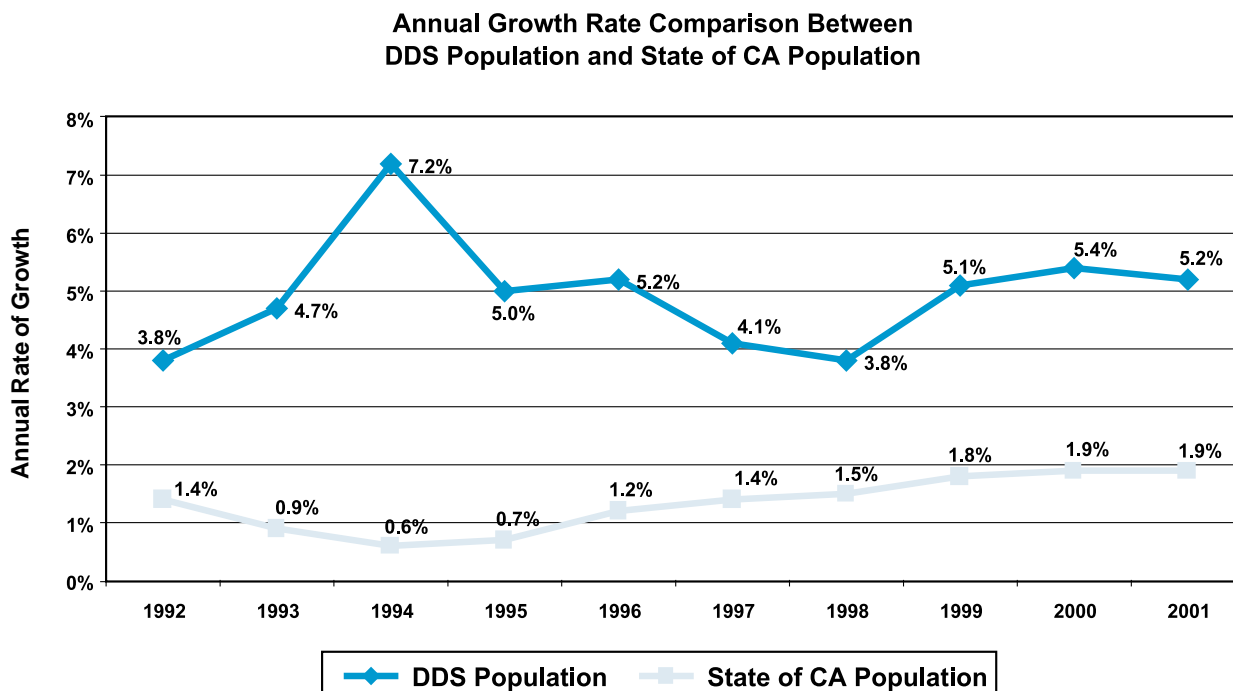
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Whom DDS Serves

Caseload

The number of persons served by the Department increased 61.6 percent between January 1992 and December 2001. During this same period, the State developmental center (SDC) population decreased 44.4 percent.

While the total DDS population (i.e., persons with status codes 1, 2 and 8)* 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 1992 to January 2002, according to Department of Finance data, California's general population grew approximately 14 percent. As of January 2002, about 0.50 percent of California's general population were being served by DDS.

*** 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.

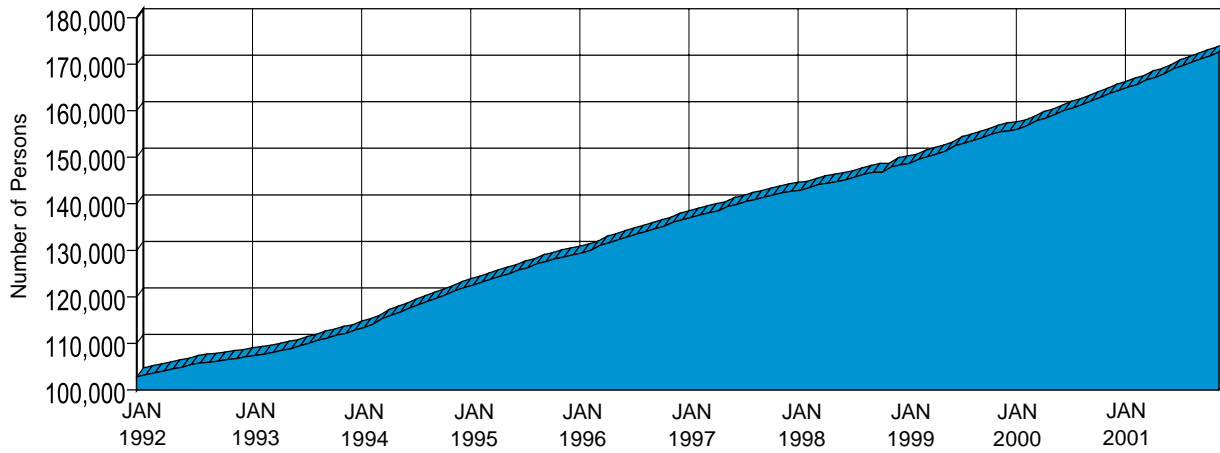
*** Status Code 2:** Persons diagnosed as having a developmental disability and being served in the community (not in an SDC). Another term sometimes used to denote status code 2 is "Active Status".

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

Note: The source of the data depicted in the Caseload charts is the Client Master File (CMF). The CMF is the primary source for demographic, case status and service coordinator information. Information on a person is initially entered into the CMF at the time of application for DDS services.

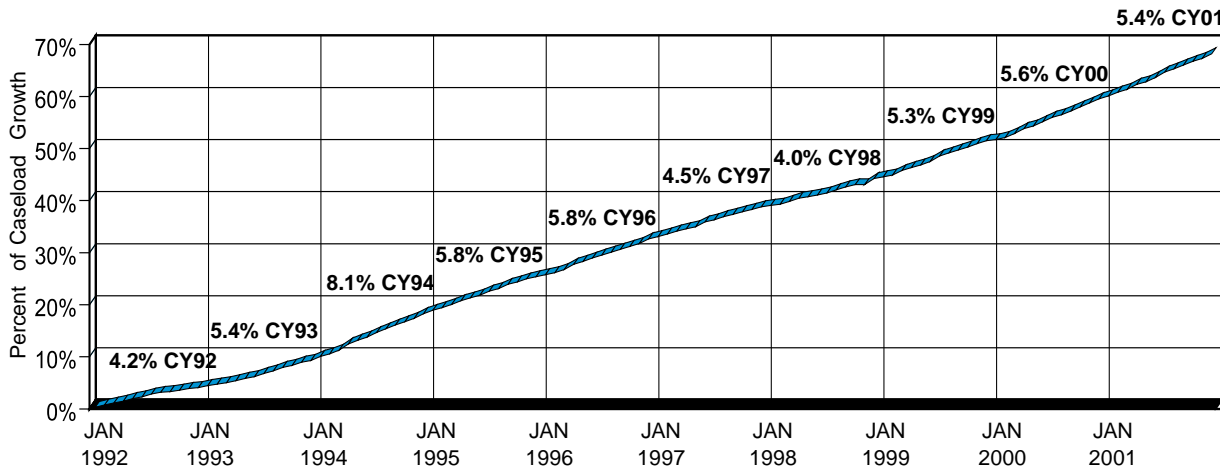
Community Caseload

Caseload Growth*
1/92 thru 12/01



*Persons with status codes 1 and 2.

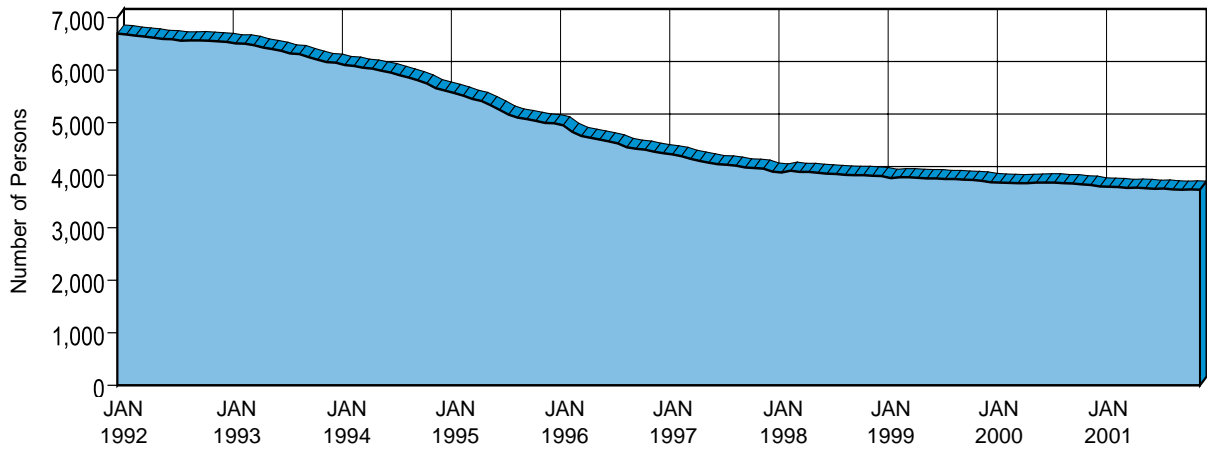
**Cumulative Percent of Caseload Growth with
Annual Percents Noted***
1/92 thru 12/01



*Persons with status codes 1 and 2.
Note: In graph above, CY means Calendar Year.

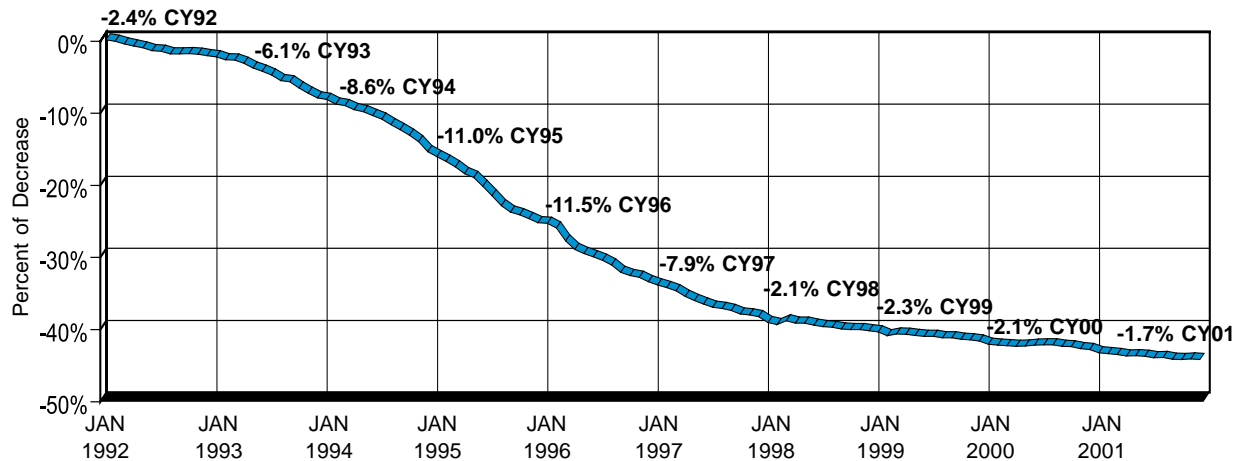
State Developmental Center Residents

Decline in Number of SDC Residents*
1/92 thru 12/01



*Persons with status code 8.

Cumulative Percent in SDC Resident in SDC Resident
Numbers with Annual Percents Noted*
1/92 thru 12/01



*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 the gender, age, residence types and ethnicity of persons with status codes 1, 2, and 8 as of December 2001. To obtain a more complete picture of the demographic changes that have occurred in the population served by DDS since December 1993, please refer to the demographic information provided in prior editions of the Fact Book.

The trend in the gender distribution of persons served by DDS continued in 2001 with males still outnumbering females. In December 1993, 56.4 percent of persons served were male versus 43.6 percent female. In December 2001, the gap widened to 59.0 percent male versus 41.0 percent female.

Age distribution trends for persons served by DDS continued as well. In general, the population is increasingly younger (*percent of persons ages birth through 21 grew from 49.4 to 55.4 between December 1993 and 2001*) and increasingly older (*the percent of individuals ages 42 and above increased from 14.4 to 17.2 during the same period*).

