## **Department of Developmental Services**

# Fact Book Thirteenth Edition



Prepared by DDS Information Technology Division April 2016

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### PREFACE

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

DDS is responsible for administering the Lanterman Developmental Disabilities Services Act (Lanterman Act) and the Early Intervention Services Act (Early Start Program). The Lanterman Act provides for the coordination and provision of services and supports to enable people with developmental disabilities to lead more independent, productive, and integrated lives. The Early Start Program provides for the delivery of appropriate services to infants and toddlers at risk of having developmental disabilities. DDS carries out its responsibilities through 21 community-based, non-profit corporations known as "regional centers" and four state-operated facilities, including three developmental centers and one smaller community facility. For purposes of this publication, the community facility is included in numbers reported for developmental centers.

A "developmental disability" is a condition that originates before an individual reaches age 18; continues, or can be expected to continue indefinitely; and constitutes a substantial impairment in three or more areas of major life activity.\* Developmental disabilities include Intellectual Disability, Autism, Epilepsy, Cerebral Palsy, and disabling conditions closely related to Intellectual Disability (formerly Mental Retardation) or requiring treatment similar to that required by people with Intellectual Disability. The service delivery system, which offers personalized supports, includes individuals with developmental disabilities, their families and/or legal representatives, advocacy and professional organizations, the State Council on Developmental Disabilities (SCDD), direct service providers, developmental centers, regional centers, and DDS.

The following pages offer a look at the demographics and characteristics of people served by DDS. The Fact Book and other information are available on the <u>DDS</u> website. Information in this publication was derived from data reported electronically to DDS Headquarters and compiled by the Data Extraction Unit.

The Facts and Stats web page on the <u>DDS website</u> contains information about DDS caseload, client characteristics, and other data available.

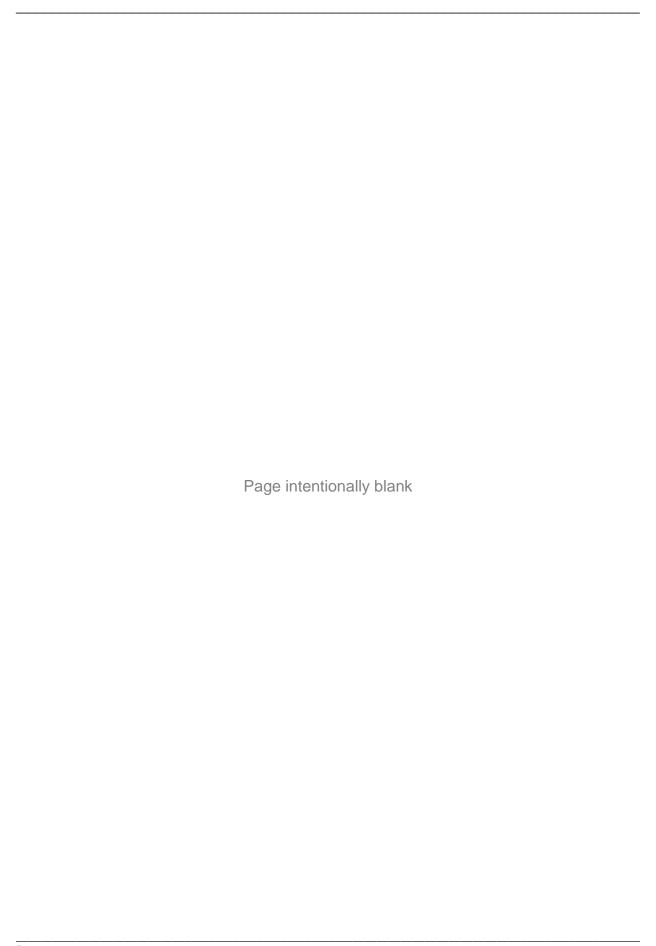
#### Ralph Sisler

Cover Art: The artwork of Ralph Sisler has been displayed in galleries throughout Northern and Southern California. His approach to recreating "Rock N Roll's" most memorable and influential artists has helped Ralph create his own unique and prolific style.

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

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## WHOM DDS SERVES



### Yelena Zhukova

Yelena's mediums of choice are ceramics and acrylic paints. Much of her work is inspired by the natural world around her. When Yelena is not creating art at Southside Art Center or at home, she can be found spending time with her family watching movies and taking care of her pet dog.

### **DDS CONSUMER INFORMATION**

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

Intake and Assessment (Status Code 0): An applicant for regional center services who is being assessed for eligibility.

**Prevention (Status Code P):** Children birth to age three who are diagnosed with genetic, medical, developmental, or environmental history that is predictive of a substantially greater risk for developmental disability than that of the general population. The Prevention Program was added as a new population category on October 1, 2009 and ended on September 30, 2012.

**Early Start Program (Status Code 1):** Children birth to age three with a developmental delay or disability, or an established risk condition with a high probability of resulting in a delay. Children with a Status Code 1 qualify for early intervention and family support services.

Active Consumer (Status Code 2): People diagnosed as having a developmental disability who are served in the community (not in a developmental center).

**Developmental Center (Status Code 8):** People diagnosed as having a developmental disability who are served in a developmental center.

All percentages in the following tables that total 100.0% are exact despite superficial differences when adding their component percentages, each of which is rounded to the nearest tenth of a percent.

### **DDS Population Categories**

The number of people served by DDS (i.e., Intake and Assessment, Early Start Program, Active Consumer, Developmental Center on the Client Master File) increased 38.4% from January 1, 2005 to January 1, 2015. According to Department of Finance estimates, California's general population grew 10.4% between March 1 and July 1 of 2015. About 0.74% of California's population was served by DDS as of July 1, 2015.

Table 1

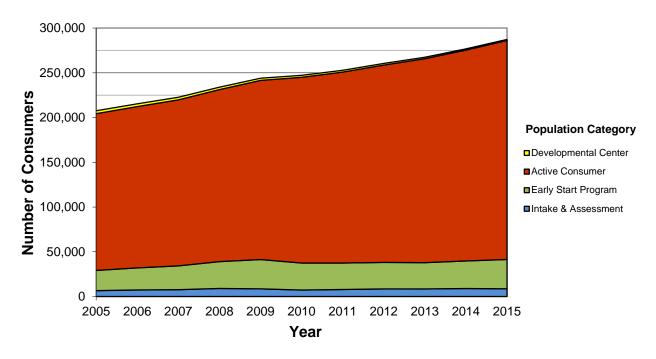
Number of Consumers in each Population Category on the Client Master File

January 2005 and January 2015

	Januar	y 2005	Januar	y 2015
Population Category	Number of Consumers	Percentage of Total Consumers	Number of Consumers	Percentage of Total Consumers
Intake & Assessment	6,584	3.2%	8,612	3.0%
Early Start Program*	22,558	10.9%	32,789	11.4%
Active Consumer	175,240	84.4%	244,748	85.2%
Developmental Center	3,253	1.6%	1,164	0.4%
Total	207,635	100.0%	287,313	100.0%

Figure 1

Number of Consumers by Population Category
January 2005 to January 2015



Early Start Program counts include those with a Prevention status, which lasted from October 2009 through September 2012.

### **DEMOGRAPHICS OF CONSUMERS SERVED BY DDS**

In the pages that follow, demographic information is provided by gender, age, residence types, ethnicity, and primary language of Early Start, Active Consumers, and Developmental Center consumers as of January 1, 2005, as compared to January 1, 2015. To obtain demographic information on the population served by DDS for other years, please refer to prior editions of the Fact Book.

### **Residence Type**

Changes in the residence types of the population are noteworthy. While 71.6% of the people resided in the home of a parent or guardian in January 2005, 76.8% reported this residence type in January 2015. During this same period, decreases continued in the proportion of people living in community care settings (13.2% to 10.2%) and developmental centers (1.6% to 0.4%).

### **Definitions of Residence Types**

**Own Home-Family:** Home of a family member or guardian.

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

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:** Developmental Center operated by DDS.

**Other:** Settings such as Hospitals, Community Treatment Facilities, Rehabilitation Centers, Psychiatric Treatment Centers, Correctional Institutions, and other settings in the community.

