Department of Developmental Services

Consumer Fact Book

For Data Reporting Period:
January 1992 through December 1997
Prepared by DDS Information Services Section
May 1998

Department of Developmental Services
1600 Ninth Street, Room 240
Sacramento, CA 95814

Preface

The Consumer Fact Book is a collection of pertinent information about persons served by the Department of Developmental Services through December 1997. This information is an overview of data reported electronically and has been compiled by the Department's Information Services Section.

It is our hope that you will find this information useful in better understanding the Department and the persons served by regional centers and state developmental centers. The information presented here is intended to provide an overview to the reader and assist in an overall understanding of services and trends in California. To obtain additional information concerning the Department and items reported here, please refer to our web page on the Internet (www.dds.ca.gov). Other questions may be directed to our Information Services Section at (916) 654-0677.

The Department of Developmental Services' (DDS) Consumer Fact Book 1997 contains the following types of information describing DDS consumers:

⇨The growth in the number of persons served by DDS is presented over a five-year period.

⇨Demographic data include gender, age, ethnicity, and living arrangements for persons served by DDS and for persons receiving intake and assessment services from regional centers.

⇨Specific consumer profiles with data describing their characteristics, such as the level of mental retardation, and the presence of epilepsy, cerebral palsy, and autism.

⇨Consumers by residency type with major medical problems and with severe behavior problems are also displayed.

Table of Contents

	Page
◆ DDS Goals	3
◆ Introduction	5
◆ Age at Intake 1/94 thru 12/97	6
◆ Caseload 1/92 thru 12/97 Monthly Caseload Growth of Persons Receiving Services from DDS Monthly Caseload Decline of Persons Residing in Developmental Centers	9
◆ Demographics of Persons Served by DDS 12/93 and 12/97	12
◆ Demographics of Persons Receiving Intake and Assessment Services from Regional Centers 12/93 and 12/97	16
◆ Characteristics of Persons with CDERs on File 12/93 and 12/97 (Mental Retardation, Epilepsy, Cerebral Palsy, Epilepsy, and Autism)	20
◆ Consumers with Major Medical or Severe Behavior Problems By Residence Type 12/93 and 12/97	24

DDS Goals*

Goal 1: Quality of Life
Persons with developmental disabilities served by regional centers and state developmental centers will receive person-centered and family-centered services and supports that are valued by consumers and their families and enrich their quality of life.

Goal 2: Service Quality and Consumer Protection
All individuals served by regional centers and state developmental centers will receive necessary protections and high quality services.

Goal 3: Increasing Community Capacity
In response to the diverse and changing needs of persons with developmental disabilities, a broad array of community services and supports that enable consumers to lead more independent, safer, productive and normal lives will be made available to consumers and their families.

Goal 4: Prevention and Early Intervention
The occurrence of preventable developmental disabilities will be reduced, and in cases where the impact of developmental disabilities can be lessened through early intervention, consumers will receive, in a timely and effective manner, the needed state-of-the-art services and supports.

Goal 5: Cost-Effectiveness
Services and supports provided to persons with developmental disabilities and to their families will maximize the use of community and other natural supports and meet the needs of individuals in an efficient and cost-effective manner for the State of California.

*DDS Strategic Plan, July 24, 1997

Introduction

The Department of Developmental Services (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 (consumers) to lead more independent, productive and normal lives. DDS carries out its responsibilities through 21 community-based, non-profit corporations known as regional centers (RCs) and through five state-operated developmental centers (SDCs).

A "developmental disability" (DD) is a disability which originates before an individual attains age 18; continues, or can be expected to continue, indefinitely; and constitutes a substantial disability for that individual. Developmental disabilities include mental retardation, epilepsy, cerebral palsy, autism, and disabling conditions closely related to mental retardation or requiring treatment similar to that required for mentally retarded individuals.

The service delivery system includes consumers, 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 Department's vision is to build partnerships with these diverse groups and to support consumer choices outlined in the consumer's Individual Program Plan or the Individual Family Service Plan.

This Consumer Fact Book offers a look at DDS' caseload, the demographics and characteristics of persons served by DDS, and other items of interest.

Additional information can be obtained at DDS' Web site. The URL for the site is:

www.dds.ca.gov

Age at Intake

The "Age at Intake" graph depicts the age at which persons entered the DDS system from January 1994 through December 1997. During this period, three peaks in the data can be observed in the graph to the right.

- Slightly over 50 percent of the persons who entered the system were age two or under.

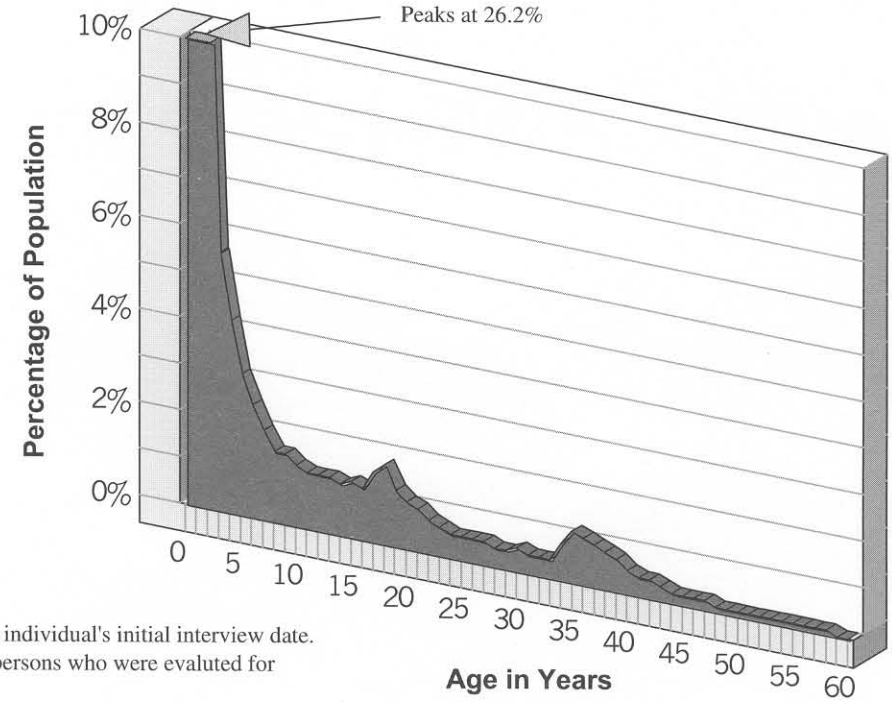
- Another peak occured when persons entered the system at around age 18. One explanation for the surge in entries at age 18 is that these persons previously depended solely on services provided by the school system. As these people transitioned from school programs, they and their families or guardians turned to the DDS system to meet their continuing service needs.