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, 69.2 percent had this residence type in December 2001. During this same period, decreases continued in the proportion of persons who resided in community care settings (19.9 to 15.2 percent) and Developmental Centers (5.1 to 2.1 percent).

Significant changes occurred in the ethnic makeup of the population. The proportion of whites decreased from 51.5 percent in December 1993 to 42.5 percent in December 2001. The proportion of Hispanics increased from 23.9 to 28.4 percent during this same period.

Definitions of Residence Types

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

Community Care: Setting such as a Community Care Facility (CCF) and other community settings, not including home of family member or guardian, ILS/SLS, and SNF/ICF.

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.

Demographics of Persons Served by DDS

**Persons with Status Codes 1, 2 and 8
Based on Client Master File as of December 2001**

| Gender | Number of Persons | Percentage of Total |
|---------------|--------------------------|----------------------------|
| Male | 104,313 | 59.0% |
| Female | 72,615 | 41.0% |
| Total | 176,928 | 100.0% |

| Age | Number of Persons | Percentage of Total |
|-----------------|--------------------------|----------------------------|
| Birth to 2 Yrs. | 18,586 | 10.5% |
| 3 to 13 Yrs. | 51,356 | 29.0% |
| 14 to 21 Yrs. | 28,025 | 15.8% |
| 22 to 31 Yrs. | 25,381 | 14.3% |
| 32 to 41 Yrs. | 23,237 | 13.1% |
| 42 to 51 Yrs. | 17,895 | 10.1% |
| 52 to 61 Yrs. | 8,275 | 4.7% |
| 62 and Older | 4,173 | 2.4% |
| Total | 176,928 | 100.0% |

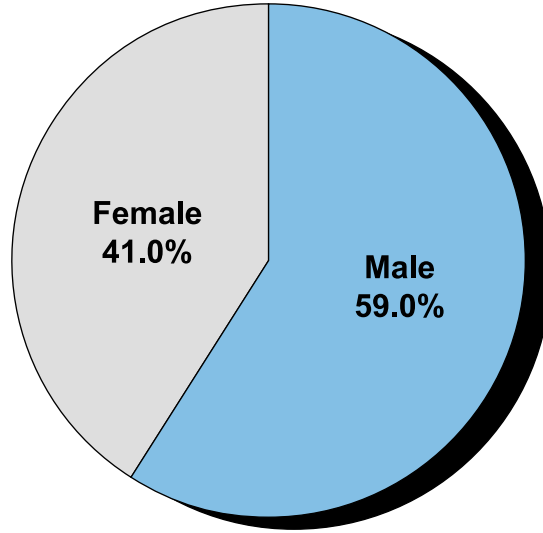
| Residence Type | Number of Persons | Percentage of Total |
|-----------------------|--------------------------|----------------------------|
| Own Home-Parent | 122,520 | 69.2% |
| Community Care | 26,851 | 15.2% |
| ILS/SLS | 15,312 | 8.7% |
| SNF/ICF | 8,550 | 4.8% |
| Developmental Center | 3,695 | 2.1% |
| Total | 176,928 | 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.

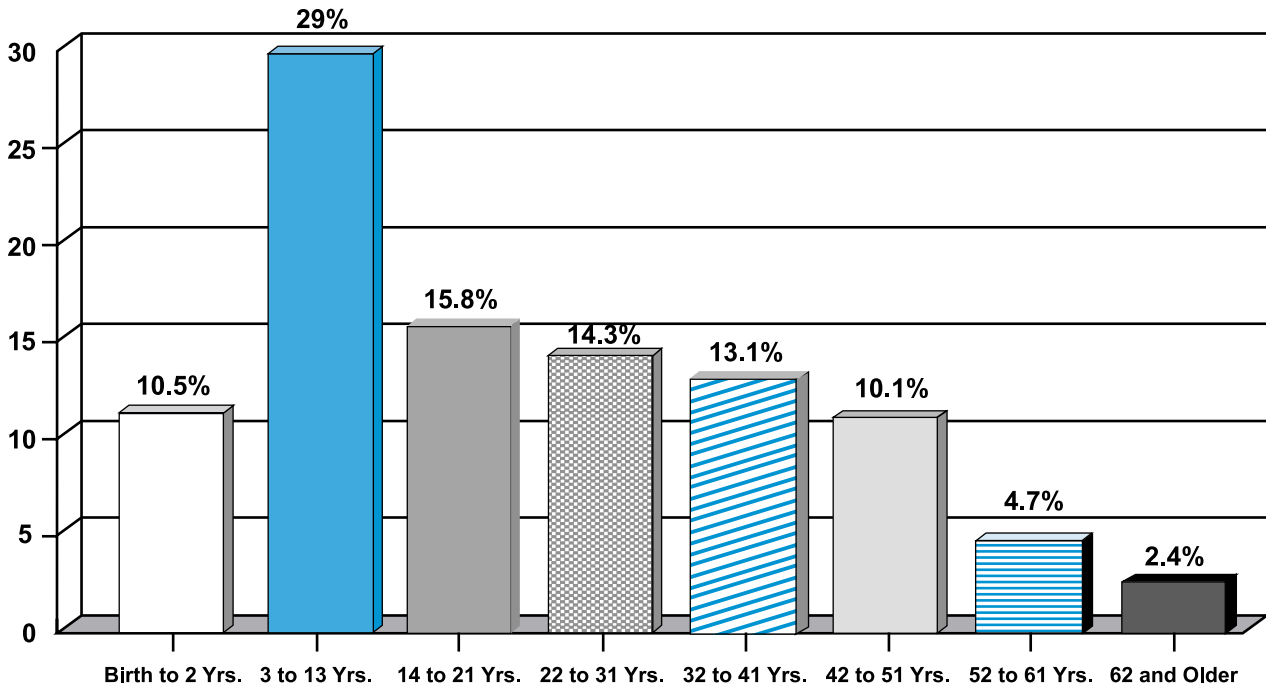
| Ethnicity | Number of Persons | Percentage of Total |
|------------------|--------------------------|----------------------------|
| White | 75,182 | 42.5% |
| Hispanic | 50,255 | 28.4% |
| Black | 17,569 | 9.9% |
| Asian | 8,243 | 4.7% |
| Filipino | 2,991 | 1.7% |
| Native American | 688 | 0.4% |
| Pacific Islander | 313 | 0.2% |
| Other | 21,687 | 12.3% |
| Total | 176,928 | 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.

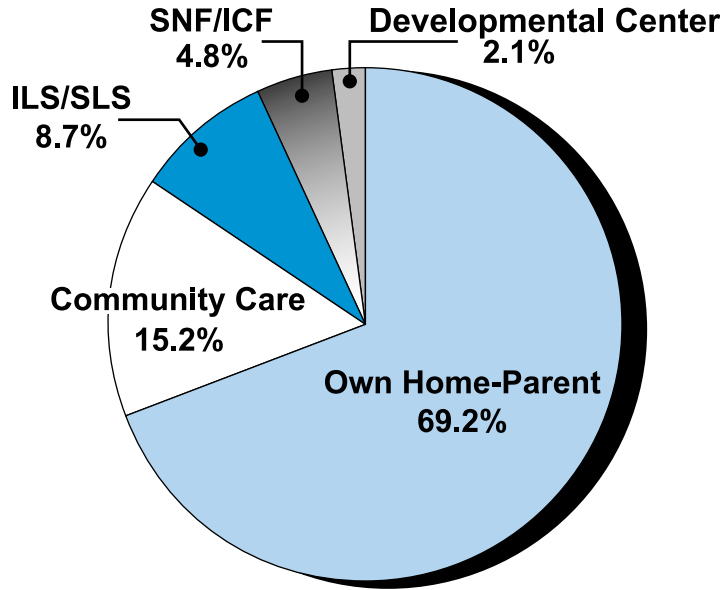
Gender of Individuals Served by DDS



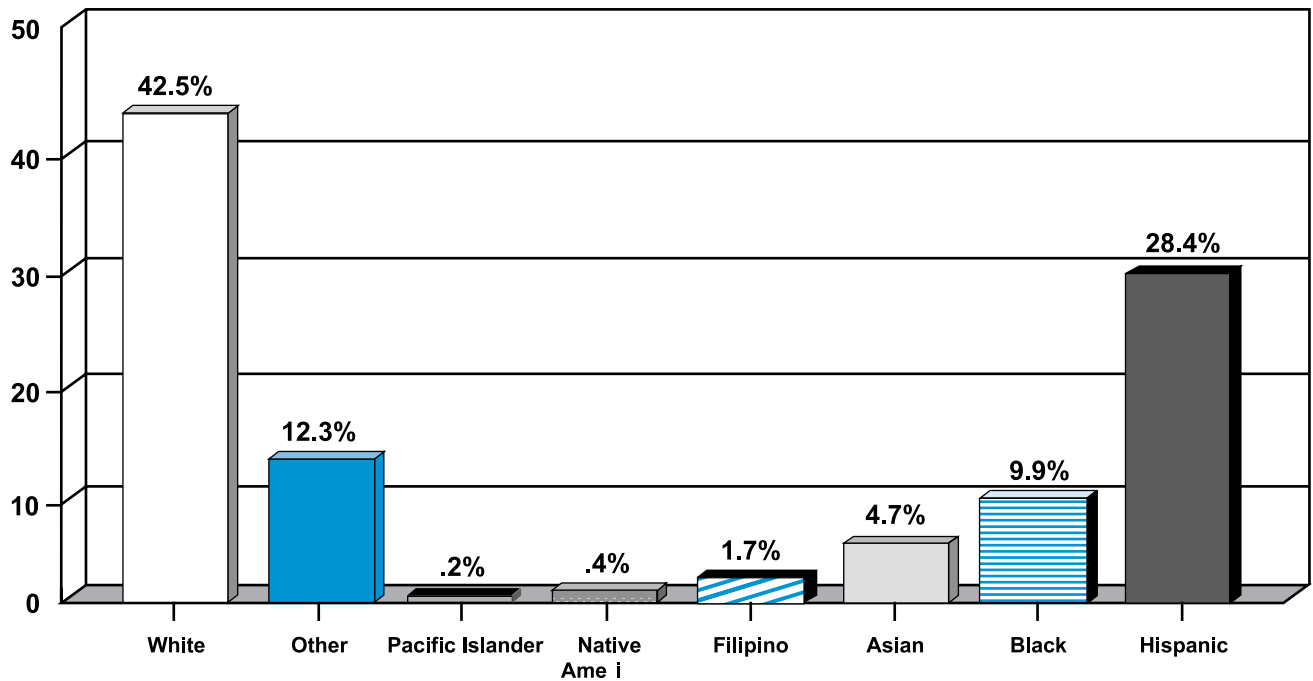
Age of Individuals Served by DDS



Residences of Individuals Served by DDS



Ethnicity of Individuals Served by DDS



Residence Types of Persons with Developmental Disabilities by Age Group in December 1996 and December 2001

During the period from December 1996 through December 2001, persons served by DDS in both the "Birth thru 17" and "18 and Older" age groups increased in the percentage residing in the home of a parent or guardian (labeled "Own Home-Parent" in the tables below) and decreased in the percentage 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 a home-like environment.