### **Residence Type**

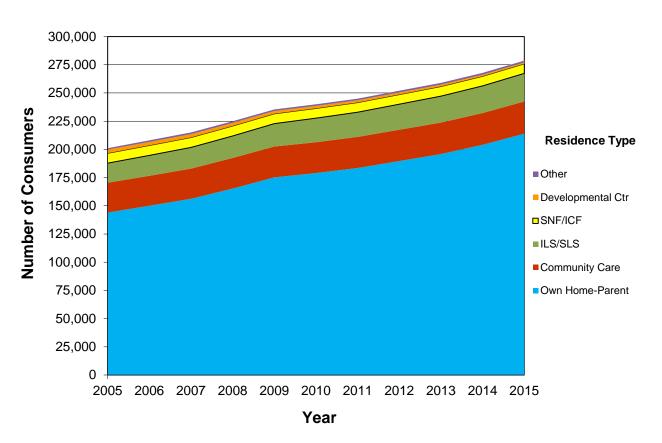
Table 2

Residence Type of Consumers
January 2005 and January 2015

	January 2005		January	/ 2015
Residence Type	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Own Home-Parent	144,023	71.6%	213,967	76.8%
Community Care	26,442	13.2%	28,524	10.2%
ILS/SLS	17,333	8.6%	24,866	8.9%
SNF/ICF	8,783	4.4%	8,509	3.1%
Developmental Center	3,231	1.6%	1,158	0.4%
Other	1,239	0.6%	1,677	0.6%
Total	201,051	100.0%	278,701	100.0%

Figure 2

Number of Consumers by Residence Type
January 2005 to January 2015



### **Age Distribution**

Age distribution trends for people served by DDS also continued. With 56.7% of the population under 22 years of age in January 2015 as compared to 56.1% in this age group in January 2005, the DDS population is becoming slightly older.

Table 3

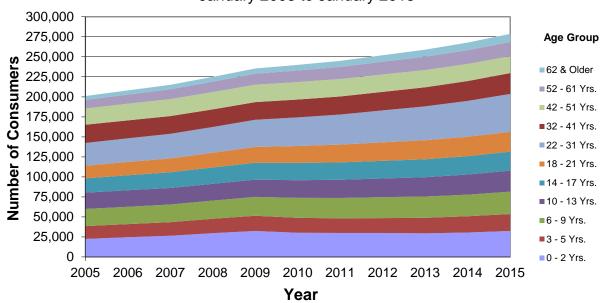
Age Group of Consumers Served by DDS

January 2005 and January 2015

	January	/ 2005	January 2015
Age Group	Number of Consumers	Percentage of Total	Number of Percentage Consumers of Total
Birth - 2 Yrs.	22,556	11.2%	32,501 11.7%
3 - 5 Yrs.	15,984	8.0%	21,080 7.6%
6 - 9 Yrs.	21,462	10.7%	28,040 10.1%
10 - 13 Yrs.	20,337	10.1%	26,211 9.4%
14 - 17 Yrs.	17,831	8.9%	23,754 8.5%
18 - 21 Yrs.	15,867	7.9%	24,675 8.9%
22 - 31 Yrs.	28,374	14.1%	47,390 17.0%
32 - 41 Yrs.	22,789	11.3%	26,057 9.3%
42 - 51 Yrs.	20,317	10.1%	21,012 7.5%
52 - 61 Yrs.	10,653	5.3%	17,797 6.4%
62 & Older	4,881	2.4%	10,184 3.7%
Total	201,051	100.0%	278,701 100.0%

Figure 3

Number of Consumers by Age Group
January 2005 to January 2015



### **Ethnicity**

The predominant trend in the ethnic makeup of the population continued in 2015. Hispanics remain the fastest growing segment of the DDS population, increasing from 31.8% in January 2005 to 36.7% in January 2015. Over this same period, the white population decreased from 42.4% to 33.8%.

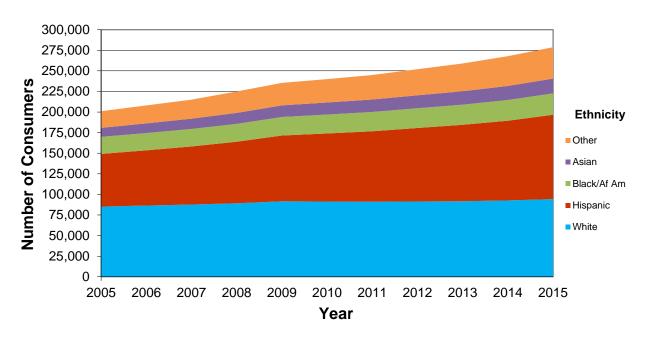
Table 4

Ethnicity of Consumers
January 2005 and January 2015

	January	y 2005	January	y 2015
Ethnicity	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
White	85,226	42.4%	94,279	33.8%
Hispanic	63,938	31.8%	102,422	36.7%
Black	20,732	10.3%	25,962	9.3%
Asian	10,946	5.4%	17,981	6.5%
Other	20,209	10.1%	38,057	13.7%
Total	201,051	100.0%	278,701	100.0%

Figure 4

Number of Consumers by Ethnicity
January 2005 to January 2015



#### Gender

The trend in the gender distribution of people served by DDS continued in 2015 with males increasing in numbers relative to females. In January 2005, 60.2% of the people served were male as compared to 39.8% female. In January 2015, the gap widened to 64.0% male compared to 36.0% female. The growing gender imbalance is due, in large part, to the growing Autism population, which is currently over 80% male.

Table 5 Gender of Consumers January 2005 and January 2015

	January	y 2005	Januar	y 2015
Number of Gender Consumers		Percentage of Total	Number of Consumers	Percentage of Total
Female	80,064	39.8%	100,463	36.0%
Male	120,987	60.2%	178,238	64.0%
Total	201,051	100.0%	278,701	100.0%

### **Primary Language**

The trend in the primary language (English and Non-English) of consumers served by DDS has continued. English was the primary language for 76.9% of consumers in January 2005 and 75.2% in January 2015.

Table 6 Primary Language (English and Non-English) of Consumers January 2005 and January 2015

January 2005			Januar	y 2015
Primary Number of Language Consumers		Percentage of Total	Number of Consumers	Percentage of Total
English	154,680	76.9%	209,710	75.2%
Non-English	46,371	23.1%	68,991	24.8%
Total	201,051	100.0%	278,701	100.0%

# RESIDENCE TYPES OF CONSUMERS WITH DEVELOPMENTAL DISABILITIES, BY AGE GROUP JANUARY 2005 AND JANUARY 2015

During the period from January 1, 2005 to January 1, 2015, the percentage of consumers served by DDS in both the "Birth through 17" and "18 and Older" age groups increased for those residing in the home of a parent, guardian, or conservator (labeled "Own Home-Family" in the tables below) and decreased for those residing in community care settings and developmental centers. These changes are consistent with the high priority the Lanterman Act places on providing opportunities for children with developmental disabilities to live with families and for people of all ages to live in home-like environments.

The percentage of people 18 years of age and older residing in supported living and independent settings also increased between January 2005 and January 2015. This change 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."

