

Department of Developmental Services

Fact Book **Fourth Edition**



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





PENCIL PORTRAITS
1971-1990

Drawings by Martha Perske
Introduction by Robert Perske

Abingdon Press
Nashville

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Preface

The Fact Book is a collection of pertinent data about persons served by the Department of Developmental Services (DDS) through December 2000. The information presented in the Fact Book is intended to provide an overview to the reader and assist in an overall understanding of services and trends in California. We hope you will find this information useful in better understanding the DDS service delivery 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 five State-operated developmental centers (SDCs).

A “developmental disability” (DD) is a condition that originates before an individual attains age 18; continues, or can be expected to continue indefinitely; and constitutes a substantial handicap. 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 fourth edition of the Fact Book also features new material on the primary languages of persons with developmental disabilities (pp. 10-11) and the Foster Grandparent Program and Senior Companion Program (pp. 20-21).

The Fact Book and additional information concerning the Department of Developmental Services is available on the DDS home page at www.dds.ca.gov. Other questions may be directed to our Information and Web Services Section at (916) 654-1753. The data contained in this publication were reported electronically to DDS Headquarters and compiled by the Department’s Information and Web Services Section.

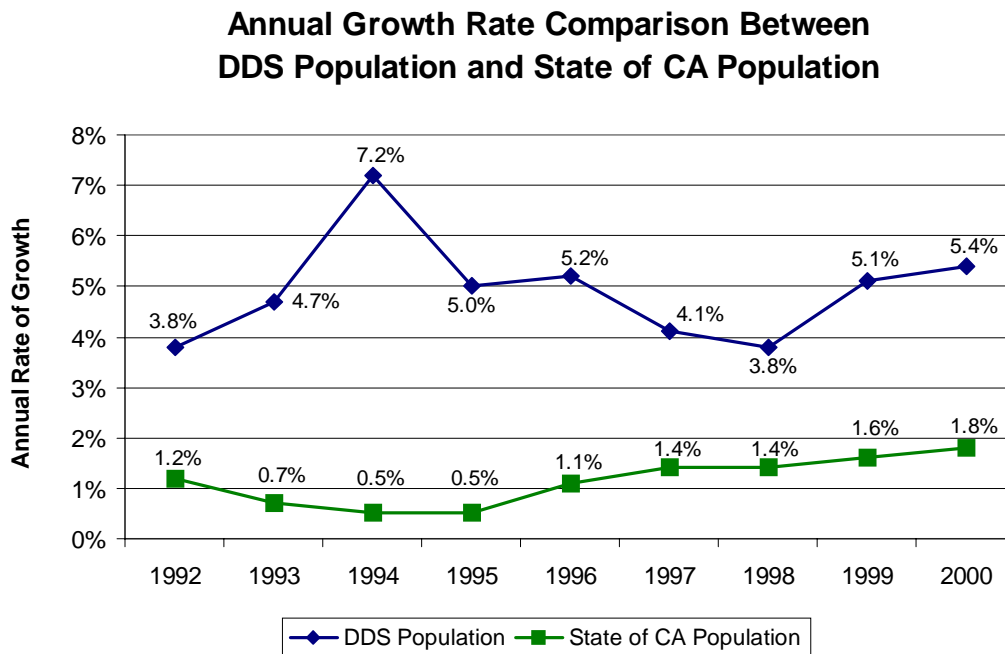
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Caseload

The number of persons served by the Department increased 53.5 percent between January 1992 and December 2000. During this same period, the State developmental center (SDC) population decreased 43.4 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 2000 according to Department of Finance data, California's general population grew approximately 9.8 percent. As of January 2000, about 0.47 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. Consumers with a status code 1 qualify for early intervention and prevention services.

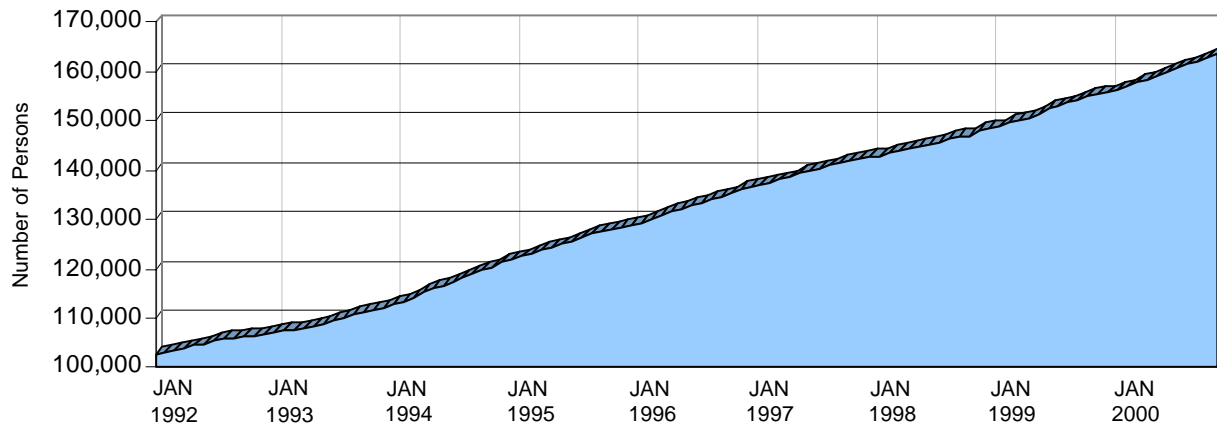
* **Status Code 2:** Persons who have been diagnosed as having a developmental disability and are served in the community (not in an SDC). Another term sometimes used to denote status code 2 is "Active Status".

* **Status Code 8:** Persons who have been diagnosed as having a developmental disability and are 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.

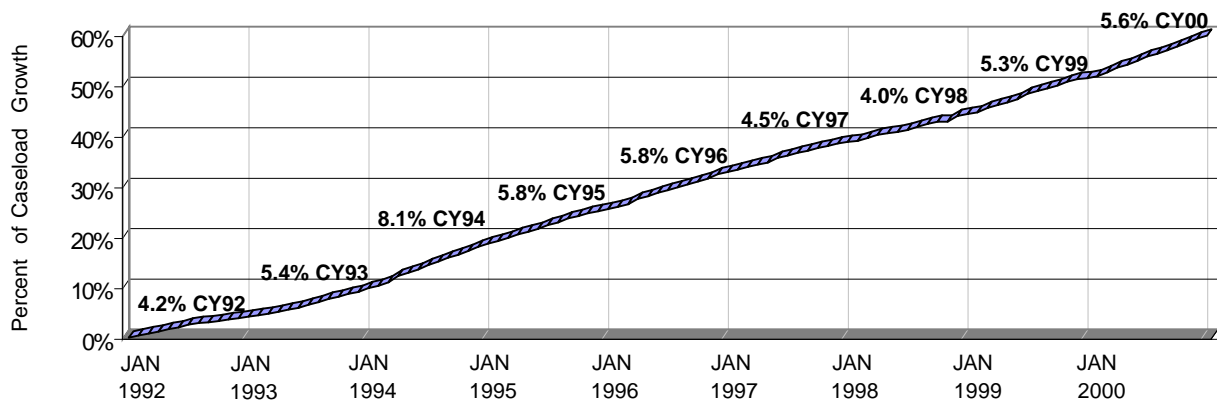
Community Caseload

Caseload Growth*
1/92 thru 12/00



*Persons with status codes 1 and 2.