The percentage of persons 18 years of age and older residing in independent and supported living settings also increased between December 1996 and December 2001. This change follows 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 thru 17 | | | | |
|---------------------------------------|------------------------|---------------------|------------------------|---------------------|
| Residence Type | as of Dec. 1996 | | as of Dec. 2001 | |
| | Number of Persons | Percentage of Total | Number of Persons | Percentage of Total |
| Own Home-Parent | 56,985 | 89.4% | 77,770 | 92.3% |
| Community Care | 5,845 | 9.2% | 5,726 | 6.8% |
| ILS/SLS | 28 | 0.0% | 1 | 0.0% |
| SNF/ICF | 728 | 1.1% | 653 | 0.8% |
| Developmental Center | 185 | 0.3% | 94 | 0.1% |
| Total | 63,771 | 100.0% | 84,244 | 100.0% |

| Individuals Ages 18 and Older | | | | |
|--------------------------------------|------------------------|---------------------|------------------------|---------------------|
| Residence Type | as of Dec. 1996 | | as of Dec. 2001 | |
| | Number of Persons | Percentage of Total | Number of Persons | Percentage of Total |
| Own Home-Parent | 34,958 | 45.6% | 44,750 | 48.3% |
| Community Care | 19,528 | 25.5% | 21,125 | 22.8% |
| ILS/SLS | 11,075 | 14.4% | 15,311 | 16.5% |
| SNF/ICF | 6,902 | 9.0% | 7,897 | 8.5% |
| Developmental Center | 4,181 | 5.5% | 3,601 | 3.9% |
| Total | 76,644 | 100.0% | 92,684 | 100.0% |

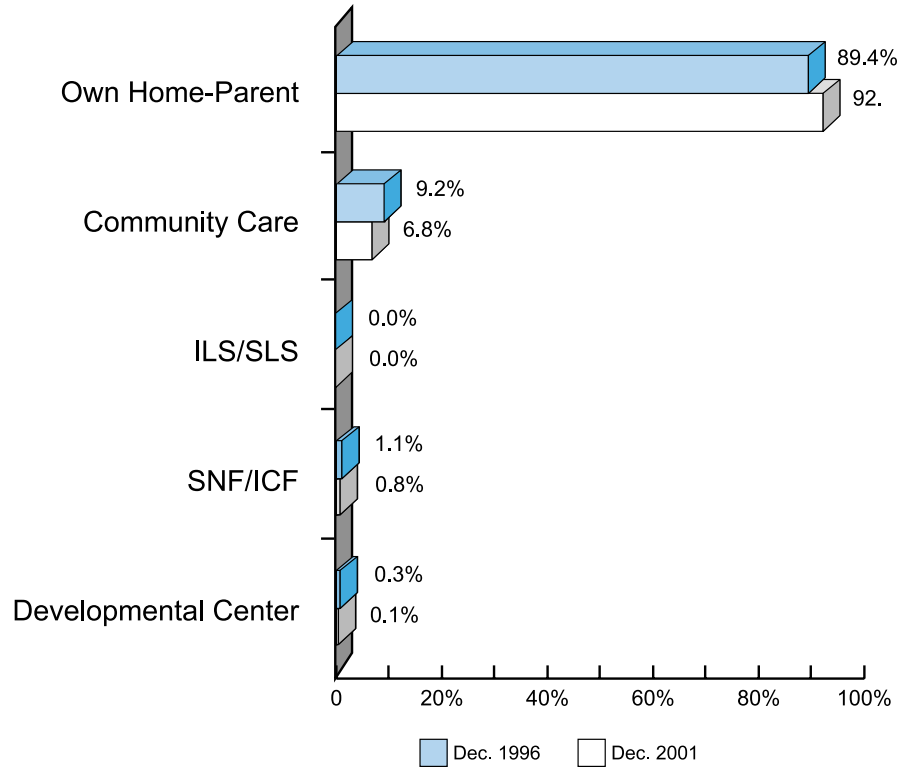
Note: The tables above include only persons with status codes 1, 2 and 8.

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

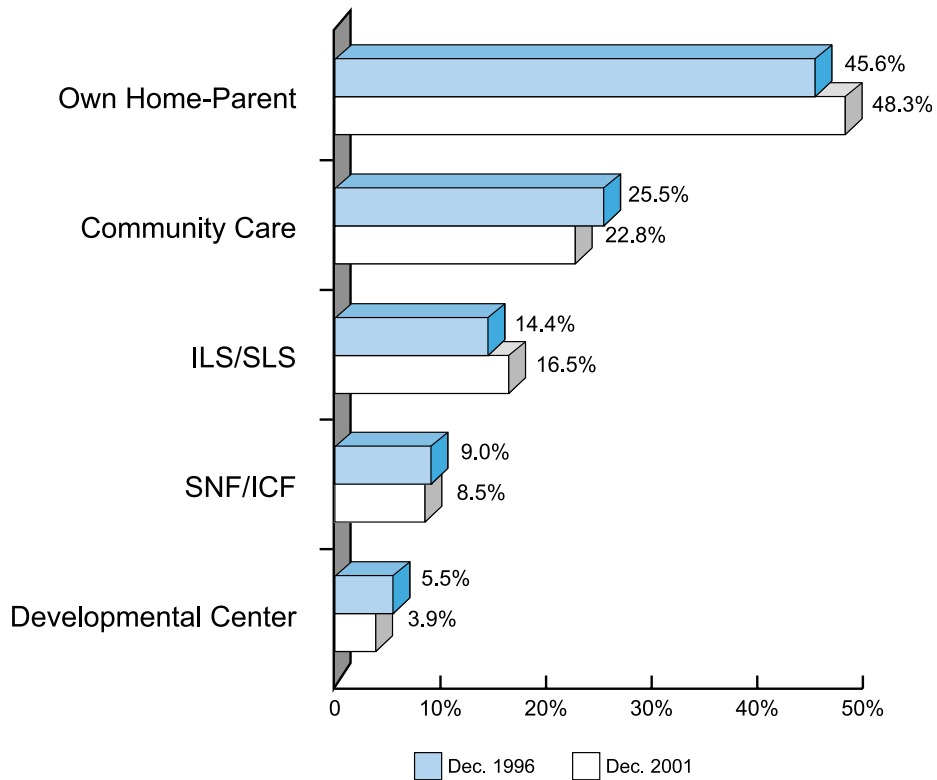
SNF/ICF: Skilled Nursing Facility/Intermediate Care Facility.

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

Individuals Ages Birth Through 17



Individuals Ages 18 and Older



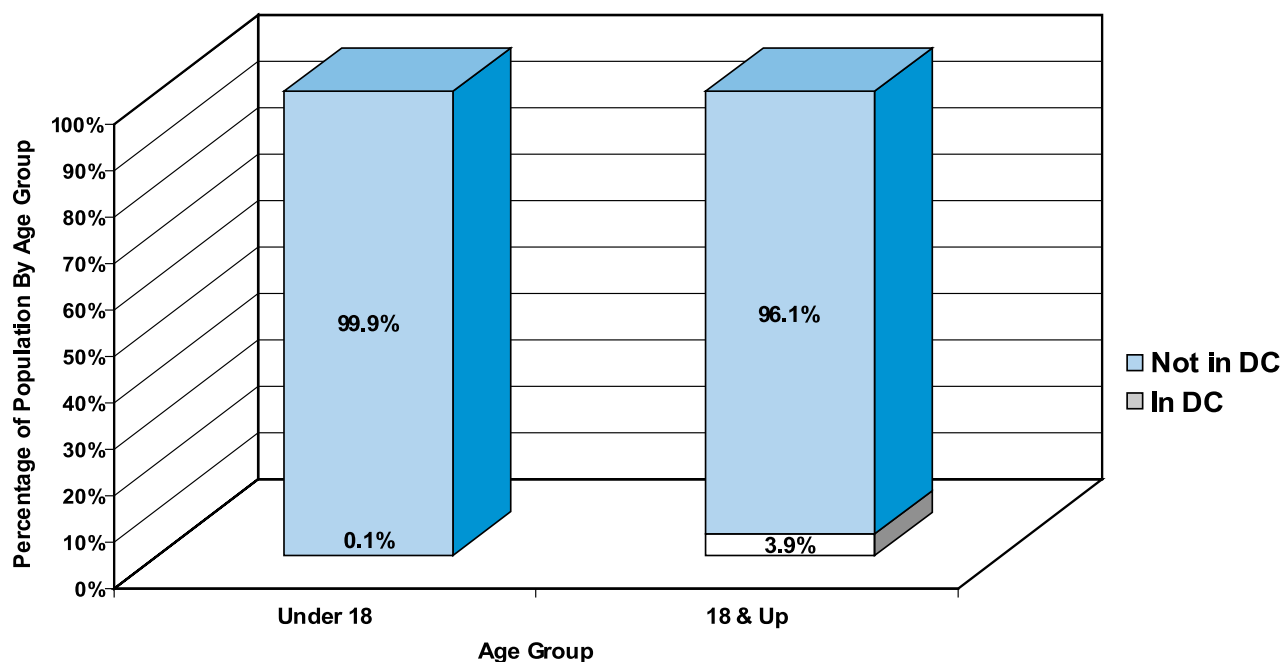
State Developmental Center Caseload by Regional Center and Age Group Compared to Statewide Average

In December 2001, DDS served about two percent of the total caseload (3,721 individuals out of the total 176,928) through its State-operated facilities. The vast majority (over 97 percent) of persons served through the State developmental centers (SDCs) were 18 or older. Only 98 of the 3,721 individuals residing in the SDCs were under age 18. Of the total caseload, individuals under age 18 residing in SDCs represented roughly one twentieth of one percent.

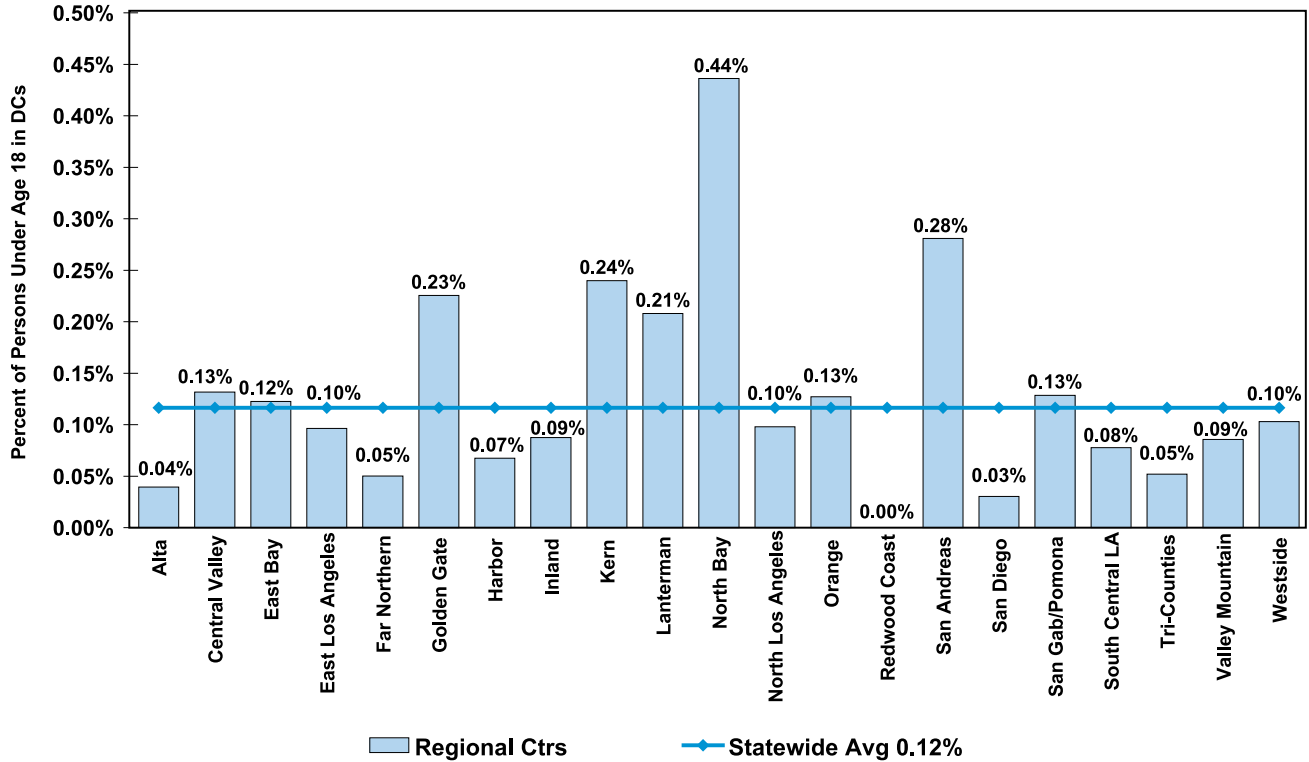
The distribution of persons residing in SDCs broken out by the regional center shows significant variation. Redwood Coast Regional Center served no minors through the SDCs. North Bay Regional Center had the highest percent of individuals under age 18 served through SDCs (0.44 percent, or 10 out of the regional center's 2,293 children served). On average statewide, DDS served 0.12 percent of individuals under age 18 through an SDC.