- A third peak occured as consumers reached their mid 30s. A possible explanation for this increase is that the parents or guardians of these persons may be reaching their elder years and are becoming less able to continue providing the services and supports needed. To provide for the future, these parents or guardians may be turning to the DDS system for services and supports for persons in their care.

Note: The source of the data depicted in the "Age at Intake" graph 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 his or her initial application for DDS services.

Age at Intake

[For the Period 1/94 thru 12/97]



Based on the individual's initial interview date. Includes all persons who were evaluted for eligibility.

Detail of Individuals 0 - 5 Years

Age	Percentage
0	26.2%
1	11.0%
2	13.1%
3	5.5%
4	4.1%
5	3.0%

Caseload

The overall growth of the DDS population has increased 33.8% from 109,506 to 146,517 between January 1992 and December 1997. During that same time period, the state developmental center (SDC) population has decreased 38.4%. Although the SDC population represented 6.1% of the total DD population in January 1992, it represented only 2.8% of the total DDS population in December 1997.

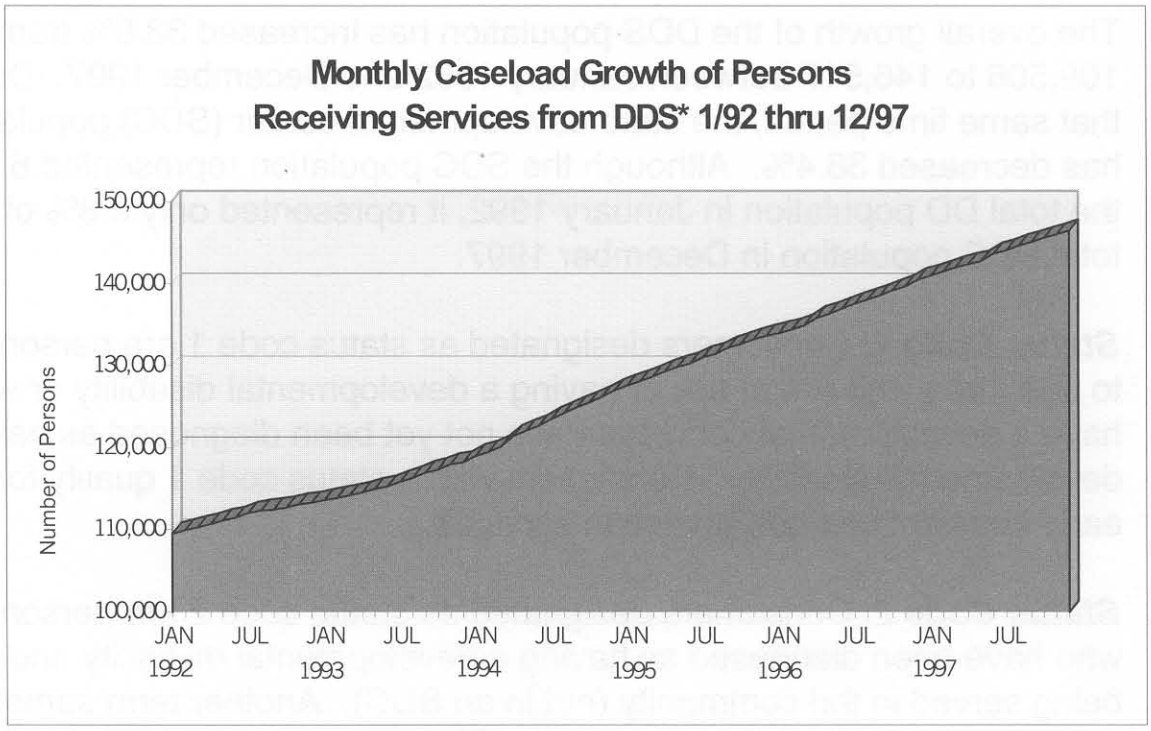
Status Code 1: Consumers designated as status code 1 are persons up to age three who are at risk of having a developmental disability or who have a developmental delay but have not yet been diagnosed as having a developmental disability. Consumers with a status code 1 qualify for early intervention and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

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

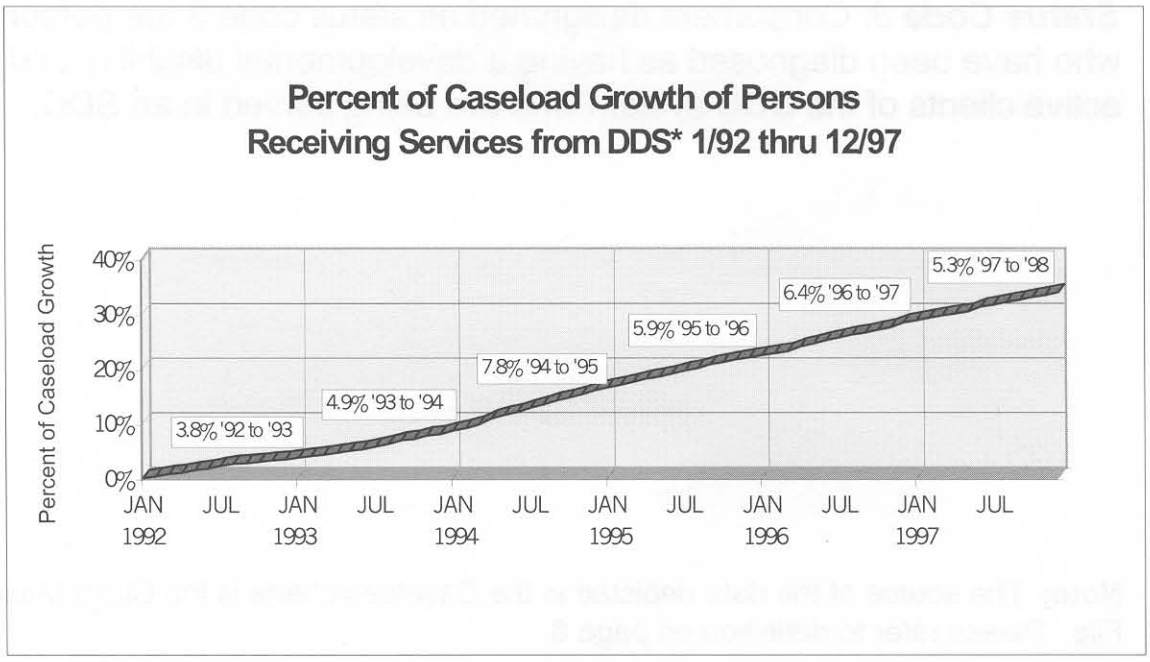
Status Code 8: Consumers designated as status code 8 are persons who have been diagnosed as having a developmental disability and are active clients of the DDS system who are being served in an SDC.