Annual Percent of Caseload Growth*
1/92 thru 12/00

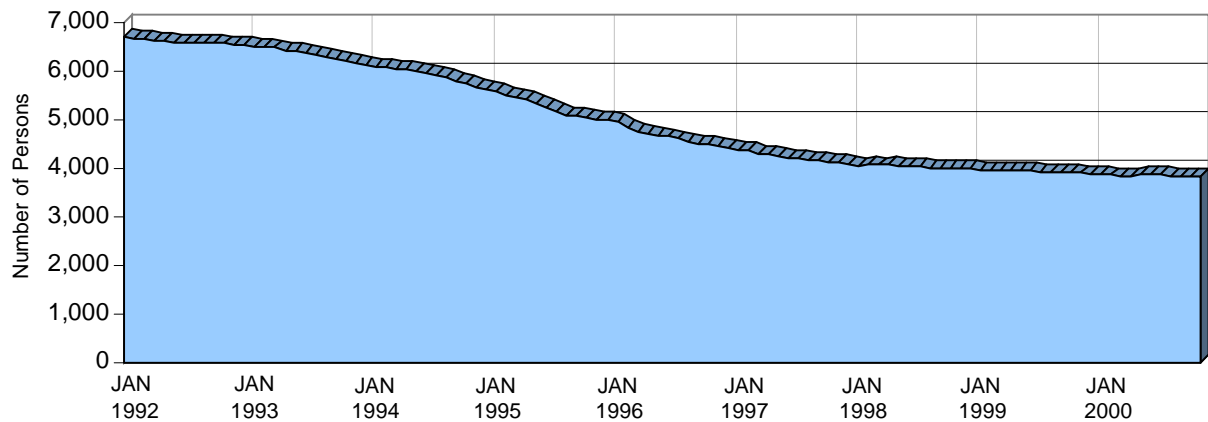


*Persons with status codes 1 and 2.

Note: In graph above, CY means Calendar Year.

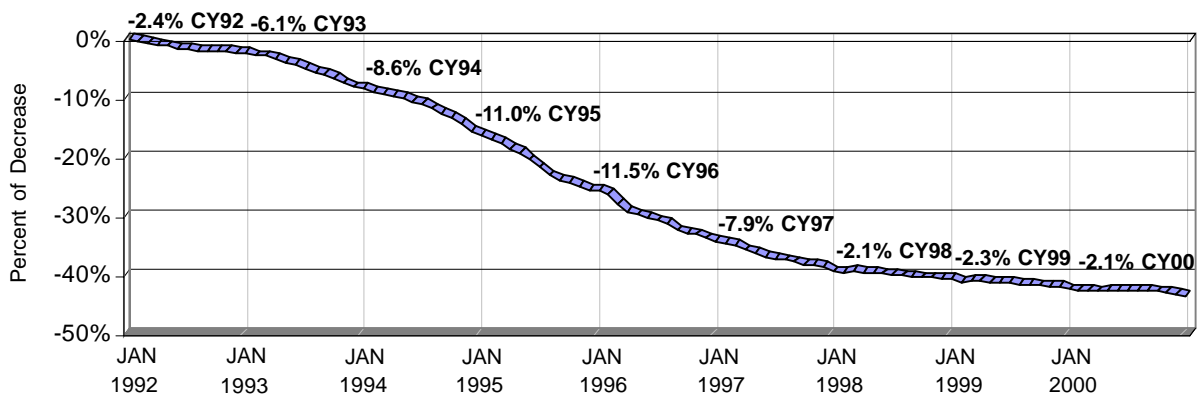
State Developmental Center Residents

Number of SDC Residents*
1/92 thru 12/00



*Persons with status code 8.

Annual Percent Decline in SDC Resident Numbers*
1/92 thru 12/00



*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 2000. 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 the prior Fact Book editions.

The trend in the gender distribution of persons served by DDS continued in 2000 with males still outnumbering females. In December 1993, 56.4 percent of persons served were male versus 43.6 percent female. In December 2000, the gap widened to 58.5 percent male versus 41.5 percent female.

Age distribution trends for persons served by DDS continued as well. In general, the DDS-served population is increasingly younger (*percent of persons ages birth through 21 grew from 49.4 to 54.7 between December 1993 and 2000*) and increasingly older (*the percent of individuals ages 42 through 61 increased from 12 to 16.9 during the same period*).

Changes in the residence types of persons served by DDS are also worth noting. While 62.6 percent of persons resided in the home of a parent or guardian in December 1993, 68.3 percent had this residence type in December 2000. During this same period, decreases continued in the proportion of persons who resided in community care settings (19.9 to 15.7 percent) and Developmental Centers (5.1 to 2.2 percent).

Significant changes occurred in the ethnic makeup of the DDS-served population. The proportion of whites decreased from 51.5 percent in December 1993 to 43.7 percent in December 2000. The proportion of Hispanics increased from 23.9 to 27.8 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 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 2000**

Gender	Number of Persons	Percentage of Total
Male	98,392	58.5%
Female	69,732	41.5%
Total	168,124	100.0%

Age	Number of Persons	Percentage of Total
Birth to 2 Yrs.	17,477	10.4%
3 to 13 Yrs.	48,286	28.7%
14 to 21 Yrs.	26,148	15.6%
22 to 31 Yrs.	24,655	14.7%
32 to 41 Yrs.	23,151	13.8%
42 to 51 Yrs.	16,906	10.1%
52 to 61 Yrs.	7,527	4.5%
62 and Older	3,973	2.4%
Total	168,123	100.0%

Residence Type	Number of Persons	Percentage of Total
Own Home-Parent	114,886	68.3%
Community Care	26,370	15.7%
ILS/SLS	14,622	8.7%
SNF/ICF	8,489	5.0%
Developmental Center	3,757	2.2%
Total	168,124	100.0%

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

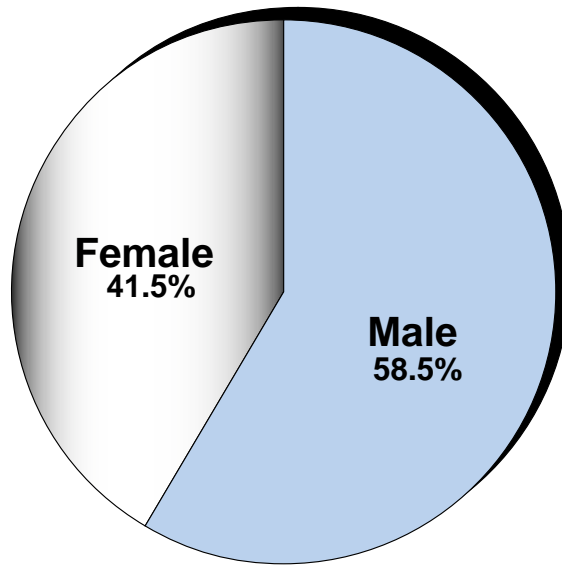
SNF/ICF: Skilled Nursing Facility/Intermediate Care Facility.