Table 7

Number of Consumers Living in each Residence Type by Age Group and Percentage of Total by Residence Type

January 2005

	January 2005					
	Birth through 17		18 and	Older		
Residence Type	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total		
Own Home-Parent	92,404	94.1%	51,619	50.2%		
Community Care	4,796	4.9%	21,646	21.0%		
ILS/SLS	0	0.0%	17,333	16.8%		
SNF/ICF	530	0.5%	8,253	8.0%		
Developmental Center	51	0.1%	3,180	3.1%		
Other	387	0.4%	852	0.8%		
Total	98,168	100.0%	102,883	100.0%		

Table 8

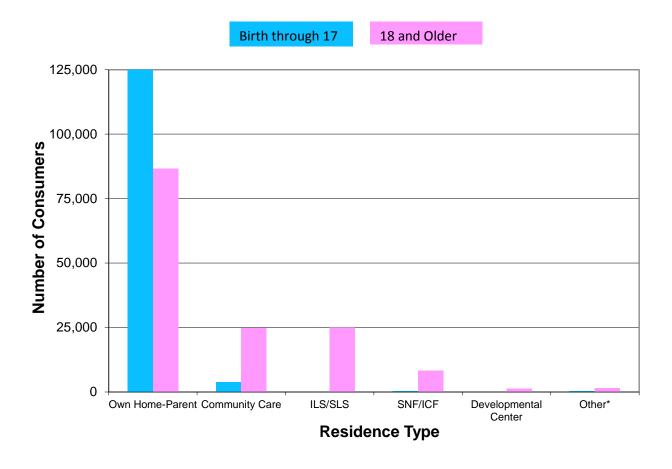
Number of Consumers Living in each Residence Type by Age Group and Percentage of Total by Residence Type

January 2015

	January 2015				
	Birth through 17		18 and	Older	
Residence Type	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total	
Own Home-Parent	127,334	96.8%	86,633	58.9%	
Community Care	3,709	2.8%	24,815	16.9%	
ILS/SLS	0	0.0%	24,866	16.9%	
SNF/ICF	212	0.2%	8,297	5.6%	
Developmental Center	2	0.0%	1,156	0.8%	
Other	329	0.3%	1,348	0.9%	
Total	131,586	100.0%	147,115	100.0%	

Figure 5

Number of Consumers by Residence Type and Age Group
January 2015



# GENDER AND AGE AT TIME OF INTAKE AND ASSESSMENT PROCESS INTO DEVELOPMENTAL SERVICES SYSTEM

The gender and age of individuals at the time of intake (based on the first CMF date) were analyzed for people who entered the developmental services system during the ten-year period from January 1, 2005 to January 1, 2015.

Of the 8,612 individuals who received intake and assessment services as of January 1, 2015, 27.1% were ultimately determined eligible to receive Early Start Program services and 30.5% were eligible to receive services as Active Consumers.

The remaining individuals were determined to be ineligible to receive regional center services.

#### Gender

The percentage of the male population engaged in intake increased from 66.1% in January 2005 to 69.5% in January 2015, while the percentage of the female population decreased from 33.9% to 30.5%.

Table 9

Gender of Consumers Engaged in the Intake and Assessment Process
January 2005 and January 2015

	January	January 2015		
Gender	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Female	2,231	33.9%	2,629	30.5%
Male	4,353	66.1%	5,983	69.5%
Total	6,584	100.0%	8,612	100.0%

### **Age Distribution**

In age distribution, the age group of birth through two years was the segment of the intake population with the largest increase, growing from 43.7% in January 2005 to 46.3% in January 2015. The age groups including age ten and older declined from 24.8% in January 2005 to 21.5% in January 2015.

Table 10

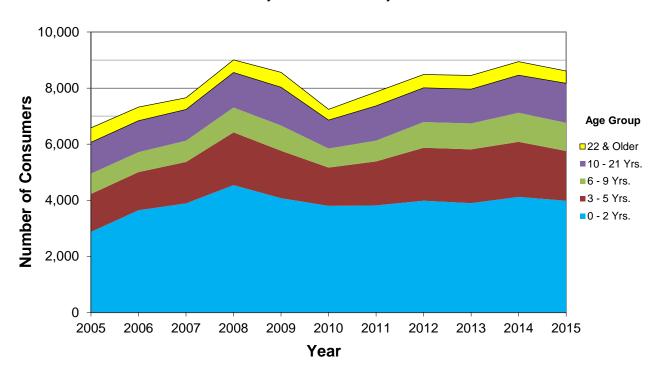
Age Group of Consumers Engaged in the Intake and Assessment Process

January 2005 and January 2015

	January	y 2005	January 2015		
Age Group	Number of Percentage Consumers of Total		Number of Consumers	Percentage of Total	
Birth - 2 Yrs.	2,874	43.7%	3,984	46.3%	
3 - 5 Yrs.	1,353	20.5%	1,775	20.6%	
6 - 9 Yrs.	725	11.0%	1,003	11.6%	
10 - 21 Yrs.	1,116	17.0%	1,411	16.4%	
22 & Older	516	7.8%	439	5.1%	
Total	6,584	100.0%	8,612	100.0%	

Figure 6

Number of Consumers by Age Group
January 2005 to January 2015



Days 40

### CONSUMERS RESIDING IN A DEVELOPMENTAL CENTER

The Lanterman Act promotes the provision of services in the least restrictive environment and emphasizes community settings as the preferred living option for most consumers. In 1999, the United States Supreme Court issued a ruling in the *Olmstead* case that required the decreased dependency on institutional services.

Based on the principles in the Lanterman Act, a notional trend away from institutional services, and the Supreme Court *Olmstead* decision, the total developmental center population has been declining dramatically as the community system expands, from a high of over 13,300 residents in 1968 to 1,150 residents in January 2015. Because of this decline, in the last 20 years, DDS has closed four developmental centers and one state-operated community facility. Over the last five years alone, the total population served in DDS-operated facilities has decreased by 1,022 residents.

Table 11 provides the number of consumers and percentage of consumers residing in each developmental center (Agnews, Canyon Springs, Fairview, Lanterman, Porterville, Sierra Vista, and Sonoma). This information was collected from monthly CMF updates.

Table 11

Number of Consumers Residing in each Developmental Center
January 2010 and January 2015

	Januai	y 2010	January	y 2015
Developmental Center	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Agnews	2	0.1%	0	0.0%
Canyon Springs	45	2.1%	50	4.3%
Fairview	470	21.6%	299	26.0%
Lanterman	401	18.5%	0	0.0%
Porterville	582	26.8%	378	32.9%
Sierra Vista	23	1.1%	0	0.0%
Sonoma	649	29.9%	423	36.8%
Total	2,172	100.0%	1,150	100.0%

### **DEVELOPMENTAL DISABILITY CATEGORY DEFINITIONS**

DDS collects data on the characteristics of the consumers it serves. The following tables and figures display information on the five major categories (Intellectual Disability, Autism, Epilepsy, Cerebral Palsy, or 5<sup>th</sup> Category) of developmental disabilities of consumers served by DDS from January 1, 2005 to January 1, 2015. Only people with a CDER on file are included. 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 individuals diagnosed with a developmental disability should have a CDER on file. For children under three years of age, a different, age-appropriate assessment tool called the Early Start Report is used instead of the CDER.

### **Definitions**

Intellectual Disability is characterized by significant limitations both in intellectual functioning (i.e., an IQ of approximately 70 or below) and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. Levels of Intellectual Disability (ID) are reported here as mild, moderate, severe, profound, no ID (i.e., Intellectual Disability is not present), or unspecified.

**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. The definition of Autism on the CDER has changed in the revised CDER. In the previous CDER, Autism was defined as consumers with Autism-Full Syndrome, Autism-Residual State, Autism Suspected or Not Diagnosed; in the revised CDER, Autism is defined as consumers with Autistic Disorder, Asperger Disorder, or Pervasive Developmental Disorder.

**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** includes two types of motor dysfunction: (1) non-progressive 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 eighteen.

**5**<sup>th</sup> **Category** is any developmental disability other than Intellectual Disability, Autism, Epilepsy, or Cerebral Palsy that is similar or closely related to Intellectual Disability, or which requires treatment similar to that required for individuals with intellectual disabilities. The revised CDER form now requires an explicit indication of 5th Category diagnosis, theoretically making the data more accurate, useful, and likely more fully reported.

# TRENDS OF THE FIVE DEVELOPMENTAL DISABILITY CATEGORIES OF CONSUMERS WITH CLIENT DEVELOPMENT EVALUATION REPORTS ON FILE

The composition of the population by type of developmental disability shows some significant shifts from January 1, 2005 to January 1, 2015. For example, only 21.8% of the population served had "No Intellectual Disability" recorded on their Client Development Evaluation Reports (CDERs) in January 2005. By January 2015, the percent without Intellectual Disability had grown to 33.8%. During this same time period, the percentage of persons reported to have "Moderate", "Severe" or "Profound" Intellectual Disability declined from a collective 32.8% to 23.9%.

The percent of the population with Epilepsy and the percent with Cerebral Palsy also declined over this period from 21.0% to 16.0% for Epilepsy and from 19.4% to 14.7% for Cerebral Palsy.