Note: The source of the data depicted in the Caseload charts is the Client Master File. Please refer to definition on page 6.

Caseload

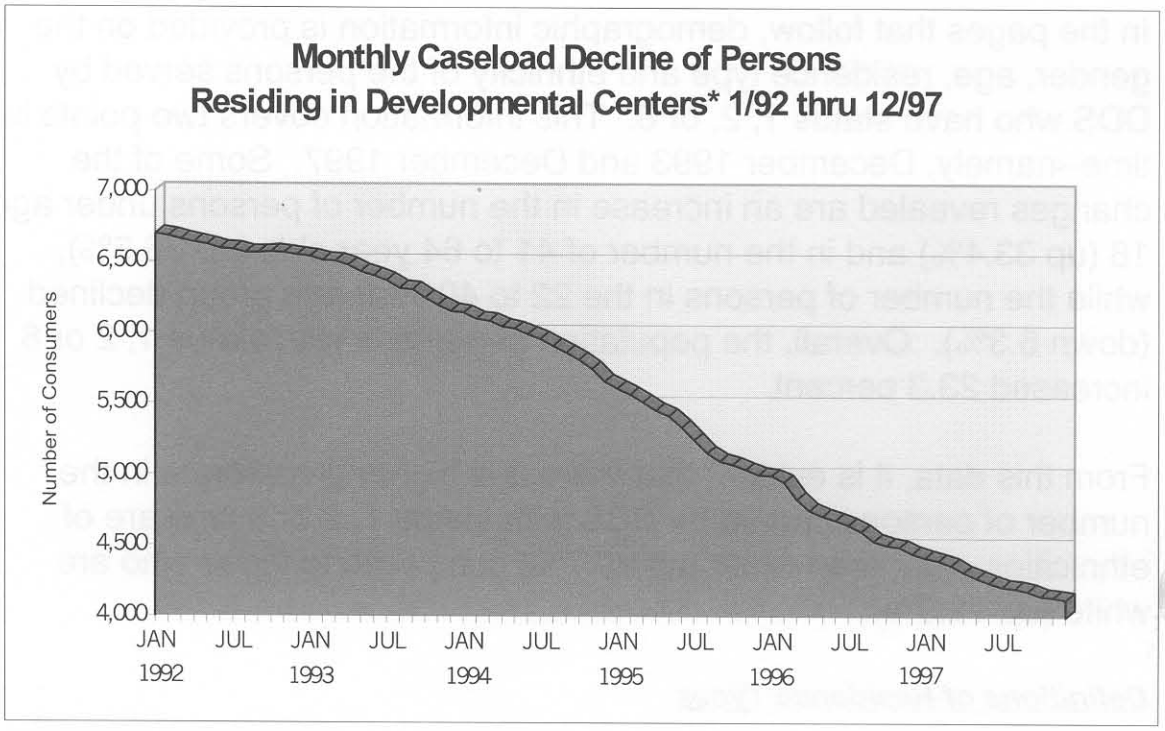


*Includes only persons with status code 1, 2 or 8.

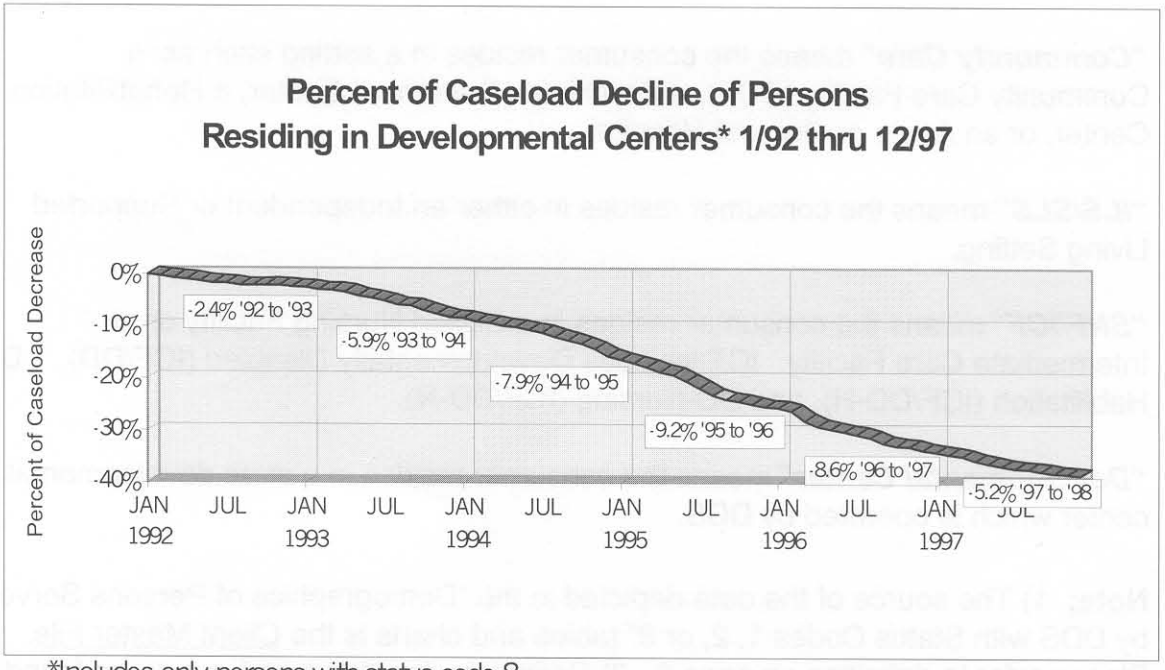


*Includes only persons with status code 1, 2 or 8.