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

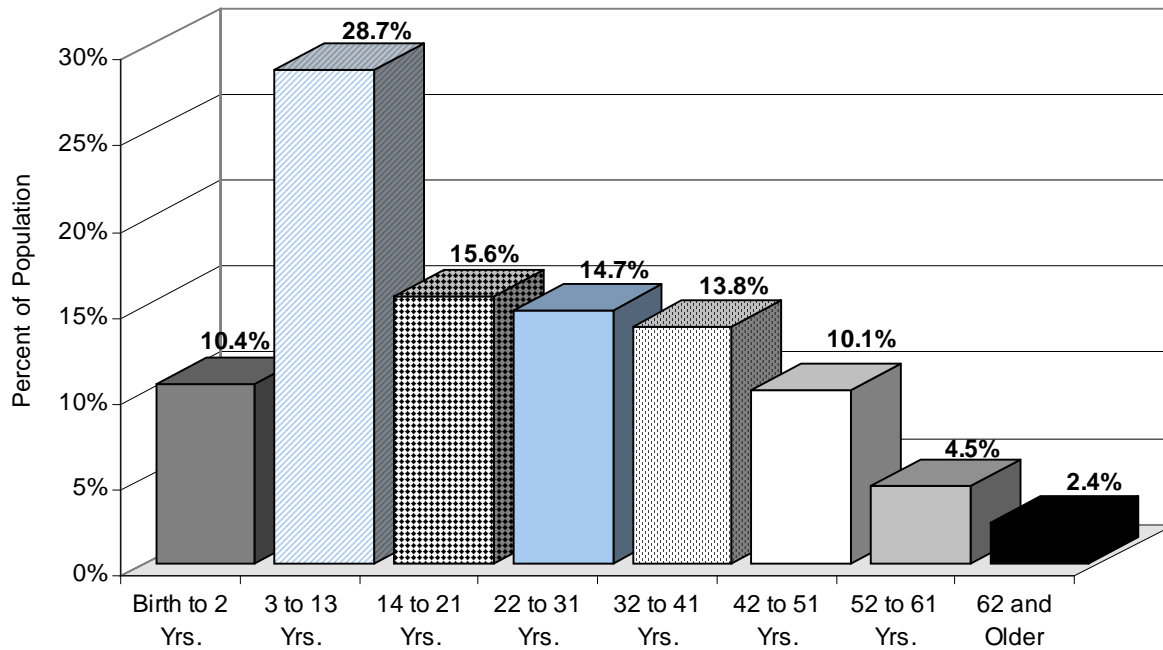
Ethnicity	Number of Persons	Percentage of Total
White	73,513	43.7%
Hispanic	46,806	27.8%
Black	16,991	10.1%
Asian	7,755	4.6%
Filipino	2,785	1.7%
Native American	635	0.4%
Polynesian	300	0.2%
Other	19,339	11.5%
Total	168,124	100.0%

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.

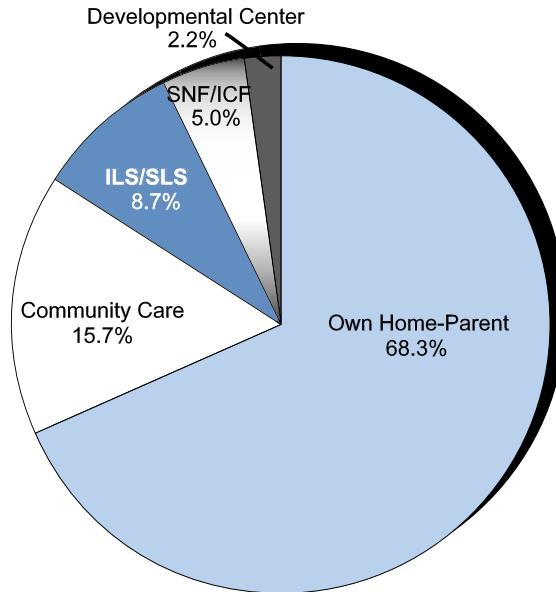
Gender of Individuals Served by DDS



Age of Individuals Served by DDS

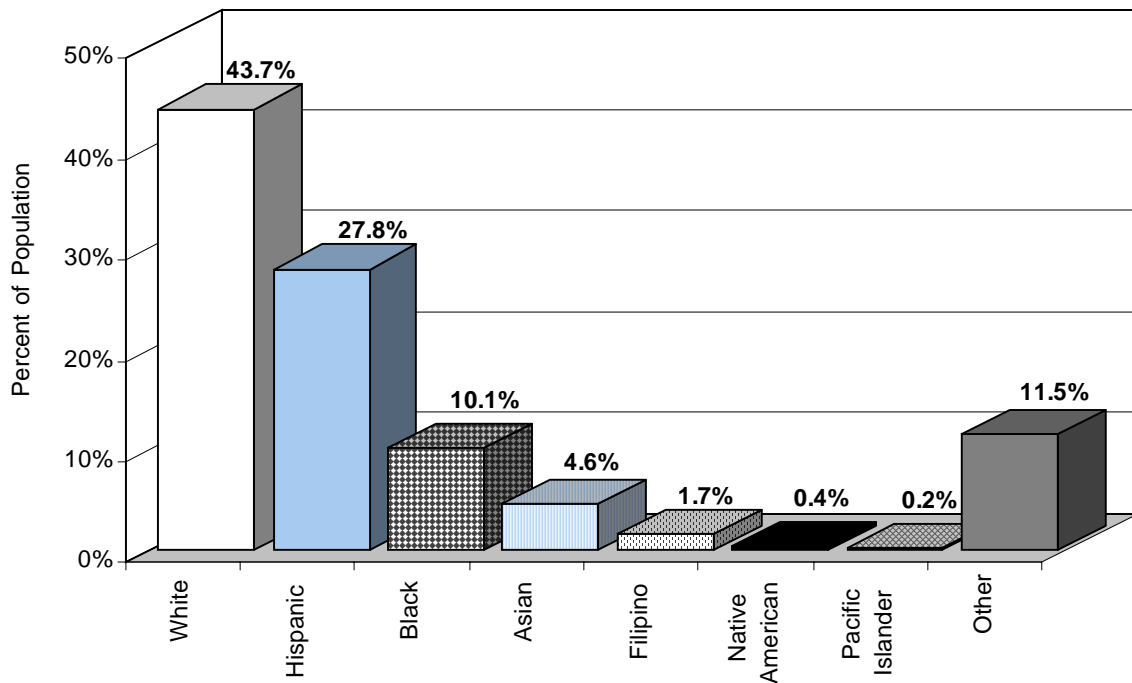


Residences of Individuals Served by DDS



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

Ethnicity of Individuals Served by DDS



Residence Types of Persons with Developmental Disabilities by Age Group in December 1995 and December 2000

During the period from December 1995 through December 2000, consumers in both the “Birth thru 17” and “18 and Older” age groups increased in the percentages residing in the home of a parent or guardian (labeled “Own Home-Parent” in the tables below) and decreased in the percentages 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 consumers 18 years of age and older residing in independent and supported living settings also increased between December 1995 and December 2000. 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 thru 17				
Residence Type	as of Dec. 1995		as of Dec. 2000	
	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
Own Home-Parent	53,078	89.3%	72,380	91.7%
Community Care	5,453	9.2%	5,792	7.3%
SNF/ICF	698	1.2%	699	0.9%
Developmental Center	233	0.4%	103	0.1%
Total	59,462	100.0%	78,974	100.0%

Individuals Ages 18 and Older				
Residence Type	as of Dec. 1995		as of Dec. 2000	
	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
Own Home-Parent	33,710	45.5%	42,505	47.7%
Community Care	19,179	25.9%	20,583	23.1%
ILS/SLS	10,047	13.6%	14,617	16.4%
SNF/ICF	6,393	8.6%	7,790	8.7%
Developmental Center	4,704	6.4%	3,654	4.1%
Total	74,033	100.0%	89,149	100.0%

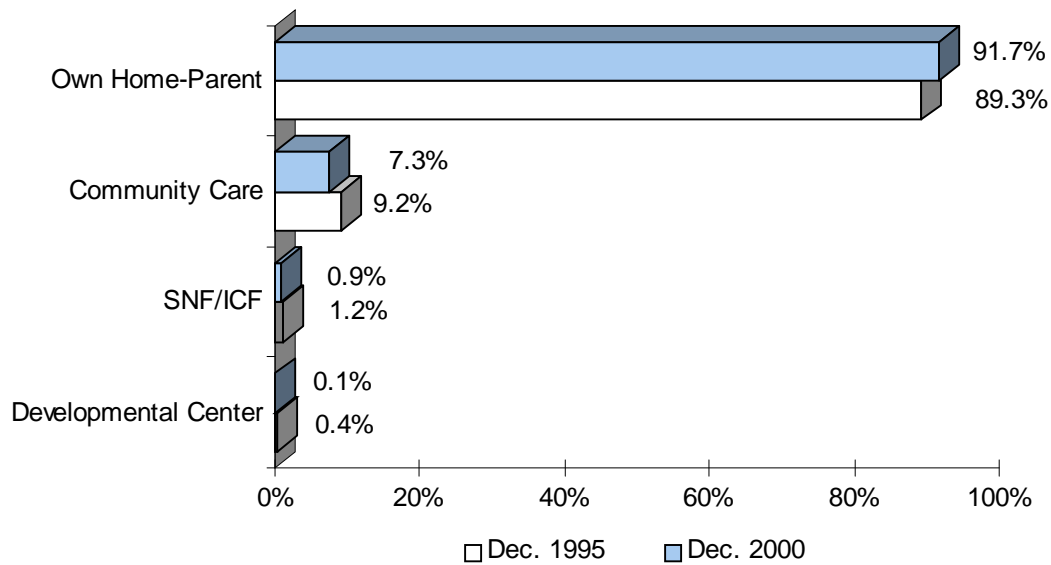
Note: The tables above include only persons with status codes 1, 2 and 8.