For individuals age 18 or older served by DDS, about 3.9 percent of the total 92,684 persons reside in an SDC. The greatest variation by regional center for the 18 and older age group is found between Golden Gate Regional Center and Valley Mountain Regional Center. Of the 3,808 persons age 18 or older served by Golden Gate Regional Center, 341 (or nine percent) resided in an SDC. Valley Mountain Regional Center had the lowest percent of individuals in the 18 and older age group residing in an SDC with only 1.2 percent of 3,954 persons living in this residential setting.

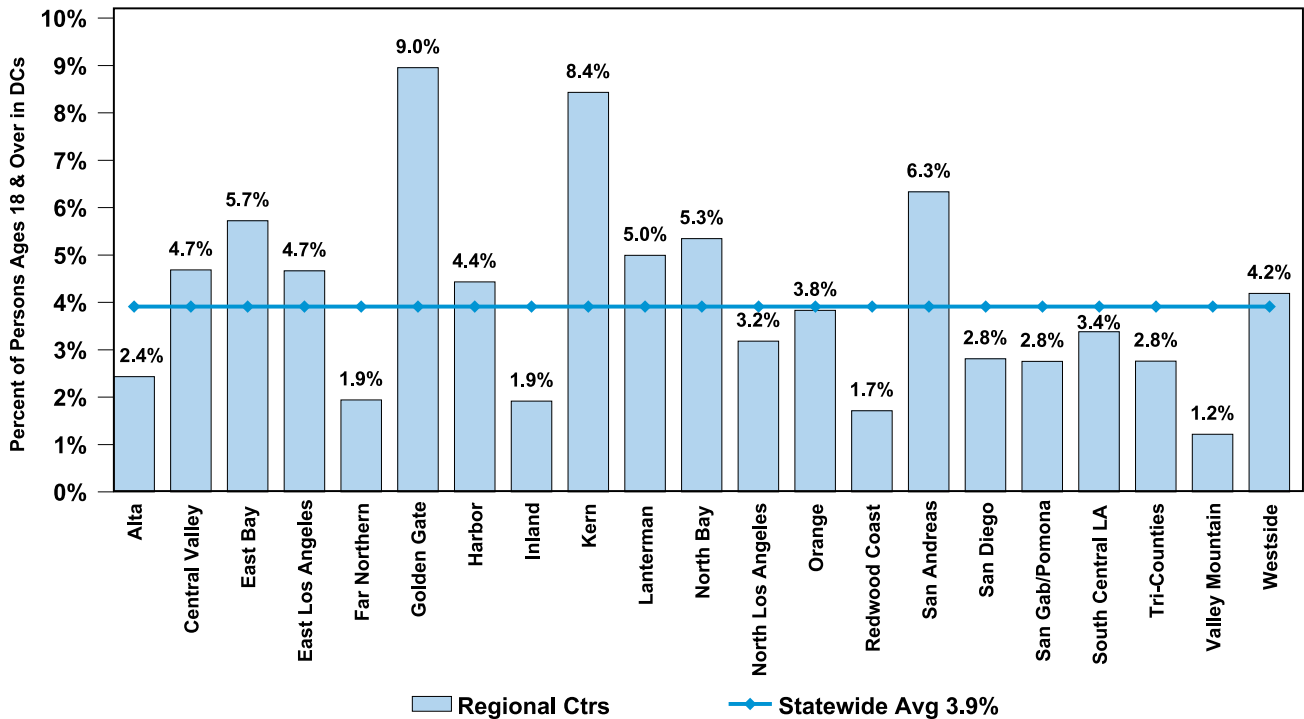
**Percentage of DDS-Served Population Residing in SDCs
Broken Out By Age Group**



Individuals Under Age 18 Residing in State Developmental Centers Broken Out By Regional Center Compared to Statewide Average



Individuals Age 18 and Over Residing in State Developmental Centers Broken Out By Regional Center Compared to Statewide Average



Caseload Age Composition Compared in 1995, 1998 and 2001

The age composition of the population DDS serves has been changing over the years. From June 1995 to June 2001, segments of the caseload from five through 19 years of age and from 45 through 54 years of age have been increasing, while the percentage of the population from 25 through 39 years of age has been decreasing. In June 1995, individuals ages five through 19 years composed 30.6 percent of the DDS caseload (39,957 persons out of 130,540 total). By June 2001, this age group represented 35.2 percent of the population (60,764 individuals out of 172,763 total). The percent of DDS's total caseload 45 through 54 years of age increased from 6.8 to 8.4 percent (8,917 out of 130,540 in June 1995 versus 14,560 out of 172,763 in June 2001).

While the number of persons ages 25 through 39 years increased from June 1995 to June 2001 (from 33,644 to 35,093 persons), this age group's share of the total population declined over these years. In June 1995, persons ages 25 through 39 represented 25.8 percent of the DDS caseload. By June 2001, this age group composed 20.3 percent of the total population served by DDS.

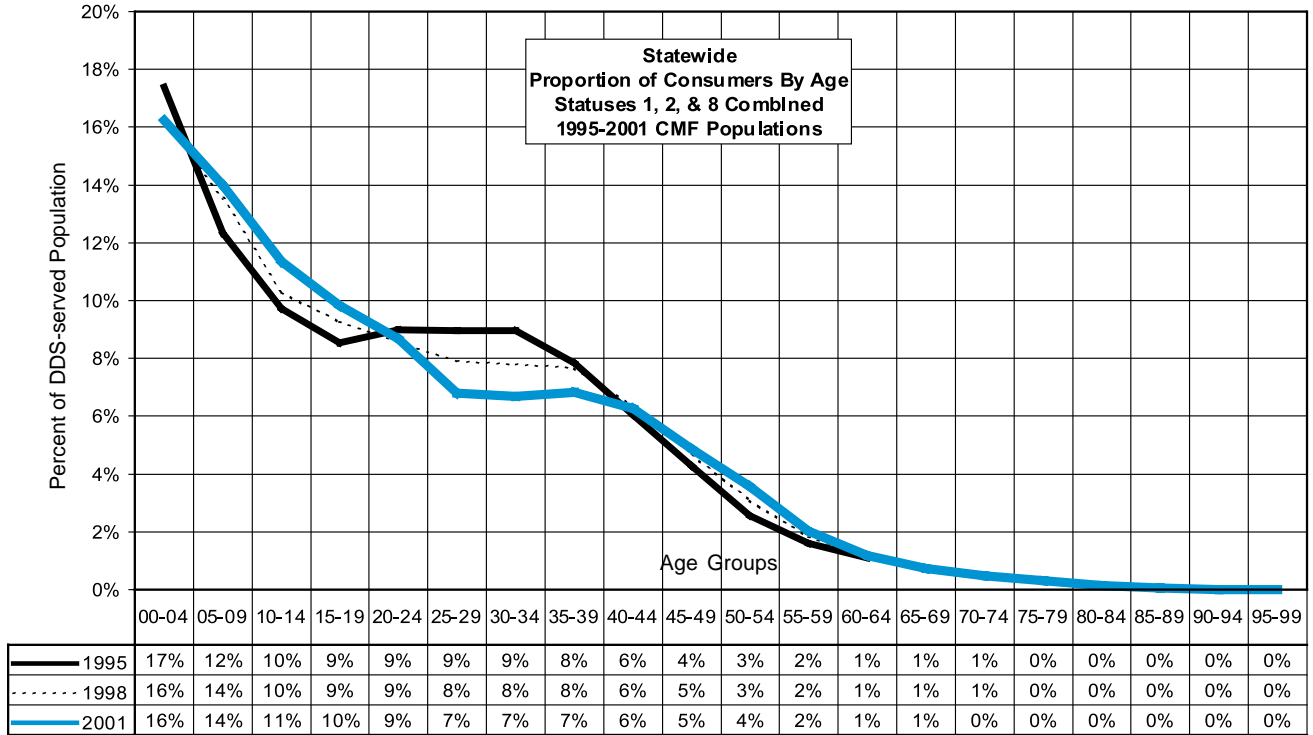
This analysis is based on caseload numbers drawn from only three points in time. Thus, caution is advised in using such a limited data set to make projections. However, the changes indicated in the graph on page 13 do warrant further attention. Implications for DDS may include increasing costs to purchase services for individuals who will no longer be eligible for services provided through the public education system (kindergarten through 12th grade) after they reach 22 years of age.

The table below provides the raw numbers by age group for the DDS caseload in June 1995, 1998 and 2001. Only persons with status codes 1, 2 or 8 were included in these caseload numbers.

**Number of Persons Served by DDS Broken Out By Age Group
in June 1995, June 1998, and June 2001
Based on Individuals with Status Codes 1, 2 or 8 on CMF**

| | | | | | | | | | | | |
|-----------|--------|--------|--------|--------|--------|--------|--------|--------|--------|-------|----------|
| Ages-> | 00-04 | 05-09 | 10-14 | 15-19 | 20-24 | 25-29 | 30-34 | 35-39 | 40-44 | 45-49 | |
| June 1995 | 22,681 | 16,111 | 12,687 | 11,159 | 11,716 | 11,711 | 11,691 | 10,242 | 7,899 | 5,586 | |
| June 1998 | 24,116 | 20,113 | 15,281 | 13,788 | 12,718 | 11,731 | 11,570 | 11,379 | 9,444 | 6,991 | |
| June 2001 | 28,046 | 24,190 | 19,593 | 16,981 | 14,978 | 11,757 | 11,532 | 11,804 | 10,841 | 8,411 | |
| Ages-> | 50-54 | 55-59 | 60-64 | 65-69 | 70-74 | C | 80-84 | 85-89 | 90-94 | 95-99 | All Ages |
| June 1995 | 3,331 | 2,076 | 1,413 | 987 | 678 | 364 | 146 | 37 | 22 | 3 | 130,540 |
| June 1998 | 4,589 | 2,708 | 1,656 | 1,084 | 767 | 440 | 167 | 66 | 15 | 7 | 148,630 |
| June 2001 | 6,149 | 3,512 | 2,042 | 1,240 | 828 | 533 | 224 | 78 | 17 | 7 | 172,763 |

**Statewide Age Distribution of Persons Served by DDS
Compared for the Years 1995, 1998 and 2001**



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 initial interview date) was analyzed for persons who entered the developmental services system during the seven-year period of January 1995 through December 2001. The following patterns were found:

- 53 percent of persons entering the developmental services system were under three years of age. Over 65 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 or guardians may be less able to continue providing the same level of support as they and their adult children age.

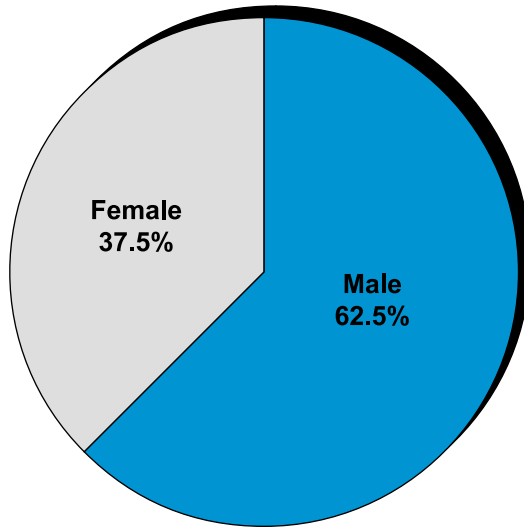
Information relating to the gender and age of persons engaged in the intake and assessment process in December 2001 is provided on the next page. Prior editions of the Fact Book offer similar information for December 1993, 1997, 1998, 1999, and 2000. Comparisons across the years may indicate changes 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 is 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 2001 (62.5% male to 37.5% female). In age distribution, the largest differences for persons engaged in intake in December 1993 compared to December 2001 was in the age groups of 3 thru 13 years and 22 thru 41 years combined. Those in the 3 thru 13 years of age group represented 30.9 percent of the intake population in December 1993 versus 36.9 percent in December 2001. Those in the 22 thru 41 years of age group composed 10.5 percent of the intake population in December 1993 compared to 6.7 percent in December 2001.