Caseload



*Includes only persons with status code 8.



*Includes only persons with status code 8.

Demographics of Persons Served by DDS

In the pages that follow, demographic information is provided on the gender, age, residence type and ethnicity of the persons served by DDS who have status 1, 2, or 8. This information covers two points in time--namely, December 1993 and December 1997. Some of the changes revealed are an increase in the number of persons under age 18 (up 33.4%) and in the number of 41 to 64 year olds (up 36.5%), while the number of persons in the 22 to 40 year age group declined (down 6.3%). Overall, the population of persons with status 1, 2 or 8 increased 23.3 percent.

From this data, it is evident that there is a higher growth rate in the number of persons served by DDS with status 1, 2 or 8 who are of ethnicities other than white (up 29.7%) compared to those who are white (up 11.9%).

Definitions of Residence Types

"Own Home - Parent" means the consumer resides in the home of a family member or guardian.

"Community Care" means the consumer resides in a setting such as: a Community Care Facility (CCF), a Psychiatric Treatment Center, a Rehabilitation Center, or an Acute or General Hospital.

"ILS/SLS" means the consumer resides in either an Independent or Supported Living Setting.

"SNF/ICF" means the consumer resides in a Skilled Nursing Facility or an Intermediate Care Facility. ICF includes Developmentally Disabled (ICF/DD), DD-Habilitation (ICF/DD-H), and DD-Nursing (ICF/DD-N).

"Developmental Center" means the consumer resides in a state developmental center which is operated by DDS.

Note: 1) The source of the data depicted in the "Demographics of Persons Served by DDS with Status Codes 1, 2, or 8" tables and charts is the Client Master File. Please refer to definition on page 6. **2)** Definitions for status codes may be found on page 9.

Demographics of Persons Served by DDS

Persons with Status 1, 2 or 8
[based on Client Master File]

	as of Dec. 1993		as of Dec. 1997	
Gender	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
Male	66,903	56.4%	84,345	57.7%
Female	51,677	43.6%	61,892	42.3%
Total	***118,580***	***100.0%***	***146,237***	***100.0%***

	as of Dec. 1993		as of Dec. 1997	
Age	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
Birth to 5 Yrs.	21,677	18.3%	28,561	19.5%
6 to 12 Yrs.	18,182	15.3%	24,477	16.7%
13 to 17 Yrs.	10,102	8.5%	13,597	9.3%
18 to 21 Yrs.	8,561	7.2%	10,439	7.1%
22 to 40 Yrs.	41,490	35.0%	44,092	30.2%
41 to 64 Yrs.	16,487	13.9%	22,509	15.4%
65 and Older	2,079	1.8%	2,561	1.8%
Total	***118,578***	***100.0%***	***146,236***	***100.0%***

	as of Dec. 1993		as of Dec. 1997	
Residence Type	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
Own Home-Parent	74,188	62.6%	96,412	65.9%
Community Care	23,608	19.9%	25,634	17.5%
ILS/SLS	8,404	7.1%	12,184	8.3%
SNF/ICF	6,287	5.3%	7,976	5.5%
Developmental Center	6,093	5.1%	4,031	2.8%
Total	***118,580***	***100.0%***	***146,237***	***100.0%***

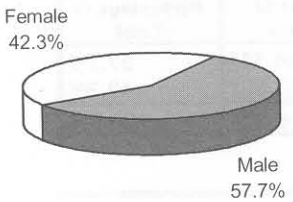
ILS/SLS: Independent Living Settings/Supported Living Settings.

SNF/ICF: Skilled Nursing Facility/Intermediate Care Facility. ICF includes ICF/DD, DD-H, DD-N.

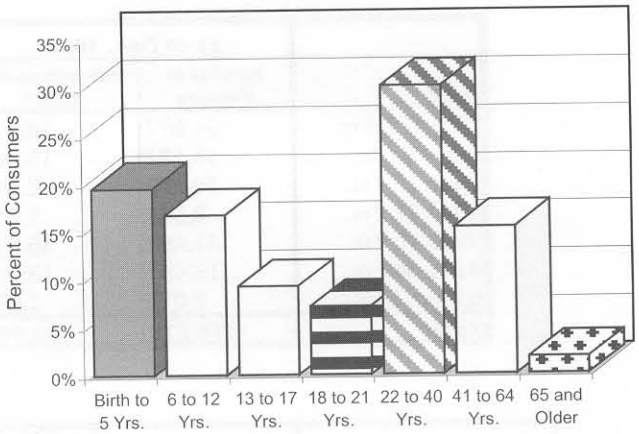
	as of Dec. 1993		as of Dec. 1997	
Ethnicity	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
White	61,118	51.5%	68,376	46.8%
Hispanic	28,324	23.9%	37,874	25.9%
Black	12,561	10.6%	15,282	10.5%
Asian	5,099	4.3%	6,578	4.5%
Filipino	1,807	1.5%	2,324	1.6%
Native American	519	0.4%	590	0.4%
Polynesian	198	0.2%	243	0.2%
Other/Unknown	8,954	7.6%	14,969	10.2%
Total	***118,580***	***100.0%***	***146,236***	***100.0%***

Demographics of Persons Served by DDS
Persons with Status 1, 2 or 8
[based on Client Master File as of *December 1997*]