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

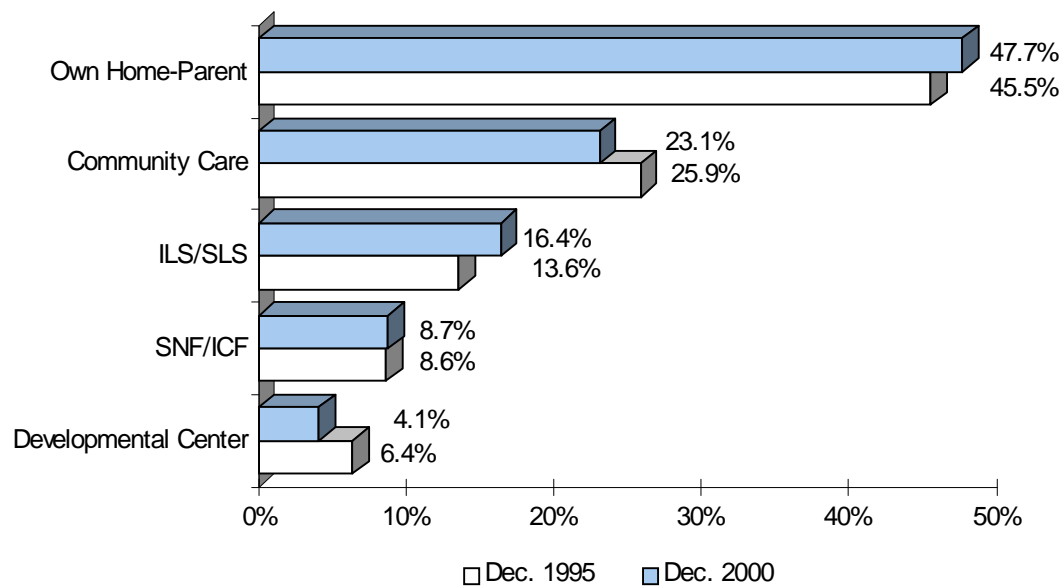
SNF/ICF: Skilled Nursing Facility/Intermediate Care Facility.

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

Individuals Ages Birth Through 17



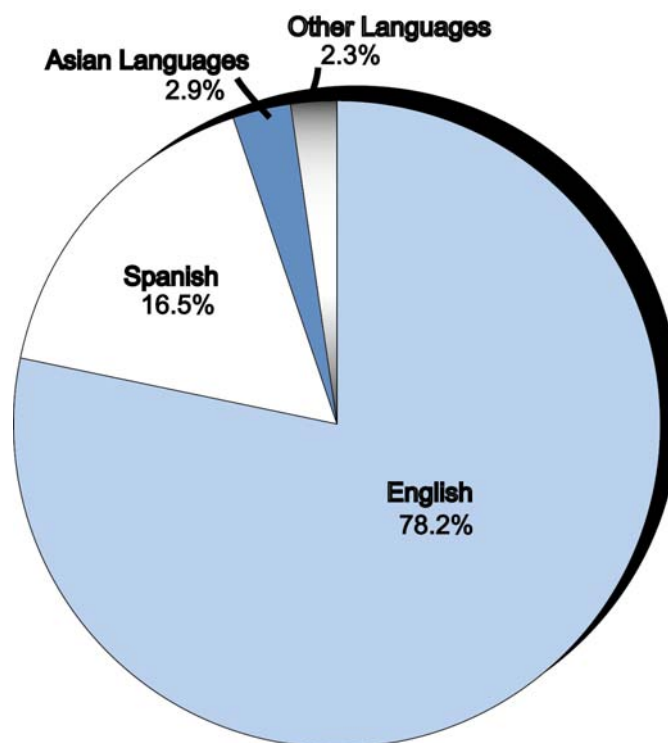
Individuals Ages 18 and Older



Primary Languages of Persons with Developmental Disabilities Based on Client Master File

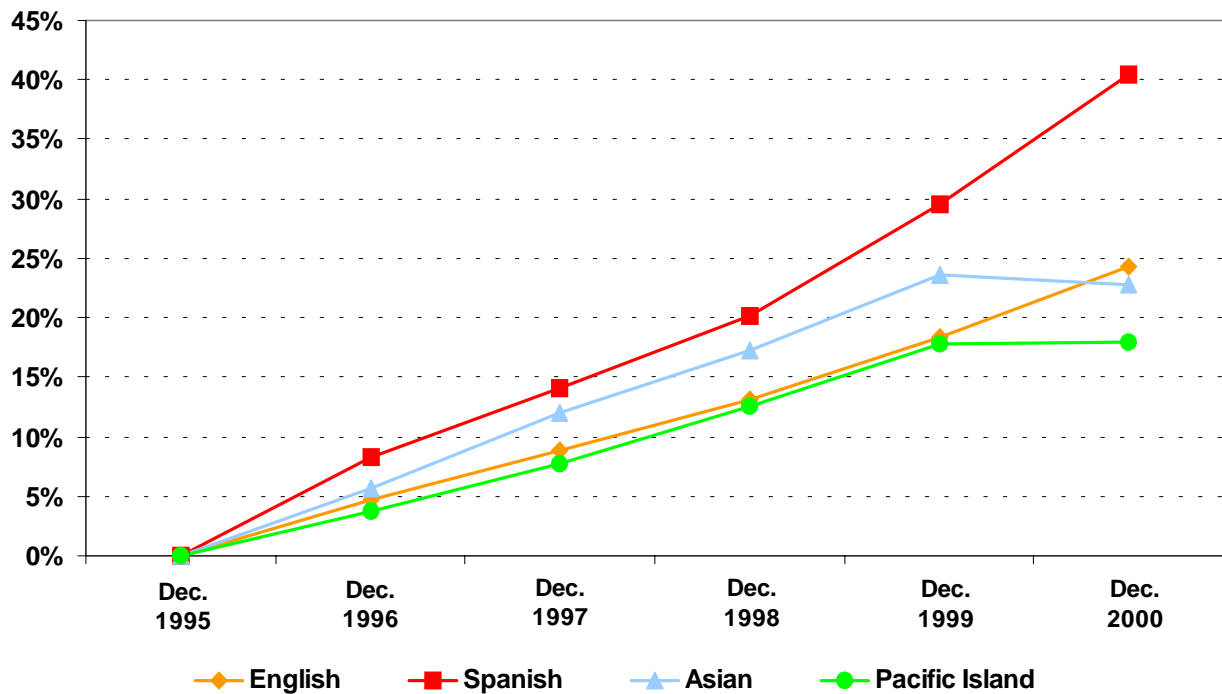
As of December 2000, over 94 percent of the persons served by DDS (i.e., persons with status 1, 2 or 8) had a primary language of English or Spanish. Asian languages¹ accounted for another three percent of the DDS caseload. Other primary language groups (i.e., Pacific Island, Indo-Iranian, Semitic, Slavic/Ural, Germanic/Scandinavian, other languages and combinations) each composed less than one percent of the population served by DDS.