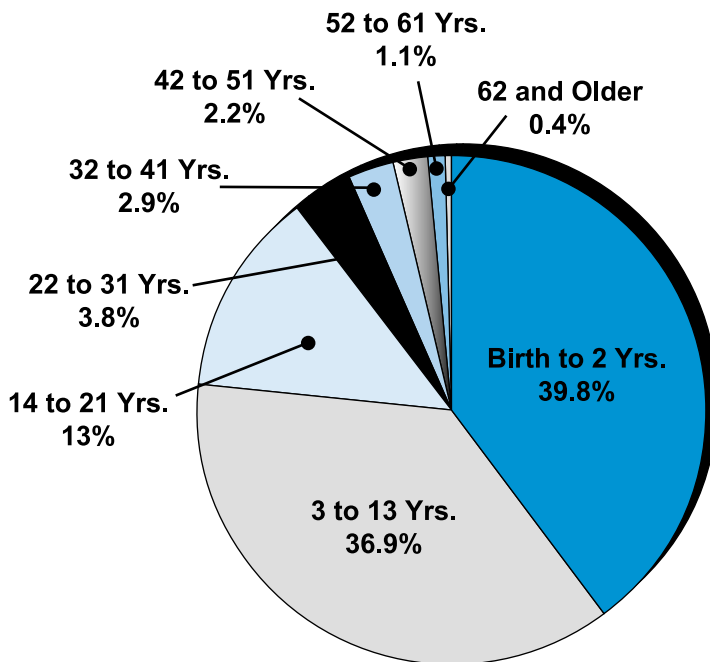
Of the 5,920 persons who received intake and assessment services in December 2001, 54.8 percent were determined eligible to receive services and had a “high risk infant” status (code 1) or an active status (codes 2 or 8) on the Client Master File as of July 5, 2002.

Demographics of Persons Engaged in the Intake and Assessment Process

Persons with Status Code 0
Based on Client Master File as of December 2001



| Gender | Number of Persons | Percentage of Total |
|--------------|-------------------|---------------------|
| Male | 3,702 | 62.5% |
| Female | 2,218 | 37.5% |
| Total | 5,920 | 100.0% |



| Age | Number of Persons | Percentage of Total |
|-----------------|-------------------|---------------------|
| Birth to 2 Yrs. | 2,357 | 39.8% |
| 3 to 13 Yrs. | 2,182 | 36.9% |
| 14 to 21 Yrs. | 768 | 13.0% |
| 22 to 31 Yrs. | 224 | 3.8% |
| 32 to 41 Yrs. | 170 | 2.9% |
| 42 to 51 Yrs. | 132 | 2.2% |
| 52 to 61 Yrs. | 65 | 1.1% |
| 62 and Older | 22 | 0.4% |
| Total | 5,920 | 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 Client Master File. Please refer to definition on page 1.

Characteristics of Persons with CDERs* on File as of December 2001

DDS collects data on the characteristics of the persons it serves. In the tables and charts that follow, information on four of the major developmental disabilities of persons served by DDS are presented for December 2001. Similar data have been reported for December 1993, 1997, 1998, 1999, and 2000 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 2001. For example, only 11.6 percent of the population served had “No Mental Retardation” recorded on their CDERs in December 1993. But by December 2001, the percent with “No Mental Retardation” had grown to 19.2 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 35.9 percent. The percent of the population with epilepsy and the percent with cerebral palsy also declined over this period from 26 to 22.4 percent for epilepsy and from 24.4 to 20.8 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 11.2 percent in December 2001.

The accumulated growth rates spanning December 1994 through December 2001 for the four major developmental disabilities are compared on page 20. In addition, the graph on page 21 displays information on the developmental disability combinations of persons served by DDS.

*Only persons with a current Client Development Evaluation Report (CDER) on file are included in the “Characteristics of Persons with CDERs on File” 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 (i.e., status code 2 - active client residing in the community or status code 8 - active client residing in a state developmental center) should have a current CDER on file. At the very least, a CDER is required to be updated every three years. As determined necessary, CDERs for some individuals are required to be updated more frequently. In addition, some regional centers may impose their own requirements that CDERs be updated more frequently (e.g., annual reviews). For children ages birth to three years, a different, age-appropriate assessment tool called the Early Start Report is used instead of the CDER.

| Mental Retardation | | |
|------------------------------------|--------------------------|-------------------|
| Level of Mental Retardation | Number of Persons | % of Total |
| Not MR | 28,694 | 19.2% |
| Mild | 58,381 | 39.0% |
| Moderate | 28,156 | 18.8% |
| Severe | 14,293 | 9.5% |
| Profound | 11,450 | 7.6% |
| Unknown | 8,832 | 5.9% |
| Total | 149,806 | 100.0% |

Mental Retardation is characterized by significantly subaverage general intellectual functioning (i.e., an IQ of approximately 70 or below) with concurrent deficits or impairments in adaptive functioning and onset before 18 years of age. Levels of retardation are reported as mild, moderate, severe, profound, or as not present or unknown.

| Epilepsy | | |
|---------------------|--------------------------|-------------------|
| Has Epilepsy | Number of Persons | % of Total |
| No | 116,282 | 77.6% |
| Yes | 33,524 | 22.4% |
| Total | 149,806 | 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 | 118,716 | 79.2% |
| Yes | 31,090 | 20.8% |
| Total | 149,806 | 100.0% |

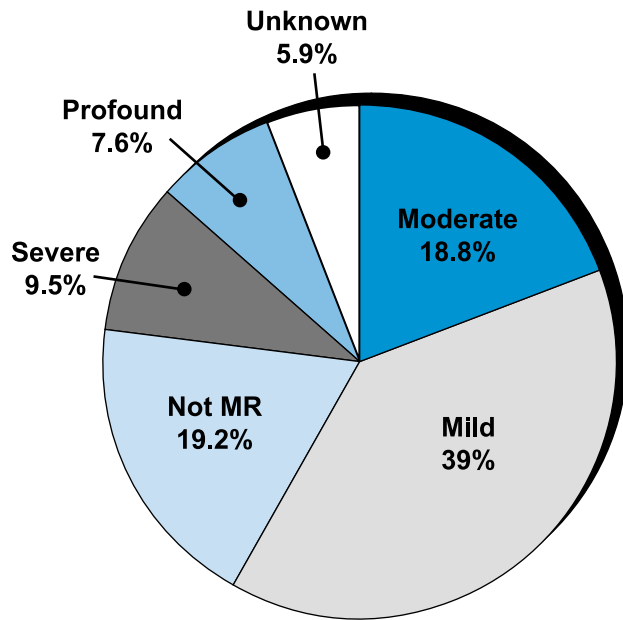
Cerebral Palsy includes two types of motor dysfunction: (1) nonprogressive lesion or disorder in the brain occurring during intrauterine life or the perinatal period and characterized by paralysis, spasticity, or abnormal control of movement or posture which is manifest prior to two or three years of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

| Autism | | |
|-------------------|--------------------------|-------------------|
| Has Autism | Number of Persons | % of Total |
| No | 133,004 | 88.8% |
| Yes | 16,802 | 11.2% |
| Total | 149,806 | 100.0% |

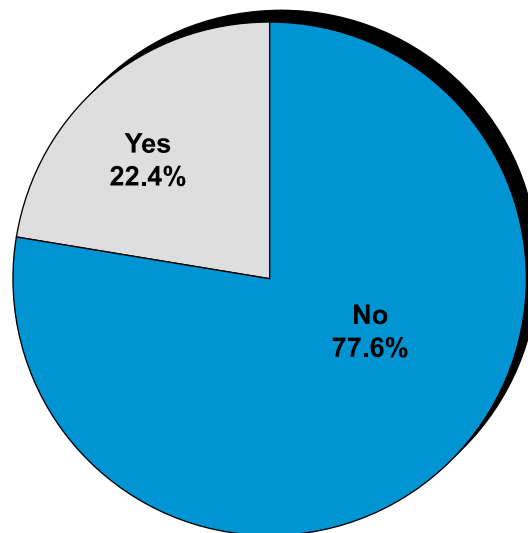
Autism is a neurodevelopmental disorder with multiple etiologies defined as a syndrome causing gross and sustained impairment in social interaction and communication with restricted and stereotyped patterns of behavior, interests, and activities that appear prior to the age of three. This item includes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

Note: Most children 0 - 3 years of age do not have a CDER and therefore are not reported.

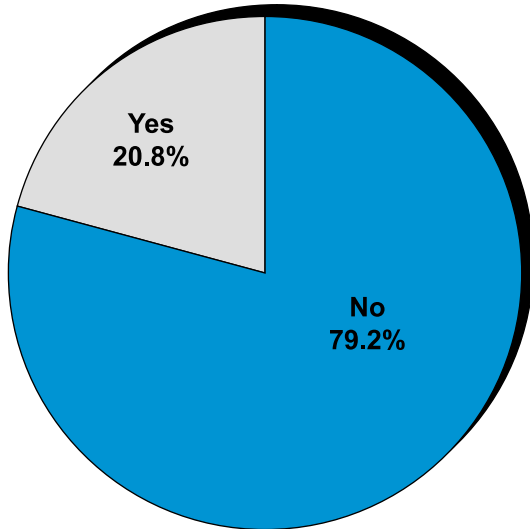
Level of Mental Retardation



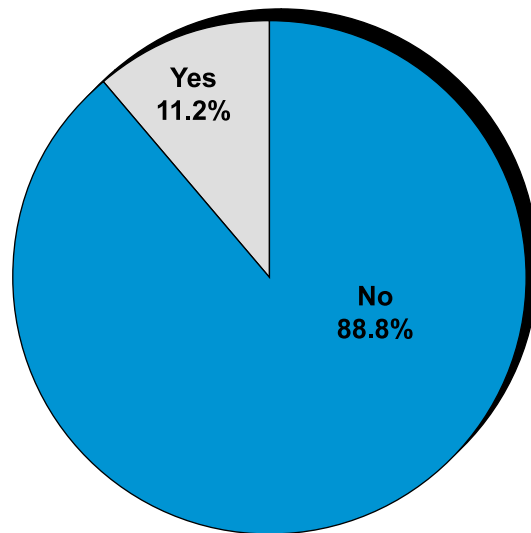
Epilepsy or Seizure Disorder



Cerebral Palsy or Similar
Motor Dysfunctions

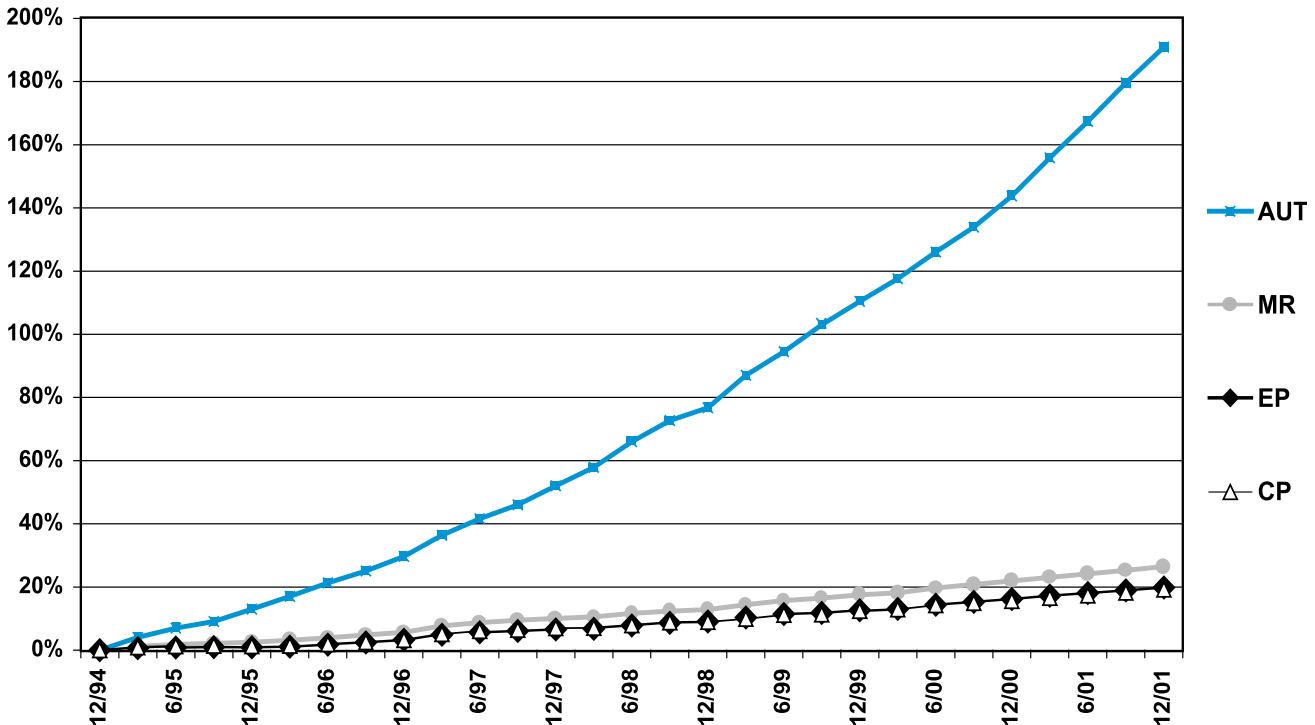


Autism



Trends of Four Major Developmental Disabilities Compared *Population Growth from December 1994 through December 2001* *Based on CDERs at Quarterly Intervals*