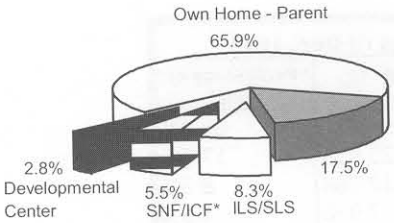
Gender of Consumers



Age of Consumers

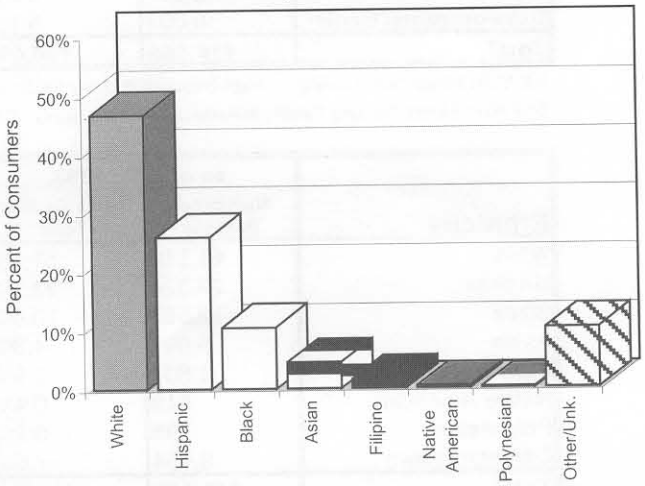


Consumers' Type of Residence



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

Ethnicity of Consumers

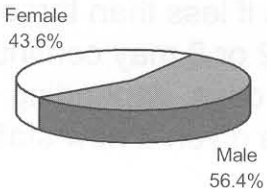


Demographics of Persons Served by DDS

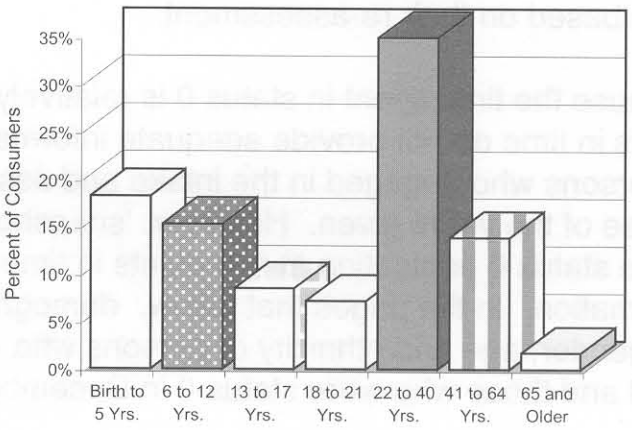
Persons with Status 1, 2 or 8

[based on Client Master File as of December 1993]

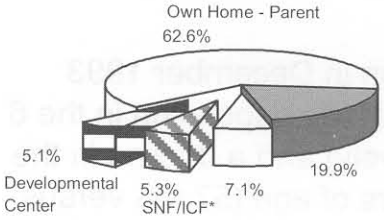
Gender of Consumers



Age of Consumers

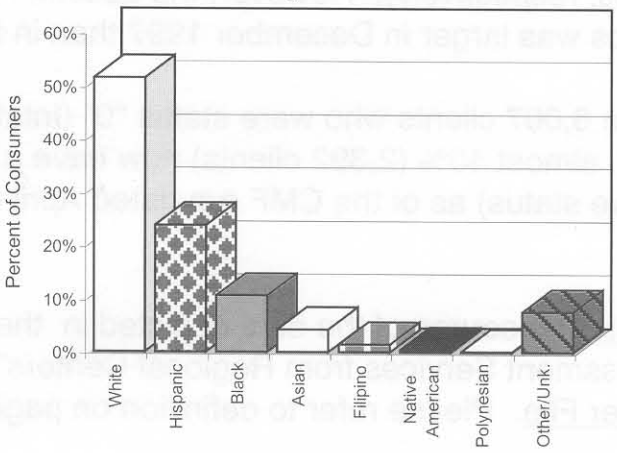


Consumers' Type of Residence



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

Ethnicity of Consumers



Demographics of Persons Receiving Intake and Assessment Services from Regional Centers

Persons designated as status code 0 are individuals who have not yet been diagnosed as having a developmental disability but who are engaged in the intake and assessment process to determine their eligibility for services provided through the DDS system. Persons with status 0 should retain such status no more than 120 days or no more than 45 days if less than three years of age. In contrast, persons with status code 1, 2 or 8 may continue in that status for longer durations. Within 120 days or 45 days, depending on age group of applicant, persons with status 0 should be given a new status code based on their re-assessment.

Because the time spent in status 0 is relatively short, data collected at two points in time do not provide adequate information regarding the total number of persons who engaged in the intake and assessment process during the course of the years given. However, 'snapshots' of the demographic makeup of the status 0 population at two points in time can provide some useful information. In the pages that follow, demographic information is provided on the gender, age and ethnicity of persons who were status 0 during December 1993 and those who were status 0 in December 1997.

A look at the age breakdown of the status 0 population in December 1993 versus December 1997 reveals a higher percentage of the population in the 6 to 12 year age group (13.8% versus 17.7%, respectively) and a decline in the percentage of the population who were birth to 5 years of age (57.0% versus 52.1%, respectively). However, the absolute number of persons in both age groups was larger in December 1997 than in December 1993 (see table).

Of the 6,007 clients who were status "0" (Intake and Evaluation) in December 1997, almost 40% (2,392 clients) now have a status code of "1, 2, or 8" (Active status) as of the CMF run dated April 8, 1998.

Note: The source of the data depicted in the "Persons Receiving Intake and Assessment Services from Regional Centers" tables and charts is the Client Master File. Please refer to definition on page 6.