During the period from 1995 through 2000, the population growth rate for persons served by DDS with Spanish as primary language was almost double the growth rate for persons with English as primary language. Through December 1999, the population growth rate for persons served by DDS with an Asian primary language also outpaced the population growth rate for persons with English as primary language. However, as of December 2000, both the number of individuals and growth rate declined for persons served by DDS who have an Asian primary language.



Population Growth Rate by Primary Language Group

Based on Client Master File, as of December 1995 thru 2000



Age of Persons at Time of Intake Into DDS 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 DDS system during the seven-year period of January 1994 through December 2000. The following patterns were found:

- Over 50 percent of persons entering the DDS system were under three years of age. About 63 percent were five years of age or younger.
- Entries into the DDS 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 DDS system was found as individuals hit their mid 30s. A possible explanation for this increase may be that parents or guardians may be less able to continue providing the same level of support as they and their adult children age.

Unlike other states where persons with developmental disabilities can experience long delays prior to receiving services, California law mandates that the eligibility of persons to receive DDS-funded services be determined as soon as possible. As of July 1, 2000, the number of days allowed for a person age three or older to be assessed reverted to 60 days. In addition to the 60 days allowed for assessment, 15 working days are allowed for the initial intake process.¹ For applicants who are under age three, the assessment process should be completed within 45 days.² At the completion of the intake and assessment process, a determination of the applicants eligibility to receive DDS services is made.

Information relating to the gender and age of persons engaged in the intake and assessment process in December 2000 is provided on the next page. Prior editions of the Fact Book offer similar information for December 1993, 1997, 1998 and 1999.

The percentage of persons ages birth through two years increased from 35.4 percent of the intake population in December 1999 to 40.7 percent in December 2000. In contrast, the age group three through thirteen years which accounted for 39.4 percent of the intake population in December 1999 decreased to 36.3 percent of the population in December 2000.

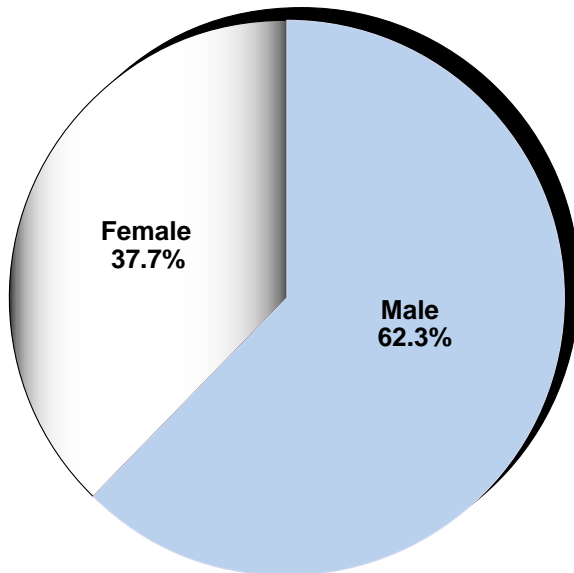
Of the 6,021 persons who received intake and assessment services in December 2000, 55 percent were determined eligible to receive DDS services and had a “high risk infant” status (code 1) or an active status (codes 2 or 8) on the CMF as of July 6, 2001.

¹Reference Lanterman Developmental Disabilities Services Act, Sections 4642-4643.

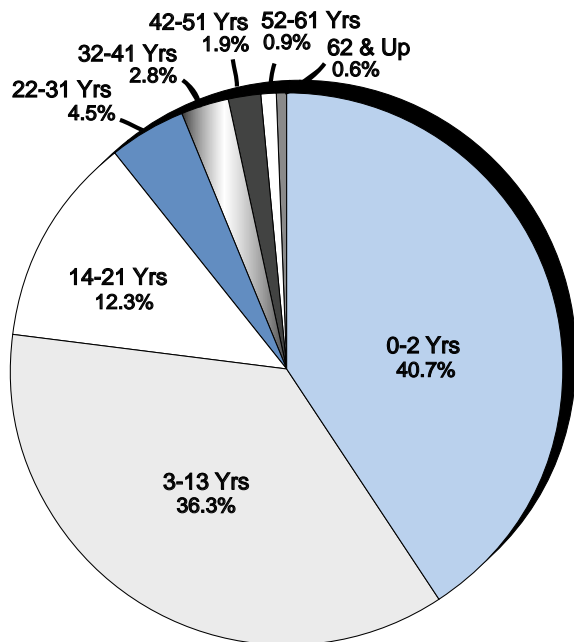
²Reference California Early Intervention Services Act, Section 52086.

Demographics of Persons Engaged in the Intake and Assessment Process

Persons with Status Code 0
Based on Client Master File as of December 2000



Gender	Number of Persons	Percentage of Total
Male	3,752	62.3%
Female	2,269	37.7%
Total	6,021	100.0%



Age	Number of Persons	Percentage of Total
Birth to 2 Yrs.	2,450	40.7%
3 to 13 Yrs.	2,183	36.3%
14 to 21 Yrs.	741	12.3%
22 to 31 Yrs.	272	4.5%
32 to 41 Yrs.	170	2.8%
42 to 51 Yrs.	114	1.9%
52 to 61 Yrs.	53	0.9%
62 and Older	38	0.6%
Total	6,021	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 2000

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 2000. Similar data have been reported for December 1993, 1997, 1998, and 1999 in prior editions of the Fact Book.

The composition of the DDS population by type of developmental disability shows some significant shifts from December 1993 to December 2000. For example, only 11.6 percent of the population served by DDS had “No Mental Retardation” recorded on their CDERs in December 1993. But by December 2000, the percent with “No Mental Retardation” had grown to 17.8 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 37.2 percent. The percent of the DDS population with epilepsy and the percent with cerebral palsy also declined over this period from 26 to 22.9 percent for epilepsy and from 24.4 to 21.2 percent for cerebral palsy. The only developmental disability type that showed an overall increase as a percentage of the DDS population was autism which grew from 4.8 percent in December 1993 to 9.9 percent in December 2000.

The accumulated growth rates spanning December 1994 through December 2000 for the four major developmental disabilities are compared on page 18. In addition, the graph on page 19 displays information on the DDS population broken out by the developmental disability combinations.

*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 consumer diagnostic and evaluation data including developmental, cognitive, behavioral and medical information that is recorded when a consumer 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/state hospital) 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 in place of the CDER.

Mental Retardation		
Level of Mental Retardation	Number of Persons	% of Total
Not MR	25,343	17.8%
Mild	55,620	39.1%
Moderate	27,482	19.3%
Severe	13,952	9.8%
Profound	11,454	8.1%
Unknown	8,263	5.8%
Total	142,114	100.0%

Mental Retardation refers to significantly subaverage general intellectual functioning (scores of 70 or below on standardized measures of intelligence) resulting in or associated with concurrent impairments in adaptive behavior and manifested during the developmental period (prior to the 18th birthday).**

Epilepsy		
Has Epilepsy	Number of Persons	% of Total
No	109,604	77.1%
Yes	32,510	22.9%
Total	142,114	100.0%

Epilepsy or Seizure Disorders are categorized into two main types: partial seizures, which have onset in a single area of the brain, and generalized seizures, which have onset from widespread and diffuse areas of the brain. Epileptic seizures can cause loss of muscle control, tremors, loss of consciousness and other symptoms.**

Cerebral Palsy		
Has CP	Number of Persons	% of Total
No	111,961	78.8%
Yes	30,153	21.2%
Total	142,114	100.0%