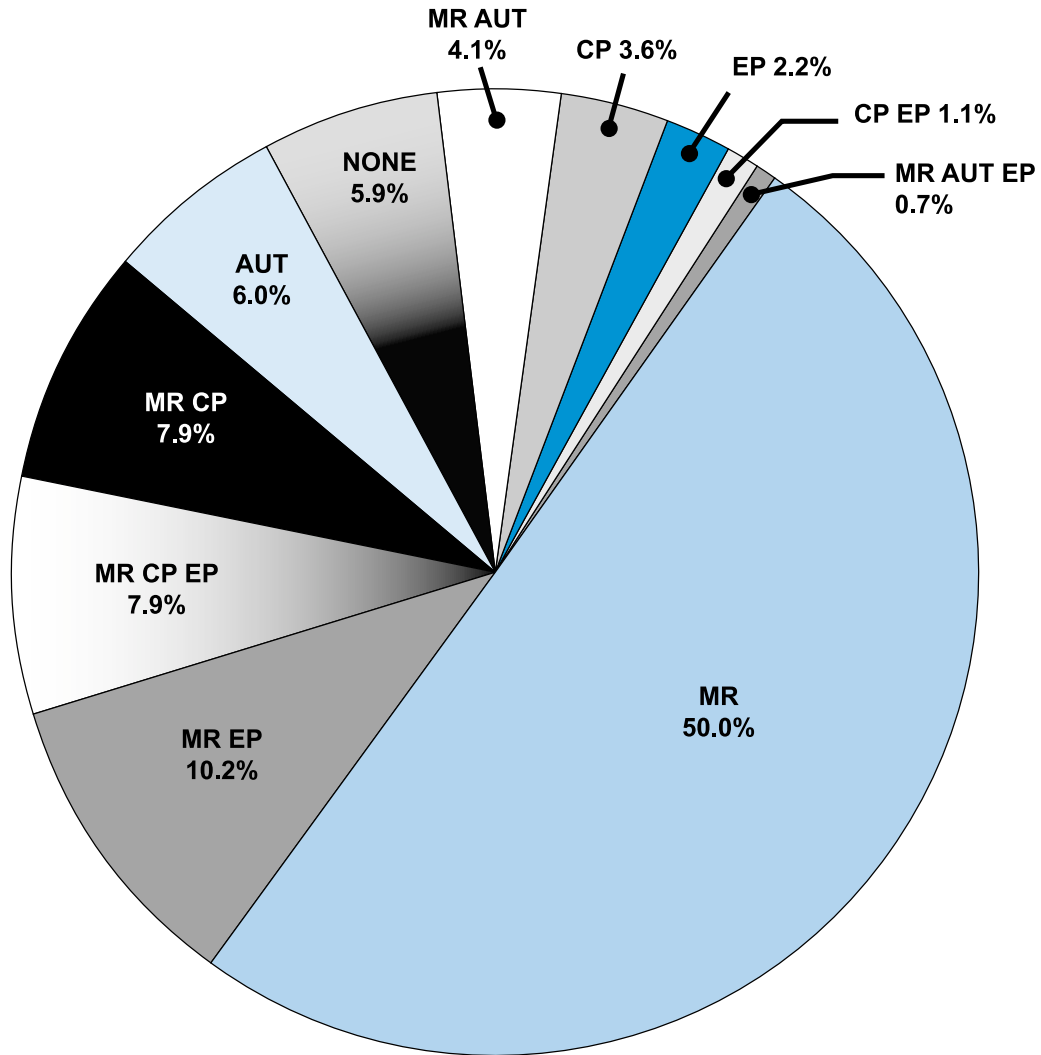
An examination of growth in the DDS-served population (defined here as persons who have current CDERs¹) for each of the four primary types of developmental disabilities over a six-year period, from December 1994 through December 2001, reveals an significant rate of growth for the group with autism compared to the other three developmental disabilities. While the total number of persons with current CDERs increased 37 percent (109,359 to 149,806), the number of persons with autism recorded on their CDERs grew 191 percent (5,775 to 16,802) from December 1994 through December 2001. During this same period, the other developmental disabilities showed the following growth: 1) mental retardation, 26 percent (95,773 to 121,112 persons); 2) epilepsy, 20 percent (27,972 to 33,524 persons); and 3) cerebral palsy, 19 percent (26,087 to 31,090 persons). As shown on the next page, individuals may have more than one type of developmental disability. Population numbers for each of the developmental disabilities mentioned above should not be added together, because there is duplication of persons across categories.



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

¹CDERs are required to be updated at least once every three years. Current CDERs, for purposes of our analysis, are those that have been updated within a three-year period.

Information on Developmental Disability Combinations
Based on December 2001 CDER



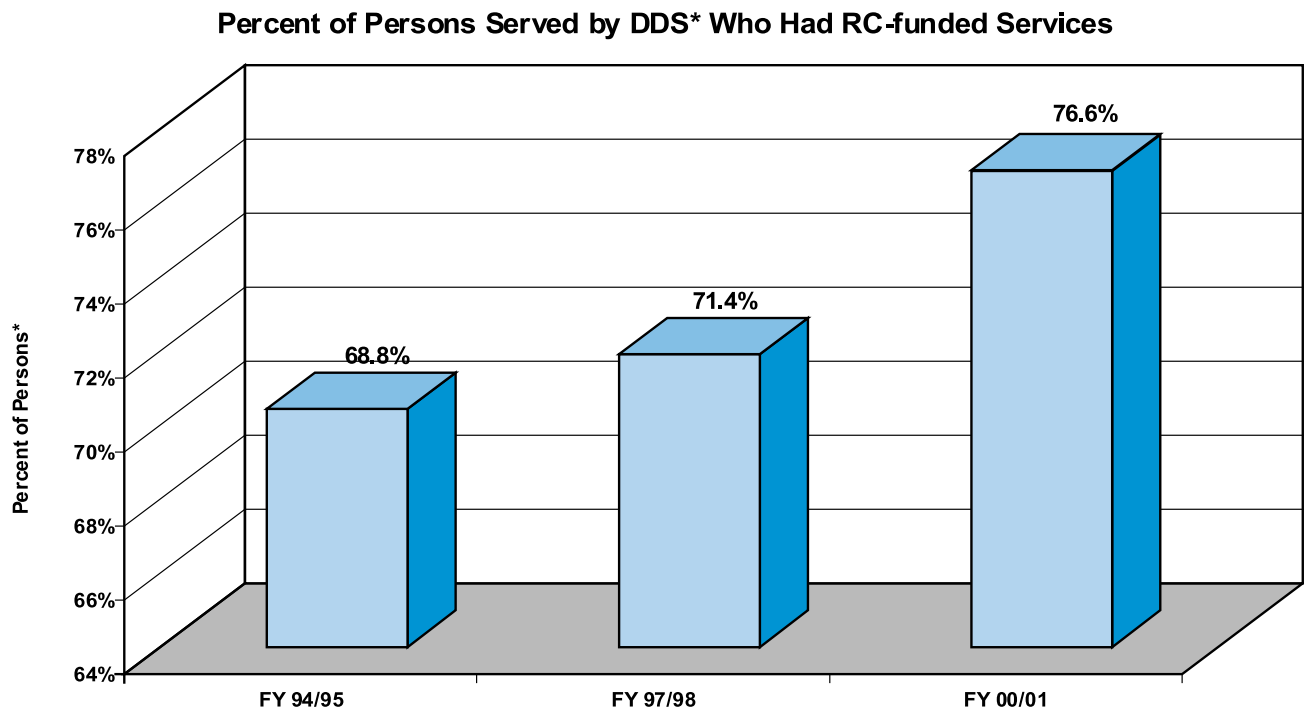
Note: The four major developmental disabilities have been abbreviated in the chart above as follows--Autism (AUT), Cerebral Palsy (CP), Epilepsy/Seizure Disorder (EP), and Mental Retardation (MR). The chart segment labeled "None" represents the fifth category of developmental disability defined as a 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

Percent of Persons Served by DDS in the Community Who Received One or More RC-funded Service(s), Fiscal Years 1994/95, 1997/98 and 2000/01 Compared

All persons served by DDS receive case management services through their local regional center (RC). However, not all persons receive purchased services through the RC system. 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).

While RCs are required to exhaust other resources available before purchasing services for individuals, the percent of the population served in the community (defined as persons with status codes 1 or 2 on CMF) who received RC-funded services increased steadily over the period from fiscal year (FY) 1994/95 through 2000/01. Of the 125,312 individuals served in June 1995, 68.8 percent (86,166 persons) received one or more service(s) purchased by an RC during FY 1994/95. In FY 1997/98, 71.4 percent of persons served as of June 1998 (103,237 persons out of 144,619 total) had at least one service purchased by the RCs. By June 2001, the percentage of persons served who had a service purchased by an RC in FY 2000/01 rose to 76.6 percent (129,439 individuals out of the total 169,022 total).

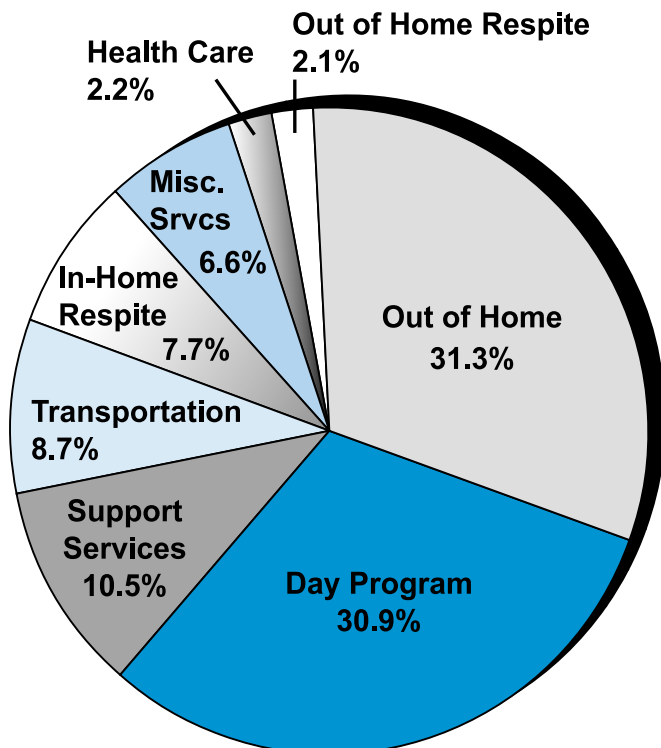


* Based solely on persons who had a status code 1 or 2 on CMF in June of the respective fiscal year.

Purchase of Service (POS) Expenditures by Budget Category for Fiscal Year 2000/01

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 fiscal year FY 2000/01, expenditures for these services totaled more than 1.4 billion dollars. In total dollars spent, each category increased from FY 1999/00 to 2000/01. However, between these years, certain budget categories decreased in terms of their relative shares of total POS dollars while others increased. Support Services and Miscellaneous Services increased the most, from 9.7 and 5.7 percents respectively, in FY 1999/00 to 10.5 and 6.6 percents in FY 2000/01. The budget categories with the largest decreases between these years were Day Program (from 32.2 to 30.9 percent) and Transportation (from 9.4 to 8.7 percent).