Two population categories showed an overall increase as a percentage of the population, with Autism increasing from 16.3% to 30.9% and 5<sup>th</sup> Category increasing from 9.6% to 10.2% from January 1, 2005 to January 1, 2015.

Did you know . . . according to the most recent CDER Personal Outcomes individual surveys,

89% of DDS consumers like living at their community home?

Table 12

Number of Consumers with Intellectual Disability
January 2005 and January 2015

	January 2005		January	y 2015
Level of Intellectual Disability	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
No ID	38,472	21.8%	82,525	33.8%
Mild	69,101	39.2%	84,908	34.8%
Moderate	31,360	17.8%	34,391	14.1%
Severe	15,057	8.5%	14,567	6.0%
Profound	11,389	6.5%	9,308	3.8%
Unspecified	11,086	6.3%	18,307	7.5%
Total	176,465	100.0%	244,006	100.0%

Figure 7

Number of Consumers with Intellectual Disability
January 2005 to January 2015

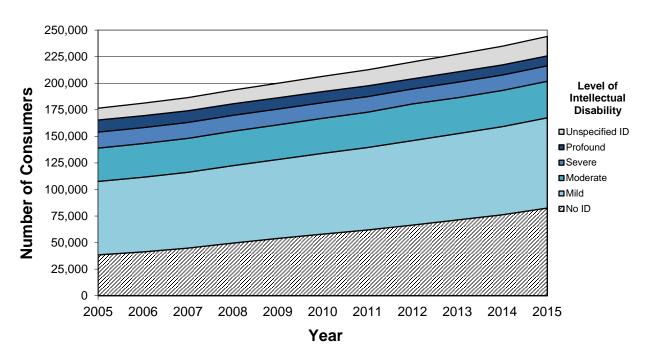


Table 13

Number of Consumers with Autism
January 2005 and January 2015

	January 2005		January 2015	
Has Autism	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Yes	28,732	16.3%	75,378	30.9%
No	147,733	83.7%	168,628	69.1%
Total	176,465	100.0%	244,006	100.0%

Figure 8

Number of Consumers with Autism
January 2005 to January 2015

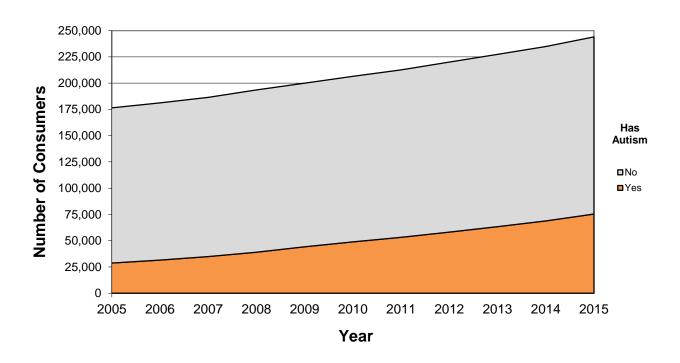


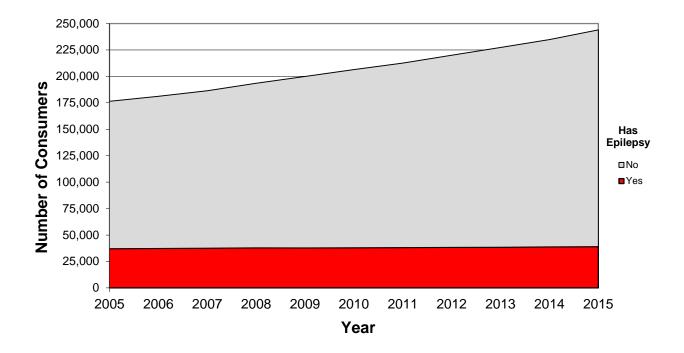
Table 14

Number of Consumers with Epilepsy
January 2005 and January 2015

	January 2005		January	January 2015	
Has Epilepsy	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total	
Yes	37,076	21.0%	39,017	16.0%	
No	139,389	79.0%	204,989	84.0%	
Total	176,465	100.0%	244,006	100.0%	

Figure 9

Number of Consumers with Epilepsy
January 2005 to January 2015



Day 00

Table 15

Number of Consumers with Cerebral Palsy
January 2005 and January 2015

January 2005			January 2015		
Has Cerebral Palsy	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total	
Yes	34,146	19.4%	35,935	14.7%	
No	142,319	80.6%	208,071	85.3%	
Total	176,465	100.0%	244,006	100.0%	

Figure 10

Number of Consumers with Cerebral Palsy
January 2005 to January 2015

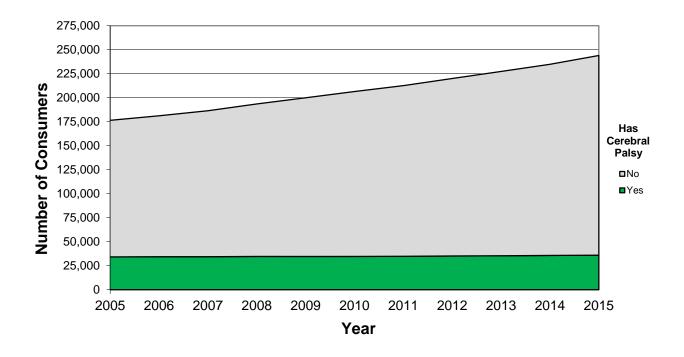


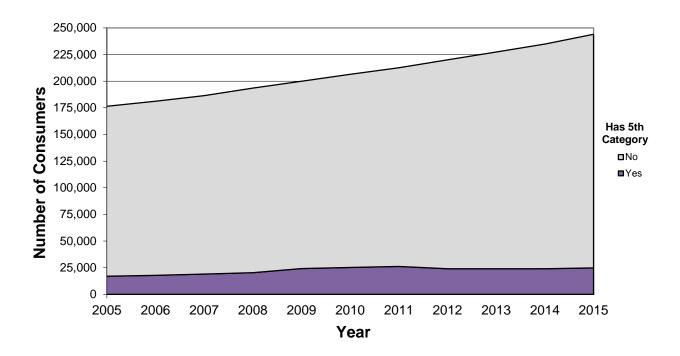
Table 16

Number of Consumers with 5<sup>th</sup> Category
January 2005 and January 2015

	January	y 2005	January 2015		
Has 5 <sup>th</sup> Category	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total	
Yes	17,014	9.6%	24,826	10.2%	
No	159,451	90.4%	219,180	89.8%	
Total	176,465	100.0%	244,006	100.0%	

Figure 11

Number of Consumers with 5<sup>th</sup> Category
January 2005 to January 2015



### **COMBINATIONS OF DEVELOPMENTAL DISABILITIES**

It is common for a consumer to have a combination of two or more developmental disabilities (Intellectual Disability, Autism, Epilepsy, Cerebral Palsy, or 5<sup>th</sup> Category) recorded on their CDER.

The majority of consumers with Intellectual Disability have only Intellectual Disability (58.6%) recorded on their CDER as of January 2015. However, the percentage of consumers with Intellectual Disability who also have Autism increased from 8.4% to 12.2% from January 2005 to January 2015.

An even larger percentage of consumers with Autism have only Autism (68.8%) recorded on their CDER as of January 2015. The percentage of consumers with Autism who also have Intellectual Disability decreased from 40.3% to 26.2% from January 2005 to January 2015.

A very small percentage of consumers have only Epilepsy (6.9%) or Cerebral Palsy (16.0%) as of January 2015. Most of the consumers with Epilepsy (80.8%) or Cerebral Palsy (73.6%) also have Intellectual Disability.

Consumers with 5<sup>th</sup> Category have only 5<sup>th</sup> Category recorded on their CDER 52.7% of the time as of January 2015.

Did you know ... according to the most recent CDER Personal Outcomes individual surveys,

86% of DDS consumers have a community outing at least weekly?