Cerebral Palsy (CP) refers to a group of nonprogressive lesions or disorders in the brain characterized by paralysis, spasticity, or abnormal control of movement or posture. Motor dysfunctions associated with conditions similar to CP (e.g., neural tube defects) are included in the table.**

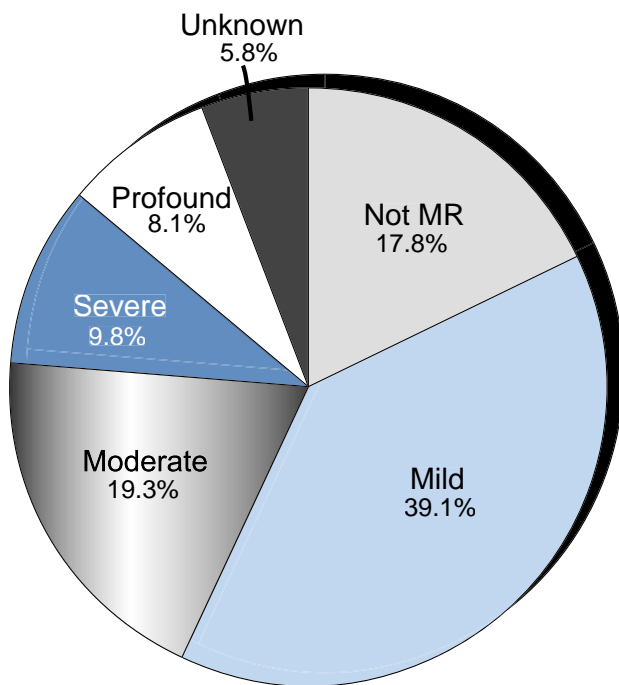
Autism		
Has Autism	Number of Persons	% of Total
No	128,037	90.1%
Yes	14,077	9.9%
Total	142,114	100.0%

Autism is a disability of uncertain etiology. Autism is defined as a syndrome first appearing in the early years of life—usually before age three—which is characterized by extreme withdrawal, language disturbance, inability to form affective ties, frequent lack of responsiveness to other people, monotonously repetitive behaviors, inappropriate response to external stimuli and an obsessive urge for maintaining sameness.**

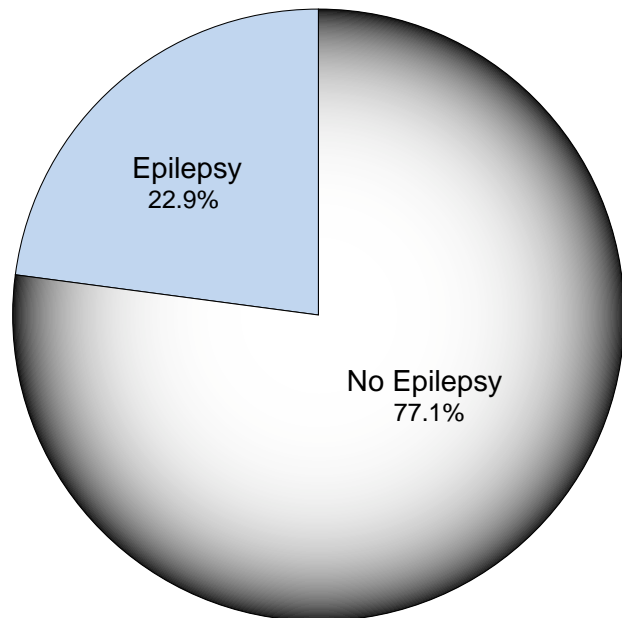
Note: Most children 0 - 3 years of age do not have a CDER and therefore are not reported.