Demographics of Persons Receiving Intake and Assessment Services from Regional Centers

Persons with Status 0
[based on Client Master File]

	as of Dec. 1993		as of Dec. 1997	
Gender	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
Male	2,960	59.1%	3,703	61.6%
Female	2,045	40.9%	2,304	38.4%
Total	***5,005***	***100.0%***	***6,007***	***100.0%***

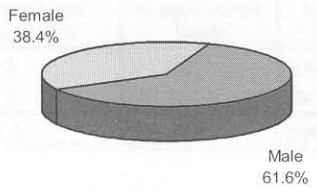
	as of Dec. 1993		as of Dec. 1997	
Age	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
Birth to 5 Yrs.	2,854	57.0%	3,131	52.1%
6 to 12 Yrs.	692	13.8%	1,063	17.7%
13 to 17 Yrs.	402	8.0%	519	8.6%
18 to 21 Yrs.	361	7.2%	437	7.3%
22 to 40 Yrs.	509	10.2%	588	9.8%
41 to 64 Yrs.	156	3.1%	243	4.0%
65 and Older	31	0.6%	26	0.4%
Total	***5,005***	***100.0%***	***6,007***	***100.0%***

	as of Dec. 1993		as of Dec. 1997	
Ethnicity	Number of Persons	Percentage of Total	Number of Persons	Percentage of Total
White	1,218	24.3%	1,438	23.9%
Hispanic	1,026	20.5%	1,334	22.2%
Black	479	9.6%	452	7.5%
Asian	211	4.2%	183	3.0%
Filipino	47	0.9%	55	0.9%
Native American	9	0.2%	24	0.4%
Polynesian	7	0.1%	14	0.2%
Other/Unknown	2,008	40.1%	2,507	41.7%
Total	***5,005***	***100.0%***	***6,007***	***100.0%***

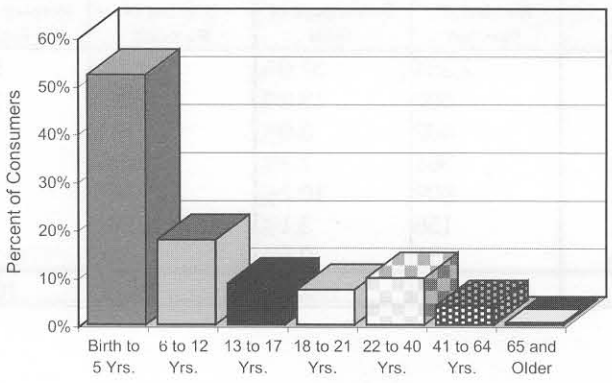
Demographics of Persons Receiving Intake and Assessment Services from Regional Centers

Persons with Status 0
[based on Client Master File as of December 1997]

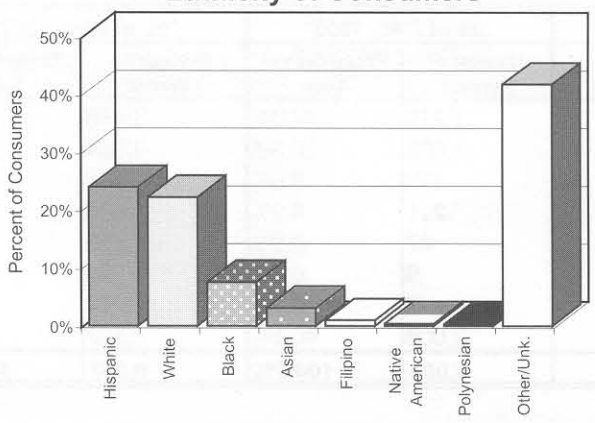
Gender of Consumers



Age of Consumers



Ethnicity of Consumers

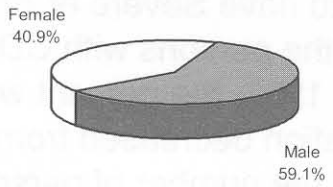


Demographics of Persons Receiving Intake and Assessment Services from Regional Centers

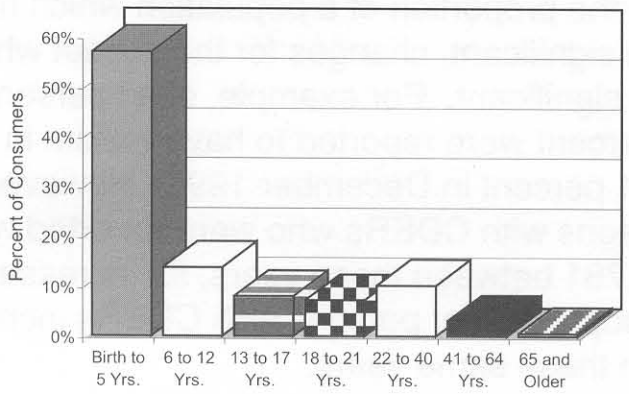
Persons with Status 0

[based on Client Master File as of *December 1993*]

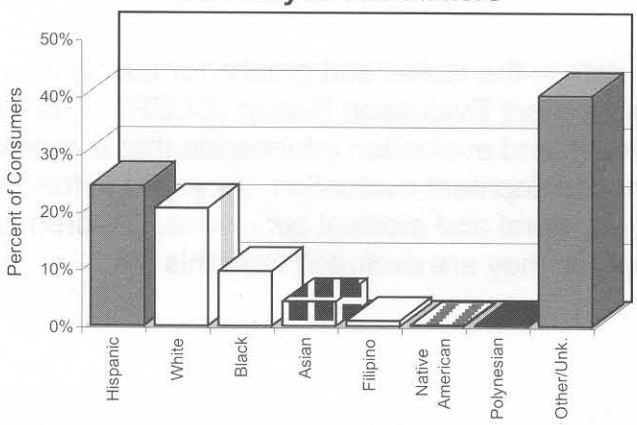
Gender of Consumers



Age of Consumers



Ethnicity of Consumers



Characteristics of Persons with CDERs* on file as of December 1993 and December 1997

The table with information concerning the Level of Mental Retardation shows that of all persons with Client Development Evaluation Reports (CDER) on file in December 1993 and December 1997, the percentage who were reported to have Severe or Profound retardation decreased. For example, of all the persons with CDERs on file in December 1993 and December 1997, the percent who were reported as having severe mental retardation decreased from 12.2% to 10.7%. However, between these years, the number of persons whose CDERs reflected severe mental retardation increased from 12,949 to 13,324.

Another item to note when viewing data relating to two points in time is that while changes in the proportion of a population which has a subset may not appear to be significant, changes for the subset when viewed alone may indeed be significant. For example, of all persons who had CDERs on file, 4.8 percent were reported to have autism in December 1993 compared to 7.1 percent in December 1997. However, the actual number of persons with CDERs who were reported with autism grew from 5,108 to 8,781 between these years, an increase of 71.9 percent. The entire population of persons with CDERs increased only 16.4 percent between these same years.