Table 17

Number of Consumers with Intellectual Disability with a Combination of Developmental Disabilities
January 2005 and January 2015

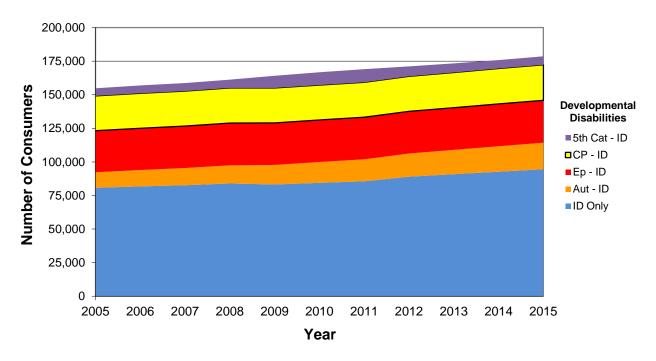
	Januar	y 2005	January 2015		
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*	
Total Number of					
Consumers with ID	137,993		161,481		
ID Only	80,728	58.5%	94,551	58.6%	
Autism	11,585	8.4%	19,764	12.2%	
Epilepsy	30,934	22.4%	31,541	19.5%	
Cerebral Palsy	25,910	18.8%	26,462	16.4%	
5 <sup>th</sup> Category	5,675	4.1%	6,341	3.9%	

<sup>\*</sup>The percentages sum to more than 100% since consumers may have a combination of 3 or more disabilities.

Figure 12

Number of Consumers with Intellectual Disability with a Combination of Developmental Disabilities

January 2005 to January 2015



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Table 18

Number of Consumers with Autism with a Combination of Developmental Disabilities January 2005 and January 2015

	Januar	y 2005	January 2015	
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*
Total Number of				
Consumers with				
Autism	28,732		75,378	
Autism Only	15,885	55.3%	51,881	68.8%
ID	11,585	40.3%	19,764	26.2%
Epilepsy	2,177	7.6%	3,443	4.6%
Cerebral Palsy	623	2.2%	948	1.3%
5 <sup>th</sup> Category	1,063	3.7%	2,905	3.9%

<sup>\*</sup>The percentages sum to more than 100% since consumers may have a combination of 3 or more disabilities.

Figure 13

Number of Consumers with Autism with a Combination of Developmental Disabilities January 2005 to January 2015

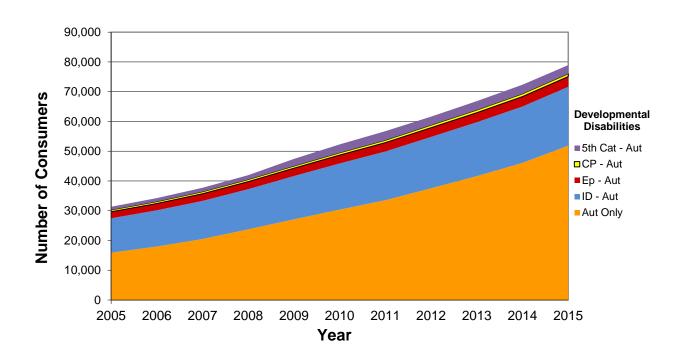


Table 19

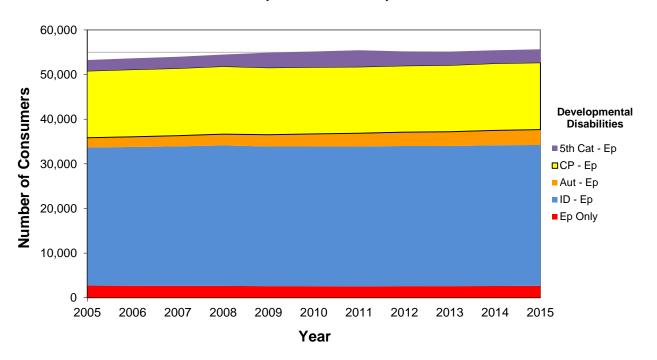
Number of Consumers with Epilepsy with a Combination of Developmental Disabilities January 2005 and January 2015

	January 2005		January	y 2015
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*
Total Number of				
Consumers with				
Epilepsy	37,076		39,017	
Epilepsy Only	2,752	7.4%	2,702	6.9%
ID	30,934	83.4%	31,541	80.8%
Autism	2,177	5.9%	3,443	8.8%
Cerebral Palsy	14,966	40.4%	14,998	38.4%
5 <sup>th</sup> Category	2,438	6.6%	2,992	7.7%

<sup>\*</sup>The percentages sum to more than 100% since consumers may have a combination of 3 or more disabilities.

Figure 14

Number of Consumers with Epilepsy with a Combination of Developmental Disabilities January 2005 to January 2015



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Table 20

Number of Consumers with Cerebral Palsy with a Combination of Developmental Disabilities January 2005 and January 2015

	Januar	y 2005	January 2015	
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*
Total Number of				
Consumers with				
Cerebral Palsy	34,146		35,935	
Cerebral Palsy Only	5,329	15.6%	5,762	16.0%
ID	25,910	75.9%	26,462	73.6%
Autism	623	1.8%	948	2.6%
Epilepsy	14,966	43.8%	14,998	41.7%
5 <sup>th</sup> Category	2,029	5.9%	2,441	6.8%

<sup>\*</sup>The percentages sum to more than 100% since consumers may have a combination of 3 or more disabilities.

Figure 15

Number of Consumers with Cerebral Palsy with a Combination of Developmental Disabilities
January 2005 to January 2015

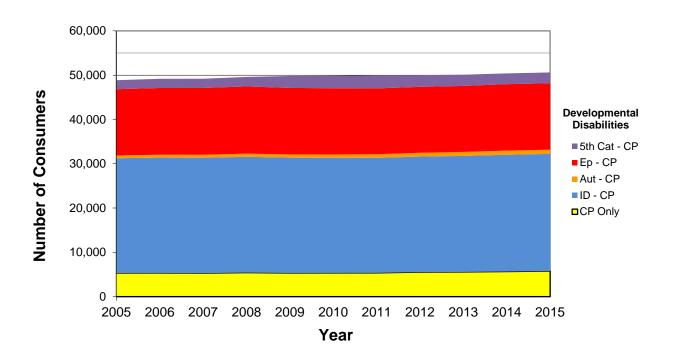


Table 21

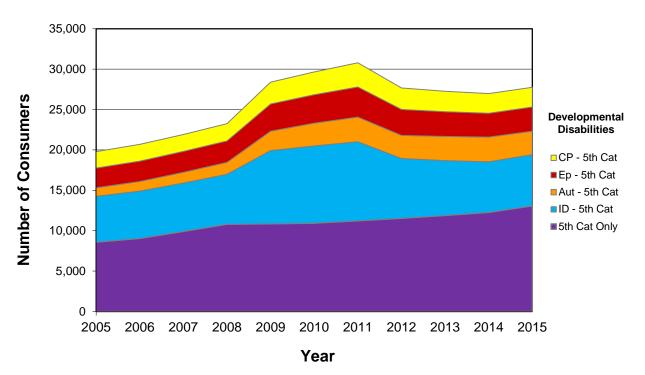
Number of Consumers with 5<sup>th</sup> Category diagnosis with a Combination of Developmental Disabilities
January 2005 and January 2015

	Januar	y 2005	January 2015	
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*
Total Number of				
Consumers with 5 <sup>th</sup>				
Category	17,014		24,826	
5 <sup>th</sup> Category Only	8,582	50.4%	13,075	52.7%
ID	5,675	33.4%	6,341	25.5%
Autism	1,063	6.2%	2,905	11.7%
Epilepsy	2,438	14.3%	2,992	12.1%
Cerebral Palsy	2,029	11.9%	2,441	9.8%

<sup>\*</sup>The percentages sum to more than 100% since consumers may have a combination of 3 or more disabilities.

Figure 16

Number of Consumers with 5<sup>th</sup> Category diagnosis with a Combination of Developmental Disabilities
January 2005 to January 2015



25.00

### WHAT CONSUMERS RECEIVE



### Carrey Jones, Xuefen (Fen) Mai, and Suzie Saldana

Since Carrey Jones has been at Southside Art Center, she has found a new and growing interest in ceramic sculpture and computers. To help her creative process, Carrey draws upon her love for animals and drawing to aid her.

Fen Mai is a talented artist who enjoys creating ceramic sculpture, mosaics, knit items and jewelry. She is a perfectionist at heart and her intricate works often reflect her acute attention to detail.