**Definitions of characteristics are taken from the DDS CDER Manual.

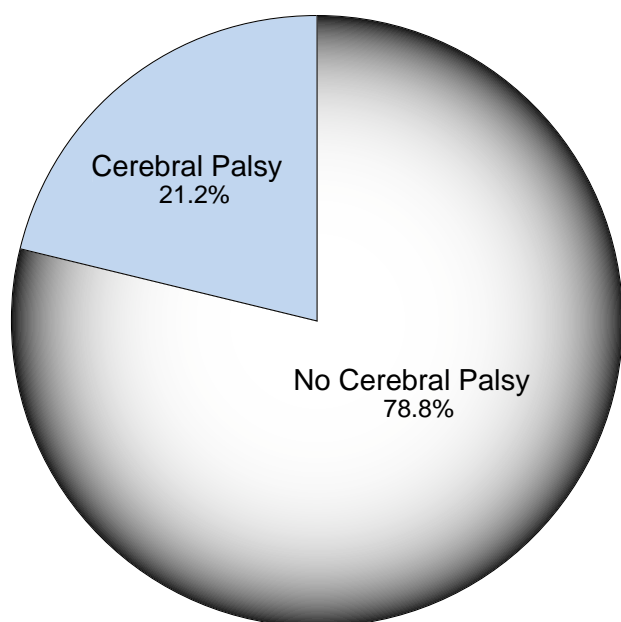
Level of Mental Retardation



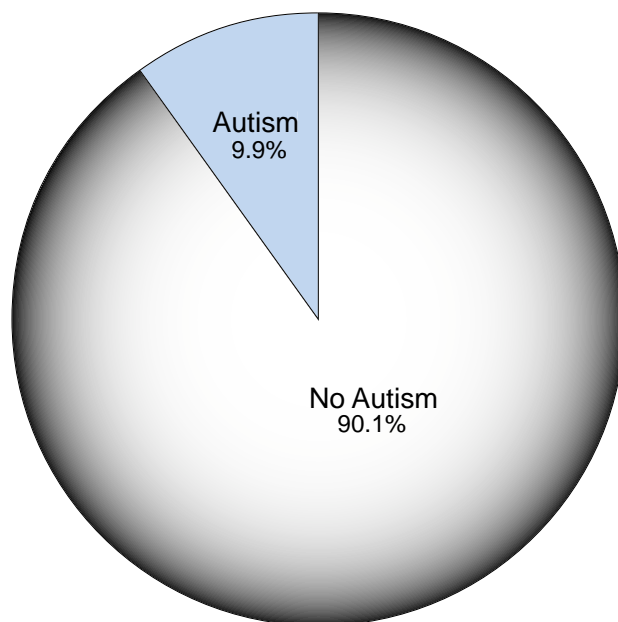
Epilepsy or Seizure Disorder



Cerebral Palsy or Similar Motor Dysfunctions

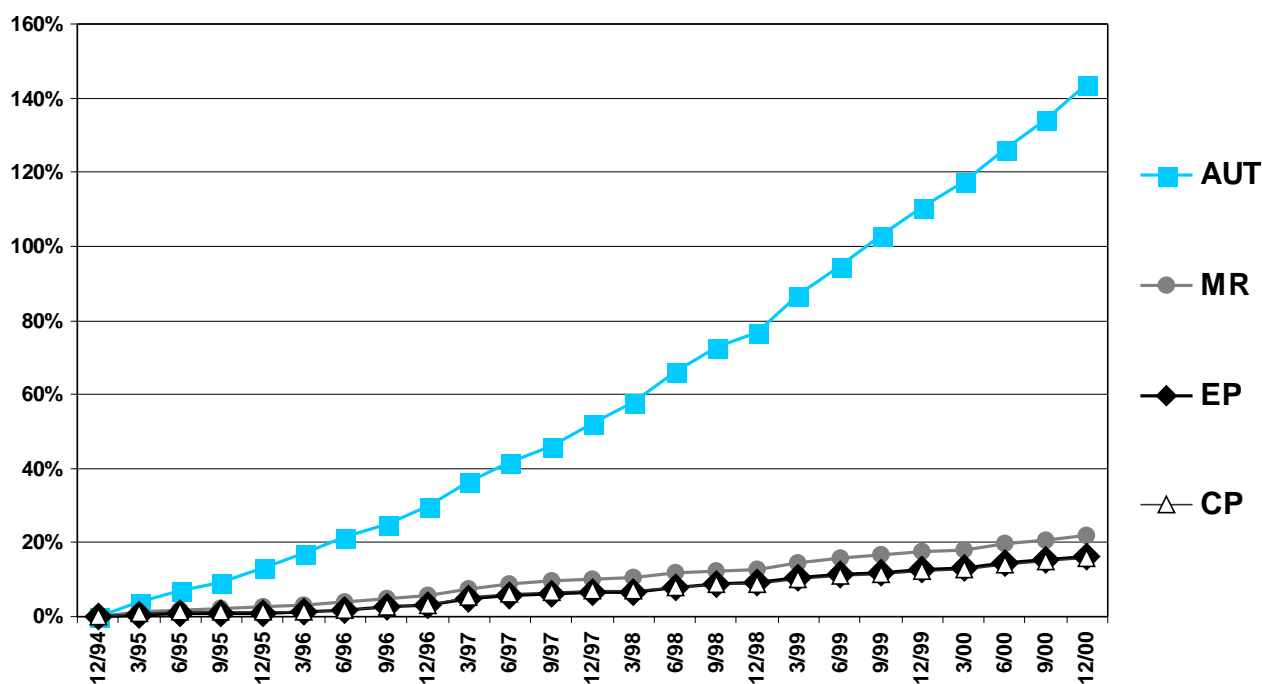


Autism



Trends of Four Major Developmental Disabilities Compared Population Growth from December 1994 through December 2000 Based on CDERs at Quarterly Intervals

An examination of growth in the DDS-served population (who have current CDERs³) for each of the four primary types of developmental disabilities over a six-year period, from December 1994 through December 2000, 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 30 percent (109,359 to 142,114), the number of persons with autism recorded on their CDERs grew 144 percent (5,775 to 14,077) from December 1994 through December 2000. During this same time period, the population growth for the other developmental disabilities were as follows: 1) mental retardation, 22 percent (95,773 to 116,771 persons); 2) epilepsy, 16 percent (27,972 to 32,510 persons); and 3) cerebral palsy, approximately 16 percent (26,087 to 30,153 persons). As shown on the next page, individuals may have more than one type of developmental disability. So, population numbers for each of the developmental disabilities mentioned above should not be added together, because there is duplication of persons across categories.

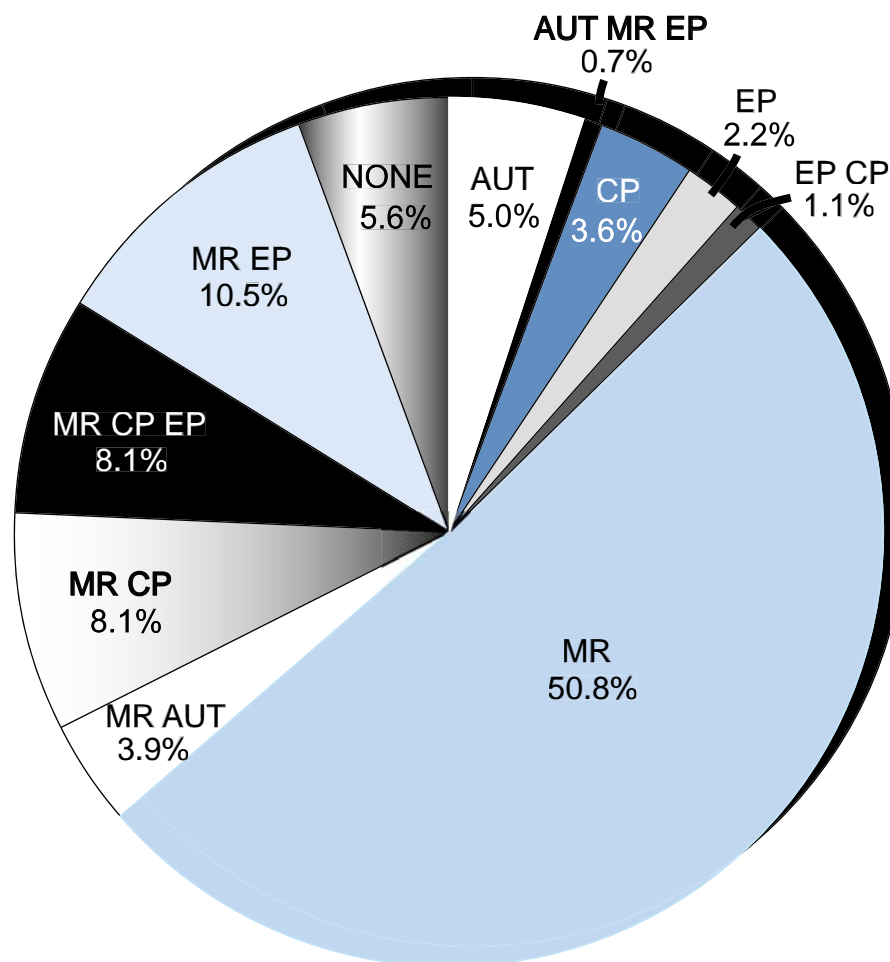


Note: MR = Mental Retardation; AUT = Autism; EP = Epilepsy/Seizure Disorder; CP = Cerebral Palsy.

³CDERs 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 2000 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=0.1%, AUT/MR/CP=0.1%, AUT/CP=0.0%, AUT/EP/CP=0.0% and AUT/MR/EP/CP=0.1%.

Foster Grandparent Program and Senior Companion Program

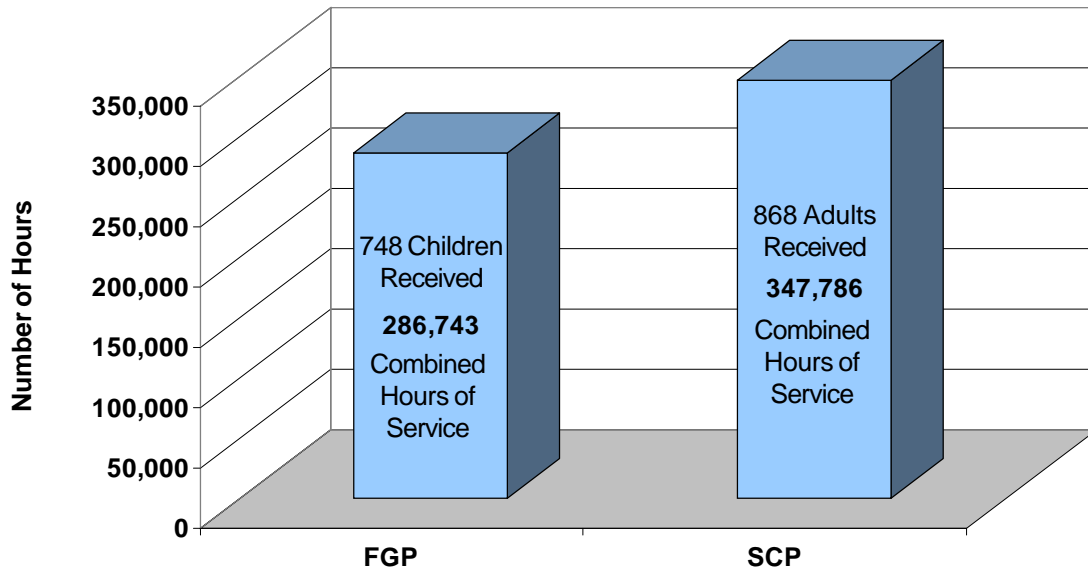
The Department of Developmental Services' Foster Grandparent and Senior Companion programs offer the opportunity for low-income men and women, 60 years of age and above, to volunteer to serve individuals with developmental disabilities. The volunteers provide mentoring, friendship, companionship, academic assistance, and much more. In return for their service, these volunteers are provided a stipend, meal and travel expenses, and recognition.