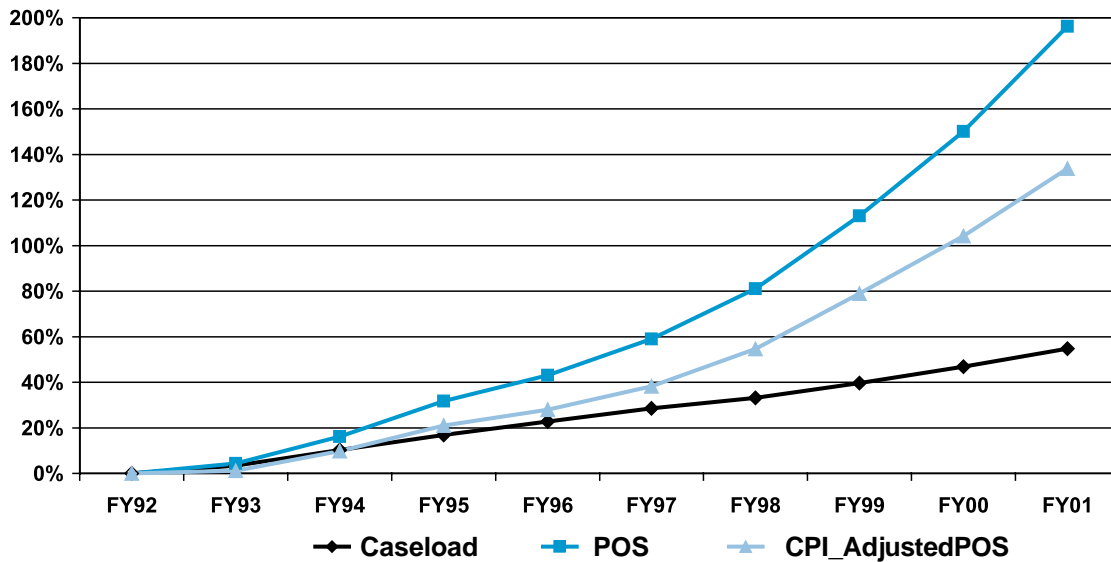


| Budget Category | POS Dollars | % of Total |
|---------------------|------------------------|---------------|
| Out of Home | 458,263,000 | 31.3% |
| Day Program | 451,964,346 | 30.9% |
| Support Services | 153,647,289 | 10.5% |
| Transportation | 127,185,577 | 8.7% |
| In-Home Respite | 113,088,953 | 7.7% |
| Misc. Services | 96,637,142 | 6.6% |
| Health Care | 32,377,771 | 2.2% |
| Out-of-Home Respite | 30,133,049 | 2.1% |
| Total | \$1,463,297,127 | 100.0% |

POS Expenditure Growth Compared to Caseload Growth During Fiscal Years 1991/92 through 2000/01

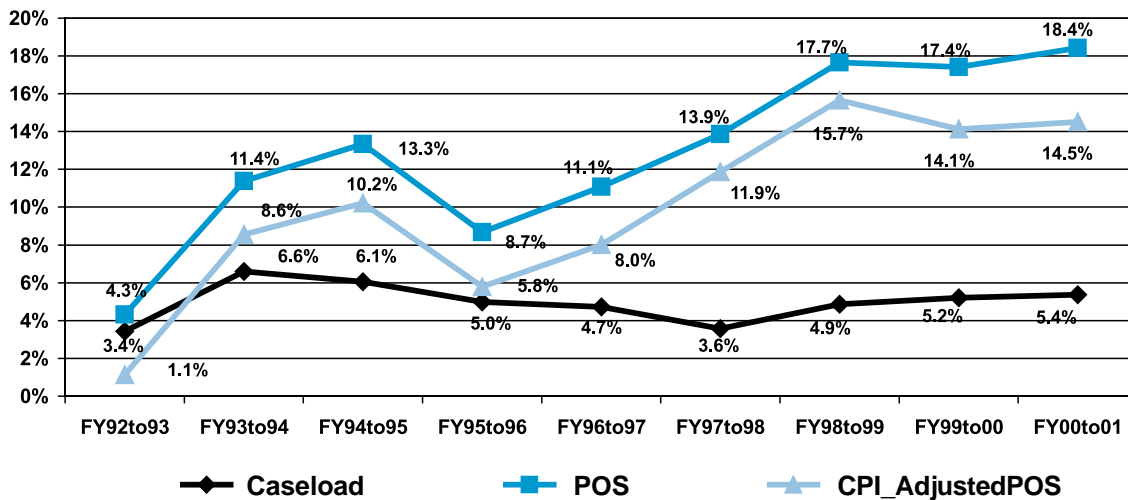
The cumulative rate of growth for POS expenditures over the period of fiscal year (FY) 1991/92 through FY 2000/01 totaled 196 percent. Even when POS expenditures were adjusted by the Consumer Price Index (CPI), the cumulative growth rate over the period totaled 134 percent. By comparison, the cumulative rate of growth for the DDS caseload (persons with status codes 1, 2 or 8 on CMF in June of each FY) totaled 55 percent.

**Comparison of Cumulative Growth in POS, CPI-adjusted POS,
and DDS Caseload Over Ten Year Period**



A look at the annual growth rates over this period reveals a somewhat different picture. While POS and CPI-adjusted dollars continued to increase between FY 1995 and FY 1996, they did so at a significantly slower pace than in the prior year and following years. The highest annual growth rate, in terms of CPI-adjusted dollars, occurred from FY 1998 to FY 1999.

**Comparison of Annual Growth Rates for POS, CPI-adjusted POS, and
DDS Caseload Over Ten Year Period**



POS Expenditure Changes : Fiscal Years 1998/99 through 2000/01

With only one exception, each of the service categories reflected increases in the POS dollars spent in fiscal year 2000/01 compared to fiscal year 1998/99. Although the dollars spent for “Day Programs” as a whole grew 25 percent between 1998/99 and 2000/01, fewer dollars were spent (7.2 percent less) for one component of “Day Programs,” namely “Social Recreation Programs,” in 2000/01 than in 1998/99.

While the total dollars expended in each service category are generally increasing, the rate of growth for expenditures in each service category varies greatly. The service category with the highest expenditure growth rate, albeit a small total dollar amount, is “Environmental & Vehicle Modifications” which increased over 110 percent between 1998/99 and 2000/01. Other service categories with high expenditure growth rates include “Supported Living & Related Services” (increased 64.7 percent), “Other ‘Look-Alike’ Day Programs” (grew 63.4 percent), “Non-medical Therapy Services” (rose 59.6 percent) and “Social/Recreational Activities” (increased 59.3 percent). In contrast, “Mobility Training” showed increased expenditures of less than one percent, and total dollars spent for “Activity Center” services, a subset of “Day Programs,” grew only 3.8 percent. Total POS expenditures increased 39.3 percent between fiscal years 1998/99 and 2000/01.

Although the rate of expenditure growth is one factor to consider when analyzing purchase of service history, the changes in total dollars for certain service categories as well as their relative shares of total POS dollars deserve attention. For example, while “Environmental & Vehicle Modifications” displayed the fastest expenditure growth rate (111.8 percent) between 1998/99 and 2000/01, the total dollar change was only \$611,224, and the service category’s share of total POS dollars in fiscal year 2000/01 was 0.08 percent. “Residential Services” had a far lower expenditure growth rate (45.6 percent) but increased \$140,908,924 from 1998/99 to 2000/01 and represented 30.8 percent of total POS dollars in fiscal year 2000/01.

Finally, it is important to note that regional centers have up to three years (the given fiscal year and two years thereafter) to submit purchase of service claims to DDS headquarters (HQ). As such, the POS file may not have final dollar amounts for a given fiscal year until two years later. The POS file at DDS HQ is updated monthly. Reports created using the POS file one month may reflect different dollar amounts than reports created in another month for the same fiscal year. Because POS-related articles featured in this Fact Book originated at different points in time, dollar amounts reflected from one article to another may not be comparable.

| POS Service Category | POS Expenditures by Fiscal Year | | | FY 99 to FY 01 % Change |
|---------------------------------------|---------------------------------|------------------------|------------------------|----------------------------|
| | FY 1998/99 | FY 1999/00 | FY 2000/01 | |
| Residential Services | \$309,330,843 | \$386,139,114 | \$450,239,767 | 45.6% |
| Adult Day Programs | \$324,140,313 | \$353,243,895 | \$405,118,530 | 25.0% |
| Activity Center | \$41,322,302 | \$41,201,608 | \$42,890,791 | 3.8% |
| Adult Development Center | \$158,469,100 | \$174,488,712 | \$200,006,687 | 26.2% |
| Behavior Management Program | \$68,667,084 | \$76,351,455 | \$89,404,756 | 30.2% |
| Independent Living Program | \$42,839,517 | \$46,299,996 | \$53,370,057 | 24.6% |
| Social Recreation Program | \$2,183,613 | \$2,049,747 | \$2,026,163 | -7.2% |
| Other "Look Alike" Programs | \$10,658,697 | \$12,852,377 | \$17,420,076 | 63.4% |
| Transportation | \$106,447,648 | \$114,363,238 | \$126,668,690 | 19.0% |
| Supported Living & Related Services | \$74,232,788 | \$91,571,755 | \$122,237,540 | 64.7% |
| Respite | \$75,782,422 | \$94,256,808 | \$118,818,945 | 56.8% |
| Infant Program Services | \$45,843,431 | \$53,760,217 | \$65,429,133 | 42.7% |
| Medical Care & Services | \$28,260,999 | \$36,055,824 | \$43,419,805 | 53.6% |
| Day Care | \$15,259,413 | \$18,828,435 | \$23,900,326 | 56.6% |
| Supplemental Program Support | \$13,677,346 | \$16,958,243 | \$21,110,602 | 54.3% |
| Behavioral Services | \$20,952,983 | \$23,171,334 | \$27,546,729 | 31.5% |
| Social/Recreational Activities | \$4,241,213 | \$4,947,485 | \$6,756,946 | 59.3% |
| Medical & Adaptive Equipment/Supplies | \$4,188,627 | \$4,360,976 | \$5,228,812 | 24.8% |
| Camps | \$2,294,979 | \$2,667,520 | \$3,227,990 | 40.7% |
| Non-medical Therapy Services | \$2,135,615 | \$2,853,200 | \$3,408,765 | 59.6% |
| Environmental & Vehicle Modifications | \$546,833 | \$677,554 | \$1,158,057 | 111.8% |
| Mobility Training | \$598,312 | \$659,435 | \$599,348 | 0.2% |
| All Other Services | \$23,390,827 | \$30,088,273 | \$39,200,274 | 67.6% |
| TOTAL | \$1,051,324,592 | \$1,234,603,306 | \$1,464,070,259 | 39.3% |

Growth in Dollars from Three Federal Sources Compared to Total POS in Fiscal Years 1997/98 through 2001/02

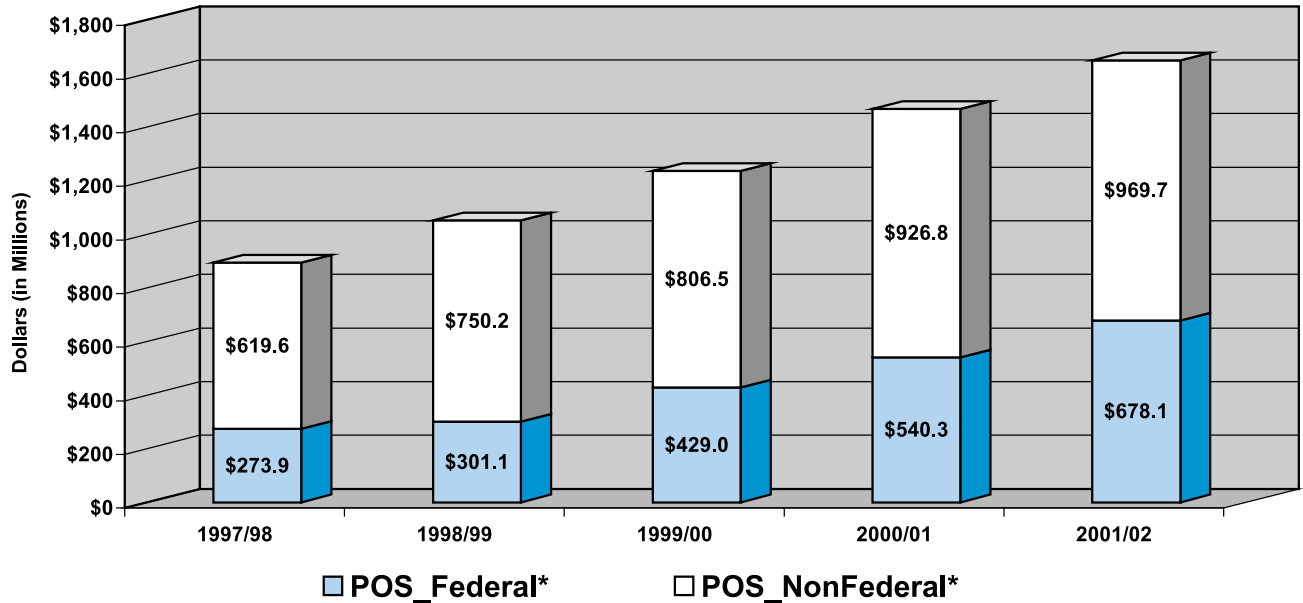
Federal sources of funding compose a significant portion of total Purchase of Services (POS) dollars. The Home and Community-based Services Waiver program (Waiver) is the largest source of federal reimbursement dollars. Through the Waiver program, the State is reimbursed approximately 50 percent for the costs of services to eligible individuals.