Suzie Saldana takes her inspiration from the music she listens to and from the other artists around her. She is a skilled painter whose art has been shown at Java City and many community shows in the Sacramento area.

# PERCENT OF CONSUMERS BY AGE GROUP RECEIVING REGIONAL CENTER-FUNDED SERVICES OF ALL CONSUMERS SERVED BY DDS IN THE COMMUNITY FY 2004-05 TO FY 2014-15

All consumers served by DDS receive case management services through their local regional center, regardless of whether they receive purchased services. Regional centers are required by law to provide or secure services in the most cost-effective way possible. They must use all other resources, including those provided by other agencies, before using any regional center funds. When alternate sources are not available, the regional center purchases services as specified in the consumer's Individual Program Plan (IPP) or Individualized Family Service Plan (IFSP).

The percentage of consumers (all ages) receiving regional center-funded services out of all consumers served in the community (Early Start and Active consumers) fluctuated moderately from FY 2004-05 to FY 2014-15, decreasing from 80.0% of consumers served in the community to 78.3%. The percent of consumers (all ages) receiving regional center funded services decreased 0.3% from FY 2013-14 to FY 2014-15.

Purchase of services are from the most recent monthly data. Over the last three fiscal years, figures for the same fiscal year will differ slightly from one annual Fact Book report to the next.

Table 22

Percentage of Consumers (Prevention\*, Early Start Program, Active Consumer)

Receiving Regional Center-Funded Services, by Age Group

FY 2004-05 to FY 2014-15

Fiscal			22-61	62 Yrs	All Ages
Year	0-2 Yrs	3-21 Yrs	Yrs	and Up	(Total)
04/05	88.0%	70.1%	88.7%	87.3%	80.0%
05/06	88.7%	66.0%	88.1%	87.2%	78.1%
06/07	87.1%	66.8%	88.3%	88.4%	78.4%
07/08	88.6%	69.2%	88.3%	88.7%	79.8%
08/09	90.3%	71.5%	88.6%	89.4%	81.1%
09/10	88.4%	68.9%	88.1%	90.1%	79.4%
10/11	85.4%	67.2%	87.7%	90.0%	78.2%
11/12	90.8%	66.4%	87.0%	90.4%	78.2%
12/13	92.9%	64.9%	86.3%	90.5%	77.6%
13/14	93.6%	65.6%	86.1%	91.3%	78.0%
14/15	94.2%	66.1%	85.8%	91.8%	78.3%

<sup>\*</sup> Prevention consumers are included in FY 09/10, FY 10/11, and FY 11/12 only.

### Purchase of Services Growth vs. DDS CaseLoad - FY 2004-05 to FY 2014-15

Community caseload (Prevention, Early Start Program, and Active Consumers on the Client Master File as of the end of each FY) grew by 82,555 consumers from FY 2004-05 to FY 2014-15. By comparison, cumulative growth for Purchase of Service (POS) expenditures increased by \$1,968.3 million over this period. Total POS expenditures leveled off from FY 2008-09 to FY 2010-11, reflecting state budget cuts.

Table 23

DDS Caseload Number and POS Expenditure Amount (in Millions)

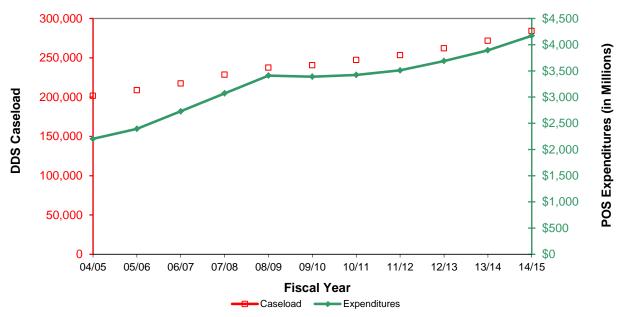
FY 2004-05 to FY 2014-15

Fiscal Year	DDS Fiscal Year Caseload (Prevention*, Early Start Program, Active Consumer)	POS Expenditures** (in Millions)
04/05	201,614	\$2,203.7
05/06	208,687	\$2,394.4
06/07	217,333	\$2,728.7
07/08	228,460	\$3,072.9
08/09	237,389	\$3,411.5
09/10	240,568	\$3,390.1
10/11	247,310	\$3,424.2
11/12	253,235	\$3,510.7
12/13	262,149	\$3,689.4
13/14	271,724	\$3,894.7
14/15	284,169	\$4,172.0

<sup>\*</sup>Prevention consumers are included in FY 09/10, FY 10/11, and FY 11/12 only.

Figure 17

DDS Caseload Number and POS Expenditure Amount (in Millions)
FY 2004-05 to FY 2014-15



<sup>\*\*</sup>Includes contract POS

# EXPENDITURES AND COUNTS BY SERVICE CATEGORY FY 2009-10 TO FY 2014-15

In order to provide a comprehensive, detailed view of Service Categories, the following three tables focus on the information collected over the past five years.

### **PURCHASE OF SERVICES EXPENDITURES**

Table 24 presents the purchase of services (POS) expenditures by Service Category from FY 2009-10 to FY 2014-15, along with the POS changes from FY 2013-14 to FY 2014-15.

Overall, the POS expenditures increased \$277.3 million (7.1%) from FY 2013-14 to FY 2014-15. Well over half of the service categories (18 of 25) showed an increase in POS expenditures from FY 2013-14 to FY 2014-15.

The service categories with the largest POS expenditure increase from FY 2013-14 to FY 2014-15 were "Residential Services", which increased by \$87.8 million (9.3%), and "Supported Living and Related Services", which increased by \$51.6 million (8.5%).

Did you know ... according to the most recent CDER Personal Outcomes individual surveys,

67% of DDS consumers who work are paid for over 10 hours of work per week?

Table 24

POS Expenditures\* (in Millions) by FY from FY 2009-10 to FY 2014-15 (and POS Change from FY 2013-14 to FY 2014-15)

Service Category	FY 10/11	FY 11/12	FY 12/13	FY 13/14	FY 14/15	Change from FY 13/14 to FY 14/15
Residential Services	\$842.2	\$868.7	\$912.2	\$946.0	\$1,033.8	\$87.8
Adult Day Program	\$733.8	\$767.9	\$821.4	\$876.0	\$922.1	\$46.1
Adult Development Center	\$296.2	\$309.2	\$327.2	\$342.8	\$356.7	\$14.0
Behavior Mgmt. Program	\$170.5	\$180.0	\$195.3	\$209.5	\$217.3	\$7.8
Other Look-Alike Programs	\$138.1	\$149.5	\$165.6	\$186.1	\$206.2	\$20.1
Independent Living Program	\$80.1	\$79.1	\$80.5	\$82.6	\$85.0	\$2.4
Activity Center	\$45.3	\$46.2	\$48.6	\$50.1	\$51.4	\$1.3
Social Recreation Program	\$3.7	\$3.9	\$4.3	\$4.9	\$5.5	\$0.6
Supported Living & Related Svcs.	\$483.4	\$515.7	\$562.0	\$610.0	\$661.7	\$51.6
Behavioral Services	\$312.9	\$304.5	\$282.8	\$286.5	\$308.6	\$22.2
Transportation	\$219.6	\$225.7	\$236.7	\$251.3	\$266.6	\$15.3
Respite	\$197.7	\$191.7	\$206.4	\$225.4	\$258.4	\$33.1
Infant Program Services	\$153.2	\$144.5	\$151.3	\$162.6	\$168.6	\$6.0
Medical Care & Services	\$79.8	\$86.3	\$95.6	\$102.7	\$115.8	\$13.1
Supported Employment Program	\$88.2	\$89.7	\$89.9	\$92.3	\$94.3	\$2.0
Supplemental Program Support	\$60.8	\$61.5	\$66.3	\$74.3	\$82.0	\$7.7
Work Activity Program	\$56.3	\$56.3	\$57.1	\$57.4	\$55.7	-\$1.6
Day Care	\$40.7	\$36.8	\$33.7	\$33.6	\$29.9	-\$3.8
Social/Recreational Activities	\$26.5	\$26.7	\$27.4	\$28.1	\$29.6	\$1.5
Non-Medical Therapy Services	\$5.0	\$5.0	\$4.9	\$5.0	\$4.6	-\$0.4
Medical & Adaptive Equip./Supplies	\$5.6	\$5.3	\$5.7	\$6.2	\$6.0	-\$0.2
Camps	\$0.5	\$1.0	\$1.3	\$1.4	\$1.7	\$0.4
Environmental & Vehicle Mod.	\$1.9	\$2.0	\$3.4	\$3.2	\$4.0	\$0.8
Mobility Training	\$0.4	\$0.4	\$0.5	\$0.4	\$0.4	\$0.0
All Other Services	\$115.8	\$121.0	\$130.9	\$132.4	\$128.3	-\$4.1
Total	\$3,424.2	\$3,510.7	\$3,689.4	\$3,894.7	\$4,172.0	\$277.3

<sup>\*</sup>Purchase of services are from the most recent monthly data. Over the last 3 fiscal years, figures for the same fiscal year will differ slightly from one annual Fact Book report to the next.