Note: The source of the data in the tables and graphs for the "Characteristics of Person" is the Client Development Evaluation Report (CDER). The CDER file contains consumer diagnostic and evaluation information that is recorded when a consumer is given a client development evaluation. Included in this file are developmental, mental, behavioral and medical conditions. Children ages 0 - 3 do not have a CDER filled out, so they are excluded from this file.

Characteristics of Persons with CDERs on file as of December 1993 and December 1997

[based on Client Development Evaluation Report*]

Mental Retardation				
	as of Dec. 1993		as of Dec. 1997	
Level of Mental Retardation	Number of Consumers	% of Total	Number of Consumers	% of Total
Not MR	12,400	11.6%	18,606	15.0%
Mild	38,555	36.2%	47,788	38.5%
Moderate	23,486	22.0%	25,347	20.4%
Severe	12,949	12.2%	13,324	10.7%
Profound	11,962	11.2%	11,536	9.3%
Unknown	7,213	6.8%	7,423	6.0%
Total	**106,565**	**100.0%**	**124,024**	**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				
	as of Dec. 1993		as of Dec. 1997	
Has Epilepsy	Number of Consumers	% of Total	Number of Consumers	% of Total
No	78,810	74.0%	94,211	76.0%
Yes	27,755	26.0%	29,813	24.0%
Total	**106,565**	**100.0%**	**124,024**	**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				
	as of Dec. 1993		as of Dec. 1997	
Has CP	Number of Consumers	% of Total	Number of Consumers	% of Total
No	80,532	75.6%	96,117	77.5%
Yes	26,033	24.4%	27,907	22.5%
Total	**106,565**	**100.0%**	**124,024**	**100.0%**

Cerebral Palsy 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				
	as of Dec. 1993		as of Dec. 1997	
Has Autism	Number of Consumers	% of Total	Number of Consumers	% of Total
No	101,457	95.2%	115,243	92.9%
Yes	5,108	4.8%	8,781	7.1%
Total	**106,565**	**100.0%**	**124,024**	**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.**

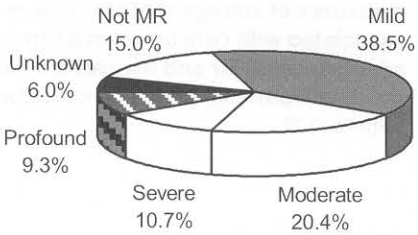
* Children 0 - 3 years of age do not have Client Development Evaluation Reports (CDER) filled out, therefore are not reported.

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

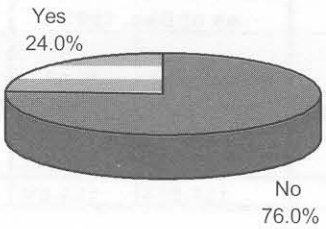
Characteristics of Persons with CDERs on file as of December 1997

[based on Client Development Evaluation Report]

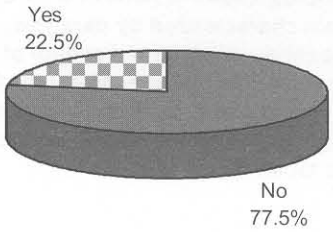
Level of Mental Retardation



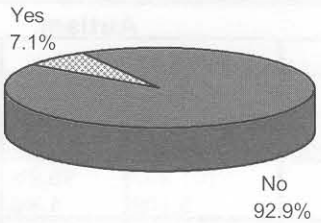
Epilepsy or Seizure Disorder Present



Cerebral Palsy or Similar Motor Dysfunctions Present



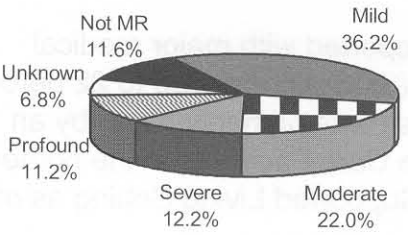
Autism Present



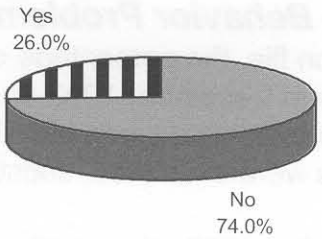
Characteristics of Persons with CDERs on file as of December 1993

[based on Client Development Evaluation Report]

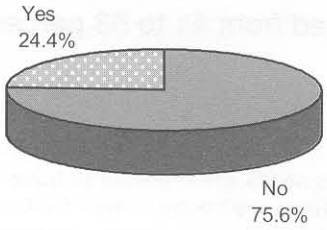
Level of Mental Retardation



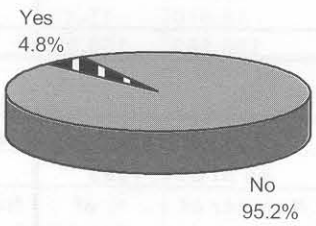
Epilepsy or Seizure Disorder Present



Cerebral Palsy or Similar Motor Dysfunctions Present



Autism Present



Consumers with Major Medical or Severe Behavior Problems by Residence Type

Major Medical Problems: Of the total persons served by DDS who had CDERs on file in December 1993 and December 1997, little change was found in the percentage of individuals reported to have major medical problems. However, an examination of the residence types of the persons reported to have major medical problems revealed significant changes between these years.

As of December 1993, 31 percent of the persons reported with major medical problems resided in State Developmental Centers (SDCs) compared to 22 percent in December 1997. (See next page.) This decrease was primarily offset by an increase in the percent who resided in Intermediate Care Facilities, in the homes of parents/guardians, or in either an Independent or Supported Living Setting as of December 1997.

Severe Behavior Problems: Of the total persons served by DDS who had CDERs on file, the percentage of individuals reported to have severe behavior problems in December 1993 and December 1997 showed little change. However, when the residence types of the persons reported to have severe behavior problems were examined, substantial changes were found between these years.