The Centers for Medicare and Medicaid Services (CMS) is the federal agency that certifies regional centers (RCs) for participation in the Waiver program. Because of deficiencies found at the RCs during CMS's compliance review in 1997, CMS froze the existing Waiver population. Beginning in fiscal year (FY) 2000/01, CMS began approving Waiver population expansion for certain RCs. Six RCs were approved in July 2000, two RCs in November 2000, and four more in December 2000. These expansions were approved retroactive to the beginning of October 1999. In August 2001, CMS approved expansion for an additional seven RCs retroactive to October 1, 2000. These changes in the Waiver population translated into increased funding, as can be seen in the graphs on the next page, especially in FY 2000/01 and FY 2001/02.

The Targeted Case Management program (TCM) provides Medicaid federal matching funds for case management services provided by RCs for eligible individuals. Case management services are defined as those that assist individuals in accessing needed medical, social, educational, and other services. As such, most of the cost of RC case managers' time spent on Medi-Cal eligible persons qualifies for federal financial participation.

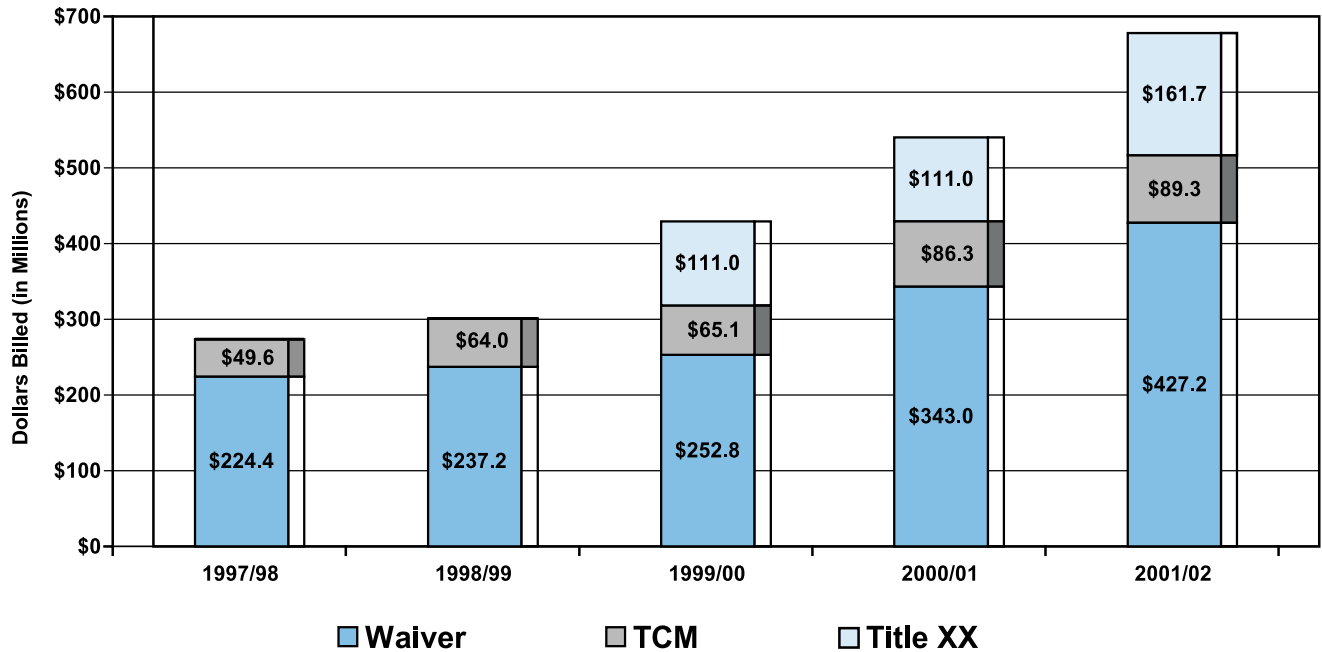
The Title XX Social Services Block Grant is a source of federal funds that requires no match in funding from state sources. The State has wide discretion in determining services to be provided using these funds, as long as they meet one of the goals established by Federal statute. These goals include: 1) achieving or maintaining economic self-support to prevent, reduce or eliminate dependency; 2) achieving or maintaining self-sufficiency; 3) preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interests, or preserving, rehabilitating or reuniting families; 4) preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care; and 5) securing referral or admission for institutional care when other forms of care are not appropriate, or providing services to people in institutions.

**Federal Billing Portion (Waiver, TCM, & Title XX) of Purchase of Service Dollars
in FY 1997/98 Through 2001/02**



*POS Federal denotes only the Federal dollars billed for Waiver, TCM and Title XX.
POS NonFederal includes all other POS dollars.

Federal Dollars Billed for Waiver (Not Including DOR Billing), TCM and Title XX
in Fiscal Years 1997/98 Through 2001/02**

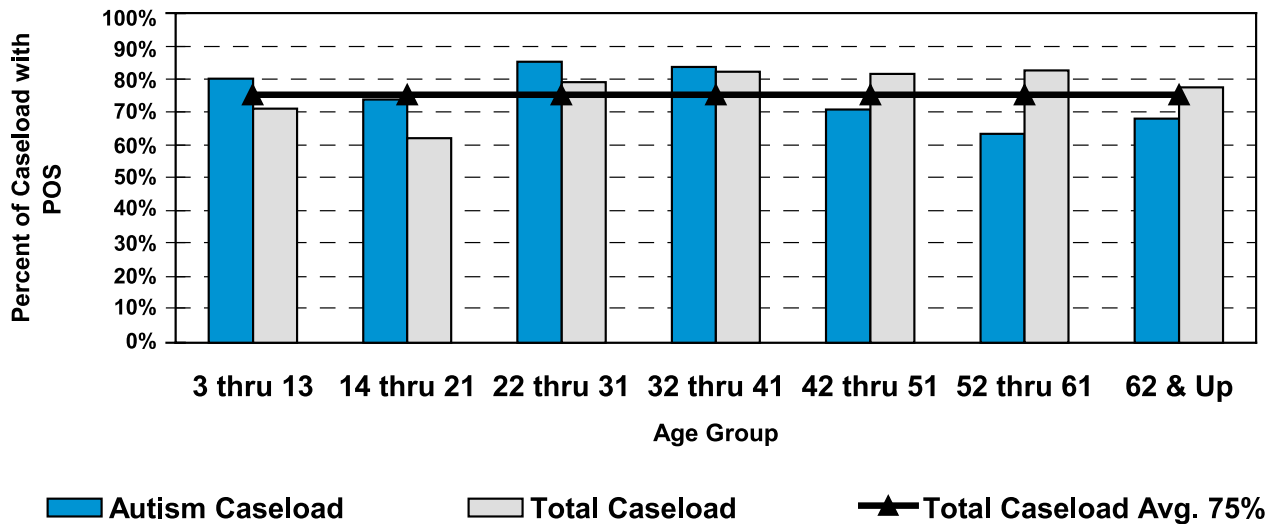


** The Department of Rehabilitation (DOR) serves some individuals who are active in the developmental services system. Federal dollars billed on behalf of DOR are not included in the graph shown above.

Persons Who Received RC-funded Services--Comparison Between Persons with Autism and Total Caseload, with Detail by Age

Persons with autism served by DDS were more likely than the general DDS-served population to receive RC-funded services in the age groups spanning three through forty-one years. However, beginning with the age group “42 thru 51” years and older age groups, the percent of the total DDS caseload who received RC-funded services was higher than the percent for persons with autism. The unique characteristics of persons with autism may be contributing factors in this shift. While there is no known cure for autism, early intervention services are known to mitigate the effects of autism in some instances. For some individuals, RC-funded services received in the earlier years may diminish or eliminate the need for RC-funded services when they are older.

Comparison of Percent of Autism Caseload with POS to Percent of Total Caseload with POS in FY 2000/01, Broken Out by Age Group



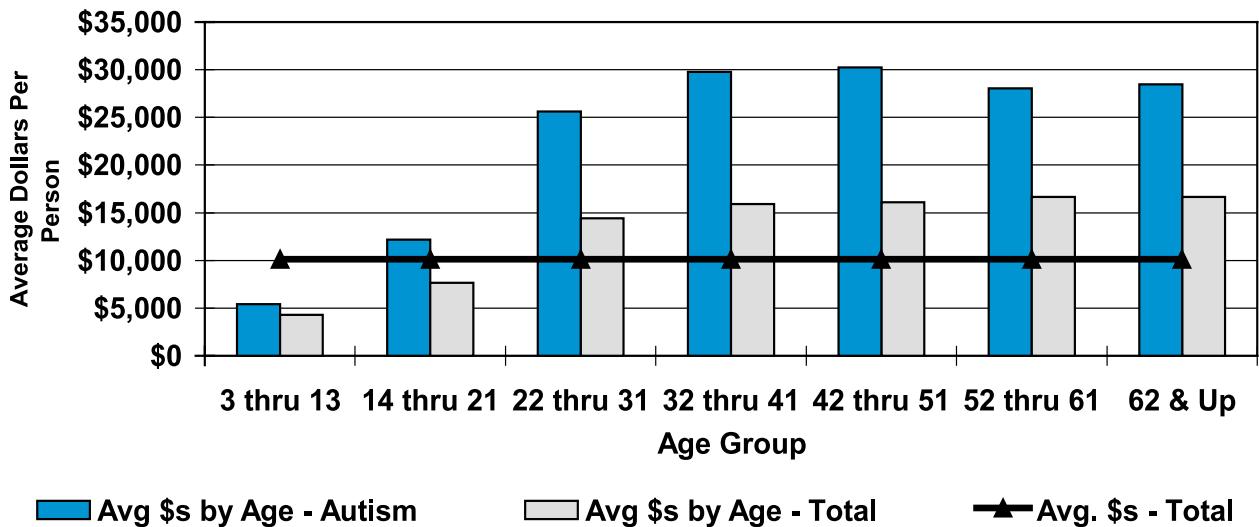
Overall, 75 percent of the total caseload (persons with status codes 1, 2, and 8) received at least one RC-funded service in fiscal year 2000-01.

Note: Individuals under age three were excluded from this article because children under age three seldom have a Client Development Evaluation Report (CDER), the data source used to identify persons with autism.

Average Per Capita POS Dollars Spent for Persons with Autism Compared to Persons in Total Caseload, with Details By Age

In fiscal year 2000/01, the average per capita Purchase of Service (POS) dollars spent for persons with autism was higher in every age group than the average per capita POS dollars spent for the DDS-served population in general. The largest variance in per capita POS dollars was for the age group “42 thru 51” years in which \$14,137 more, on average, was spent on persons with autism than on persons in DDS’s total caseload. The age group “32 thru 41” years followed closely with a spread of \$13,858 dollars between the average amount spent on individuals with autism and average dollars spent on persons in the total caseload. The smallest difference in per capita POS dollars occurred in the age group of “3 thru 13” years. In this age group, persons with autism received on average only \$1, 116 more in RC-funded services than the general DDS-served population. Overall, the average per capita POS dollars spent in fiscal year 2000/01 was \$10,148.

Comparison of Average Dollars by Age for Autism Caseload to Average Dollars by Age for Total Caseload in FY 2000/01



Note: Individuals under age three were excluded from this article because children under age three seldom have a Client Development Evaluation Report (CDER), the data source used to identify persons with autism.

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