### Number of Consumers Receiving Services

Table 25 presents the number of consumers receiving services by Service Category from FY 2009-10 to FY 2014-15, along with the changes in the number of consumers from FY 2013-14 to FY 2014-15.

Overall, the number of consumers receiving services increased by 13,118 (5.0%) from FY 2013-14 to FY 2014-15. Well over half of the service categories (20 of 25) showed an increase in the number of consumers receiving the service from FY 2013-14 to FY 2014-15.

Individual service categories with the largest increase in the number of consumers receiving the service from FY 2013-14 to FY 2014-15 were "Respite", which increased by 10,843 consumers (14.9%), and "Supported Living & Related Services" category, which increased by 4,433 consumers (11.0%).

The service category with the largest decrease in the number of consumers receiving the service from FY 2013-14 to FY 2014-15 was "Medical Care and Services", which decreased by 566 consumers (0.9%).

Did you know ... according to the most recent CDER Personal Outcomes individual surveys,

93% of DDS consumers with medical or dental conditions received full appropriate care?

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Table 25

Number of Consumers Receiving Services by Service Category
FY 2009-10 to FY 2014-15

Service Category*	FY 10/11	FY 11/12	FY 12/13	FY 13/14	FY 14/15	Change from FY 13/14 to FY 14/15
Residential Services	29,543	29,976	30,039	30,628	31,219	591
Adult Day Program*	65,046	67,514	70,298	73,462	76,837	3,375
Adult Development Center	27,607	28,728	29,902	31,218	32,412	1,194
Behavior Mgmt. Program	12,428	13,160	13,869	14,667	15,277	610
Other Look-Alike Programs	11,116	11,594	12,580	13,682	14,838	1,156
Independent Living Program	13,532	13,461	13,519	13,755	14,599	844
Activity Center	6,356	6,518	6,684	6,768	6,826	58
Social Recreation Program	1,114	1,139	1,197	1,281	1,405	124
Supported Living & Related Svcs.	24,601	32,532	38,986	40,397	44,830	4,433
Behavioral Services	34,935	37,198	39,147	41,297	42,763	1,466
Transportation	72,113	74,182	75,558	80,888	83,089	2,201
Respite	68,528	68,772	68,142	72,713	83,556	10,843
Infant Program Services	34,633	35,686	37,859	39,819	42,814	2,995
Medical Care & Services	57,604	58,036	57,693	61,020	60,454	-566
Supported Employment Program	10,991	10,843	10,807	10,809	11,037	228
Supplemental Program Support	5,680	5,739	5,865	6,650	7,077	427
Work Activity Program	11,335	10,962	10,960	10,688	10,302	-386
Day Care	7,016	6,683	6,138	5,932	5,798	-134
Social/Recreational Activities	5,748	5,657	5,471	5,469	5,746	277
Non-Medical Therapy Services	3,312	3,150	2,817	2,584	2,390	-194
Medical & Adaptive Equip./Supplies	4,605	4,215	4,261	4,633	4,822	189
Camps	590	1,004	1,114	1,279	1,552	273
Environmental & Vehicle Mod.	328	372	482	485	589	104
Mobility Training	468	377	345	342	316	-26
All Other Services	86,770	89,823	93,656	97,118	102,970	5,852
Total*	238,687	244,786	252,101	262,191	275,309	13,118

<sup>\*</sup>The total counts are unduplicated by consumer to avoid double counting consumers who receive more than one type of service.

Counts are based on most recent purchase of services data. Over the last three fiscal years, figures for the same fiscal year can differ slightly from one annual Fact Book to the next.

### Number of Vendors Providing Services

Table 26 presents the number of vendors providing services by Service Category from FY 2009-10 to FY 2014-15, along with the changes in the number of vendors from FY 2013-14 to FY 2014-15.

Overall, the number of vendors providing services decreased by 978 (2.2%) from FY 2013-14 to FY 2014-15. Just over half of the service categories (13 of 25) showed a decrease in the number of vendors providing the service from FY 2013-14 to FY 2014-15.

The service category with the largest increase in the number of vendors providing services from FY 2013-14 to FY 2014-15 was "Supplemental Program Support", which increased by 56 vendors (3.4%).

Service categories with the largest decrease in the number of vendors providing services from FY 2013-14 to FY 2014-15 were "Transportation", which decreased by 319 vendors (5.8%) and "Day Care", which decreased by 237 vendors (17.3%).

The vendor counts for Transportation, Respite, and Day Care services began decreasing in FY11/12 with the implementation of the new requirement to use a Financial Management Service (FMS) in conjunction with participant-directed/vouchered services. Many consumers/families, who were individually vendored for these services when using vouchers, switched to using vendored agencies for coordination of services. As a result, these consumers/families are no longer vendored and are no longer reflected in the vendor counts.

Did you know ... according to the most recent CDER Personal Outcomes individual surveys,

83% of DDS consumers in school have contacts with non-developmentally disabled persons?

 Table 26

 Number of Vendors Providing Services by Service Category

FY 2009-10 to FY 2014-15

Service Category*	FY 10/11	FY 11/12	FY 12/13	FY 13/14	FY 14/15	Change from FY 13/14 to FY 14/15
Residential Services	5,968	5,959	5,914	5,941	5,853	-88
Adult Day Program*	1,917	1,959	2,023	2,077	2,125	48
Adult Development Center	593	599	599	624	633	9
Behavior Mgmt. Program	298	307	320	336	344	8
Other Look-Alike Programs	513	538	573	576	594	18
Independent Living Program	372	379	396	403	416	13
Activity Center	141	139	142	142	145	3
Social Recreation Program	28	24	21	22	21	-1
Supported Living & Related Svcs.	1,967	2,164	2,174	2,216	2,237	21
Behavioral Services	1,012	1,034	1,039	1,045	1,069	24
Transportation**	9,177	9,239	6,566	5,477	5,158	-319
Respite**	22,946	18,064	4,517	2,171	1,963	-208
Infant Program Services	487	469	444	437	453	16
Medical Care & Services	2,632	2,476	2,295	2,239	2,170	-69
Supported Employment Program	360	373	369	375	372	-3
Supplemental Program Support	1,490	1,510	1,570	1,671	1,727	56
Work Activity Program	120	116	116	115	110	-5
Day Care**	5,048	4,587	2,301	1,369	1,132	-237
Social/Recreational Activities	197	176	166	161	162	1
Non-Medical Therapy Services	260	240	219	193	174	-19
Medical & Adaptive Equip./Supplies	1,791	1,618	1,615	1,592	1,573	-19
Camps	62	54	50	49	46	-3
Environmental & Vehicle Mod.	59	61	65	58	64	6
Mobility Training	39	32	31	30	27	-3
All Other Services	25,483	25,903	26,089	25,638	25,098	-540
Total*	70,370	66,714	49,872	45,305	44,327	-978

<sup>\*</sup>Total counts are unduplicated by vendor to avoid double counting vendors providing multiple services.

Counts are based on most recent purchase of services file. Over the last three fiscal years, figures for the same fiscal year can differ slightly from one annual Fact Book to the next.

<sup>\*\*</sup>The vendor counts for these services began decreasing in FY 11/12. See note on previous page.