In December 1993, almost 28 percent of the persons reported with severe behavior problems resided in SDCs compared to 14 percent in December 1997. Between these same years, the percent of persons reported with severe behavior problems who resided in the home of a parent/guardian increased from 41 to 53 percent.

Note: Please refer to page 20 for definition of CDER file.

Major Medical Problems				
	as of Dec. 1993		as of Dec. 1997	
	Number of Consumers	% of Total	Number of Consumers	% of Total
No	94,292	88.7%	111,658	90.0%
Yes	12,070	11.3%	12,368	10.0%
Total	106,362	100.0%	124,026	100.0%

Consumers are reported to have ***major medical problems*** if their CDERs reflect that they have a medical condition which has a major impact upon their ability to obtain an appropriate placement or requires that they have a considerable amount of supervision or care.

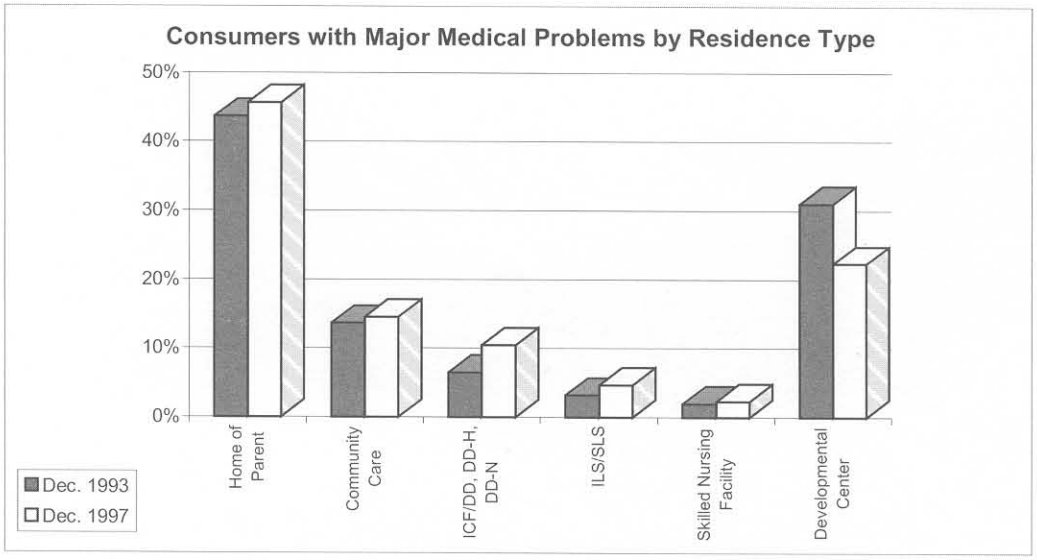
Severe Behavior Problems				
	as of Dec. 1993		as of Dec. 1997	
	Number of Consumers	% of Total	Number of Consumers	% of Total
No	96,057	90.3%	111,626	90.0%
Yes	10,305	9.7%	12,400	10.0%
Total	106,362	100.0%	124,026	100.0%

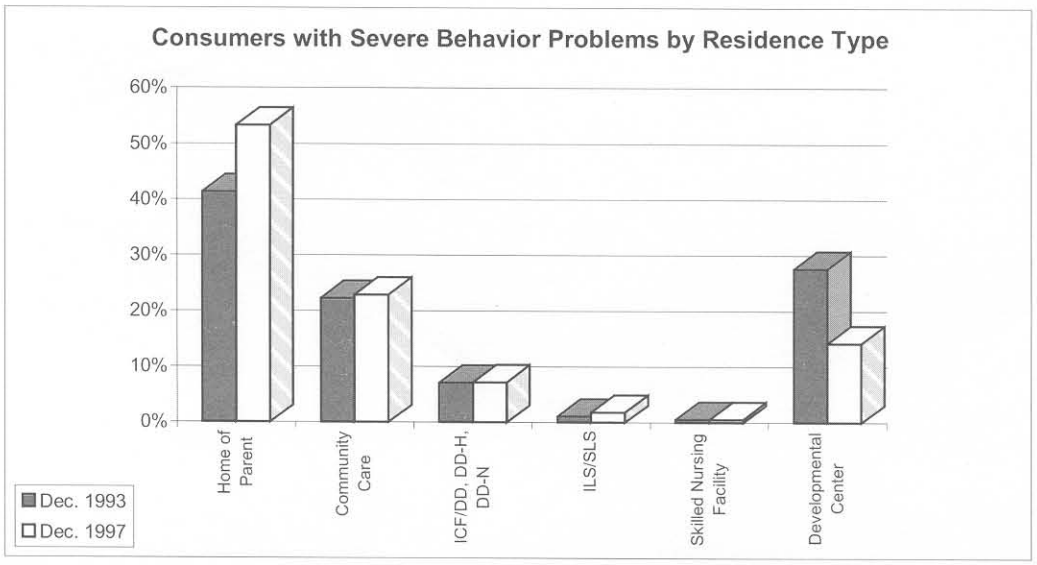
Consumers are reported to have ***severe behavior problems*** based on an analysis of their weighted severity score taken from ten CDER maladaptive behavior items.

Consumers with Major Medical or Severe Behavior Problems By Residence Type

	Major Medical		Severe Behavior	
Residence Type	**Dec. 1993**	**Dec. 1997**	**Dec. 1993**	**Dec. 1997**
Home of Parent	43.66%	45.67%	41.31%	53.29%
Community Care	13.65%	14.56%	22.26%	22.83%
ICF/DD, DD-H, DD-N	6.45%	10.45%	7.06%	7.21%
ILS/SLS	3.22%	4.69%	1.15%	1.87%
Skilled Nursing Facility	1.97%	2.30%	0.62%	0.59%
Developmental Center	31.05%	22.32%	27.59%	14.21%
Total	**100.00%**	**100.00%**	**100.00%**	**100.00%**

Note: Refer to Residence Type definitions on page 12.





Notes

Department of Developmental Services
1600 Ninth Street, Room 240
Sacramento, CA 95814
TEL (916) 654-1897
TTY (916) 654-2054
FAX (916) 654-2167

DDS Home Page: **http://www.dds.ca.gov**