The DDS Foster Grandparent Program (FGP) provides volunteer services to persons with developmental disabilities who are under age 22. The FGP began in 1967 and is now active at the five state developmental centers, Napa and Metropolitan state hospitals, and four regional centers (i.e., Central Valley, Kern, Tri-Counties and Valley Mountain). From July 1, 2000 through June 30, 2001, 350 foster grandparents provided 286,743 combined hours of service to 748 children. The FGP received over 2.7 million dollars in fiscal year 2000/01 (\$1,116,383 in federal funds, \$1,559,633 in state general funds, and \$40,003 in Area Agencies on Aging funds).

The DDS Senior Companion Program (SCP) began in 1973 and provides services to adults with developmental disabilities who are 22 years of age and older. The SCP is active at the five developmental centers, Napa state hospital, and two regional centers (i.e., Tri-Counties and Valley Mountain). From July 1, 2000 through June 30, 2001, 410 senior companions provided 347,786 combined hours of service to 868 adults. The SCP received over 1.6 million dollars in fiscal year 2000/01 (\$1,626,223 in state general funds and \$58,481 in Area Agencies on Aging funds).

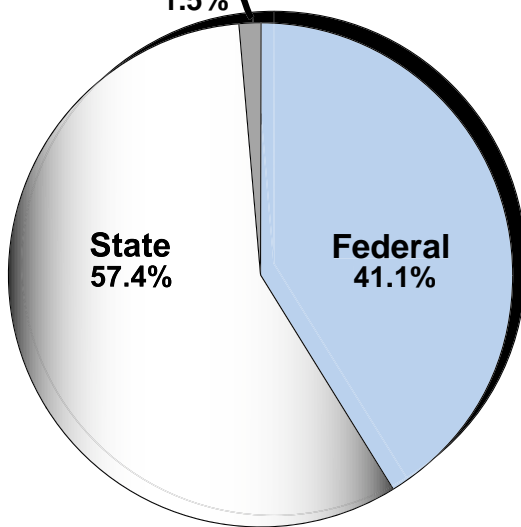


***Number of Hours Foster Grandparents and Senior Companions
Spent Serving Persons with Developmental Disabilities***



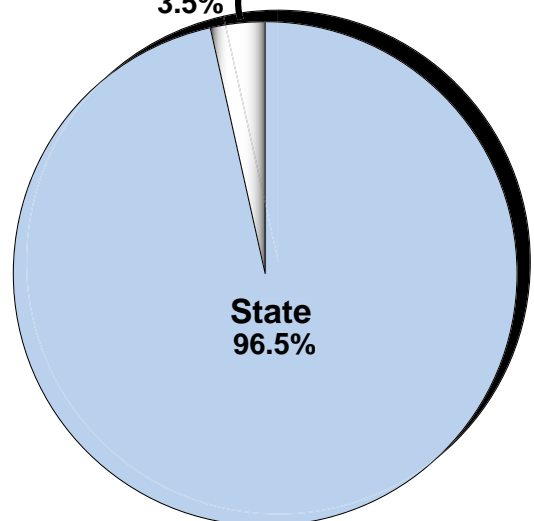
***Funding for the Foster Grandparent
Program in Fiscal Year 2000/01***

Area Agencies on Aging
1.5%



***Funding for the Senior Companion
Program in Fiscal Year 2000/01***

Area Agencies on Aging
3.5%

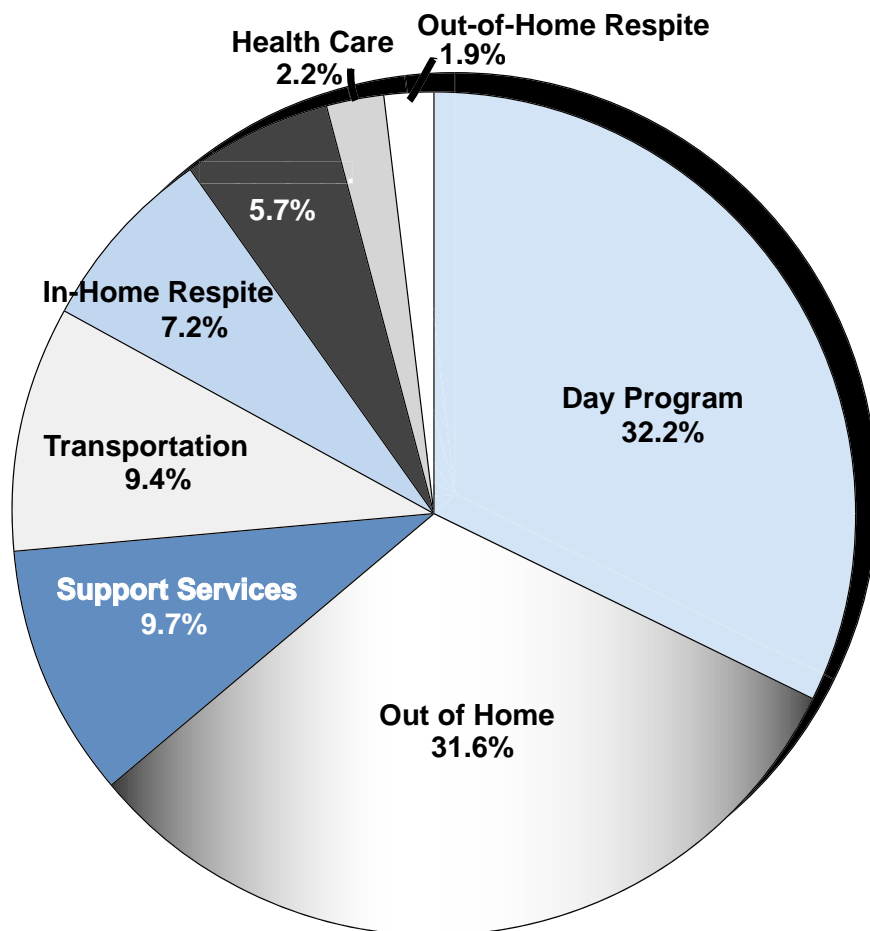


POS Expenditures by Budget Category for FY 1999/2000

Regional centers (RCs) are required by law to provide 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 Individual Program Plan (IPP) of persons served by DDS. In fiscal year 1999/2000, expenditures for these services totalled more than one billion dollars. Not all persons in the DDS system receive purchased services. Of all persons who had a status code 0, 1 or 2 as of 2/2/2000, 74 percent received DDS purchased services sometime during fiscal year 1999/2000.

Purchase of service (POS) budget categories include Out-of-Home, Day Programs, Transportation, and Other Services. The "Out-of-Home" category includes costs of care, supervision and training for individuals who reside in community care facilities. The "Day Programs" category includes costs for community-based training, such as behavior management, community integration, self-help and self-care skills. The "Transportation" category includes costs for transporting individuals using the services of a transportation company, residential facility, day program, public transportation, family member, friend or ambulance. Other services are broken out into five categories: 1) Health Care, 2) In-Home Respite, 3) Out-of-Home Respite, 4) Support Services, and 5) Miscellaneous Services. The "Support Services" category includes services such as community integration training, community activities support, adaptive skills training, behavior management consulting, supplemental residential, day services or program support, and supported living services. The "Miscellaneous" category includes the services of tutors, special education teachers, recreational therapists, counselors, infant development specialists, and speech pathologists.

Budget Category	POS Dollars	% of Total
Day Program	\$396,928,364	32.2%
Out of Home	389,774,217	31.6%
Support Services	120,138,837	9.7%
Transportation	115,281,863	9.4%
In-Home Respite	89,010,374	7.2%
Misc. Services	70,218,210	5.7%
Health Care	27,509,674	2.2%
Out-of-Home Respite	23,963,691	1.9%
Total	\$1,232,825,230	100.0%



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