POPULATION AND PER CAPITA COST BY DEVELOPMENTAL DISABILITY AND AGE GROUP

As of July 2015, the majority of consumers with Intellectual Disability (63.1%), Epilepsy (70.6%), Cerebral Palsy (63.2%), or 5<sup>th</sup> Category (53.9%) were age 22 years or older, whereas the majority of consumers with Autism (81.2%) were 3-21 years of age.

The average per capita cost of consumers with each developmental disability category increased considerably after age 21. Specifically, Autism is the most expensive developmental disability per capita for all age groups compared with Intellectual Disability, Epilepsy, Cerebral Palsy, or 5<sup>th</sup> Category.

Expenditures for consumers typically rise after age 21 when Department of Educationfunded services are no longer available, and out-of-home placement and day services are needed. As the growing proportion of young consumers with Autism ages into adulthood, the projected impact on increasing costs is unknown, but may be significant.

Did you know ... according to the most recent CDER Personal Outcomes individual surveys,

90% of DDS consumers like their day activity?

Figure 18

Number of Consumers (Early Start Program, Active Consumer, Developmental Center) by Developmental Disability and Age Group (3-11 years, 12-21 years, 22-31 years, 32-41 years, 42-51 years, 52-61 years, and 62+ years) as of July 2015

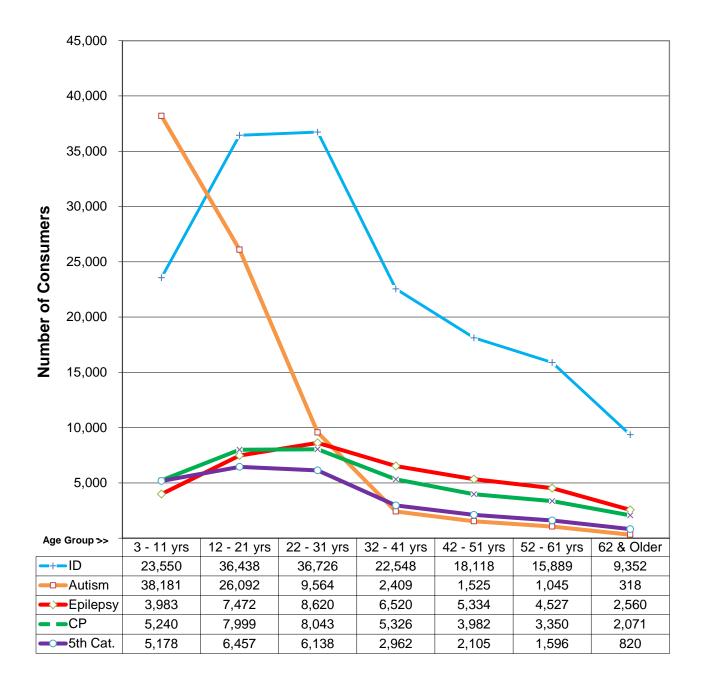
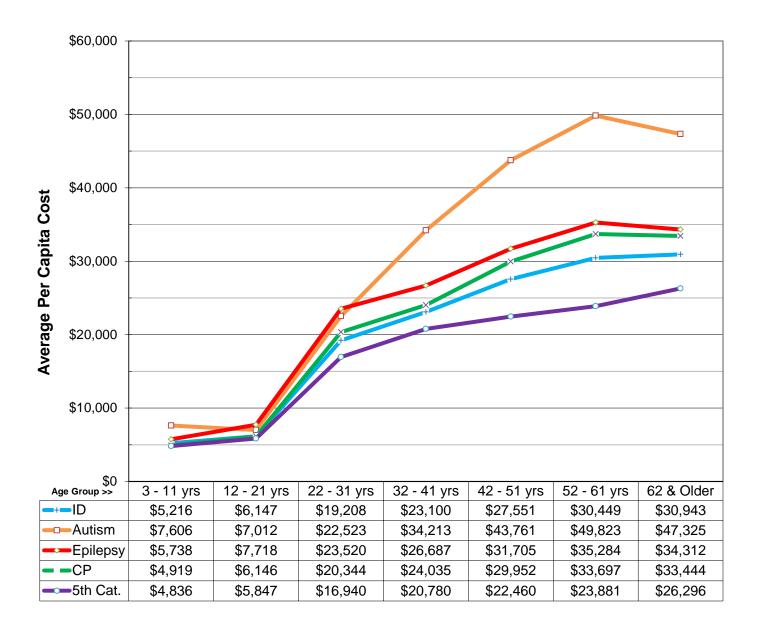


Figure 19

Average Per Capita Expenditures (Early Start Program, Active Consumer, Developmental Center) by Developmental Disability and Age Group (3-11 years, 12-21 years, 22-31 years, 32-41 years, 42-51 years, 52-61 years, and 62+ years) as of July 2015





### Carrey Jones, Xuefen (Fen) Mai, and Suzie Saldana

See all three artists' biographical information on page 31.

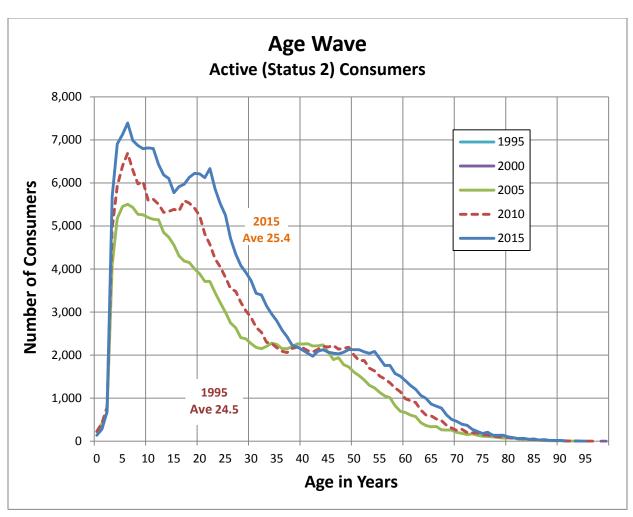
### **DEMOGRAPHIC TRENDS: AGE WAVE OVER THE PAST 20 YEARS**

Over the past 20 years the success of the Early Start program and intake of school-aged children has resulted in a large overall growth in the 3-30 age group within this population. Note the tremendous growth in primary school-age consumers, as well as those in young adulthood. The rise of consumers ages 18-22 presumably comes from consumers transitioning to DDS from services in schools as well as those needing housing and other adult services provided by DDS.

The over-30 population has remained essentially stable. Note the rightward population shifts due to aging, but otherwise modest growth. Consumers are living longer now in 2015, with the rapid decline due to mortality starting in the population's late fifties, whereas the mortality decline in 1995 had started in the population's forties.

Figure 20

Consumer Count on July 1 of every 5<sup>th</sup> Year for the Past 20 Years



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### PERSONAL OUTCOMES HIGHLIGHTS FOR DDS CONSUMERS

In 2008, DDS added a Personal Outcomes element to the Client Development Evaluation Report (CDER), the Department's diagnostic tool. Service coordinators at the regional centers ask survey questions of the best informant available for each question as it pertains to their assessment of the consumer's situation at the time the CDER is updated.

These are some of the highlights of the outcomes portion of the report:

#### Education

56% of those in school have integrated classrooms

83% of those in school have contacts with non-developmentally disabled persons

97% of those in school have contacts with the same primary language

### **Work and Day Programs**

98% of those in day programs or work interact with persons with the same language

67% of those working are paid for over 10 hours of work per week

40% of those working are paid minimum wage or over

### **Social Well-Being**

86% of consumers have a community outing at least weekly

79% have one or more personal friends

91% of consumers have moved only once or not at all in two years

98% have persons in their house speaking the same language

### **Medical and Dental Care**

97% had medical care in the past year and had their needs met

87% had dental care in the past year and had their needs met

93% of those with medical or dental conditions received full appropriate care

### **Living Situation**

89% like living at their community home

93% like the people they live with

88% wish to keep living at their community home

### Day Activity

90% like their day activity

92% like the people at their day activity

91% want to continue going to their day activity

### **Emotional Security**

94% name someone with whom they can talk when unhappy

87% feel safe all the time

81% feel happy most of the time

83% feel comfortable telling people what they want most of the time

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