Department of Developmental Services

Fact Book Fifteenth Edition



Prepared by DDS Information Technology Division June 2018

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

PREFACE

The Fact Book presents pertinent data about the individuals served by the Department of Developmental Services (DDS) over a ten-year period and includes an overview of services and trends in California. 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, three state-operated developmental centers and one state-operated community facility. In this publication, the community facility counts and percentages are included with the developmental centers.

To be eligible for services, a person must have a disability that begins before the person's 18th birthday, is expected to continue indefinitely, and presents a substantial disability as defined in <u>Section 4512 of the California Welfare and Institutions Code</u>. Eligibility is established through diagnosis and assessment performed by regional centers. The data presented in this Fact Book includes only those developmentally disabled persons who are eligible for and have requested DDS services.

A developmental disability is a condition that 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, or requiring treatment similar to, that required by a person with Intellectual Disability (referred to as Fifth Category). 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 provide DDS consumer characteristic and demographic information derived from data stored in DDS automated systems; percentages are rounded and may not always total 100 percent when added. This and other DDS consumer information are available on the <u>DDS website</u>. Additional information about DDS consumer characteristics and caseload are on the <u>Facts and Stats</u> webpage. For DDS consumer demographic information for prior years, please refer to prior editions of the Fact Book.

Cover Art: Spring Flowers - by Helen ("Suzie") Saldana & Shawyna Mays

Helen is a multimedia artist who has been making art at Southside Unlimited for the last fifteen years. She is skilled in a variety of different media including wire sculpture, collage, drawing, and painting.

Shawyna has worked with Southside since 2012, drawing inspiration from wildlife, nature, and landscapes. She is also skilled in watercolor, mosaic, and mixed media.

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¹ 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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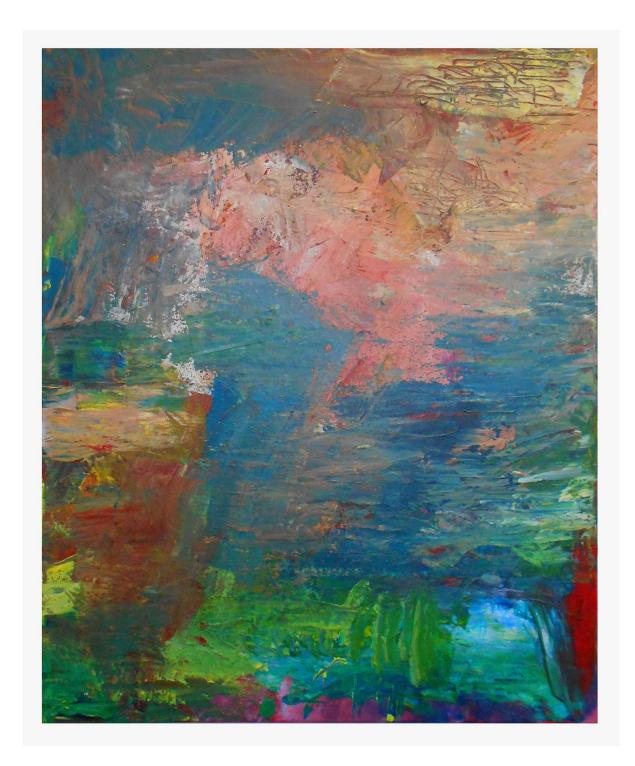
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ARTWORK

Participants in Work of Art at Southside Unlimited created the artwork in our Fact Book. Southside Unlimited, formerly known as Southside Art Center, is a 501(c)(3) not-for-profit corporation that creates a forum for applying the medium of opportunity, blending artistic expression, personal progress, and active citizenship toward individual empowerment. Southside Unlimited sees people with developmental challenges as full citizens of the community who have the ability and the opportunity to contribute to society, prosper financially, and make decisions that affect their lives. Southside Unlimited believes the philosophy of "People First": If you see us as equal, but different, and do not include us in the decisions that affect our lives, *you will see us as your disabled client.* "People First" believes if you get out of our way and we have the opportunity to gather power and knowledge over OUR own lives, we will become strong and successful.

SECTION 1: WHOM DDS SERVES



Auburn Scape - Chris Francee

Chris is a long-time Auburn resident and artist. He has explored landscape painting throughout the years and has a loyal local following. His expanding repertoire includes plein air and studio oil landscape.

DDS Consumer Information

The consumer information charts display Client Master File (CMF) data. Regional centers add consumers to CMF at the time of initial application for regional center services. The CMF is the primary source of demographic, case status, and service coordinator information. CMF status codes include:

- Intake and Assessment (Status Code 0): Applicants for regional center services being assessed for eligibility.
- Early Start Program (Status Code 1): Children birth to age three with a developmental delay, disability, or an established risk condition with a high probability of resulting in a delay or disability. Children with Status Code 1 qualify for early intervention and family support services.
- Active Consumer (Status Code 2): People with a diagnosed developmental disability served in the community rather than a developmental center.
- **Developmental Center (Status Code 8):** People with a diagnosed developmental disability served in a developmental center.
- Prevention (Status Code P): Children birth to age three diagnosed with a genetic, medical, or developmental disability or an environmental history that is predictive of a substantially greater risk for a developmental disability than that of the general population. The Prevention Program began October 1, 2009 and ended on September 30, 2012. Unless otherwise noted, prevention status counts and percentages are included with Early Start Program information.

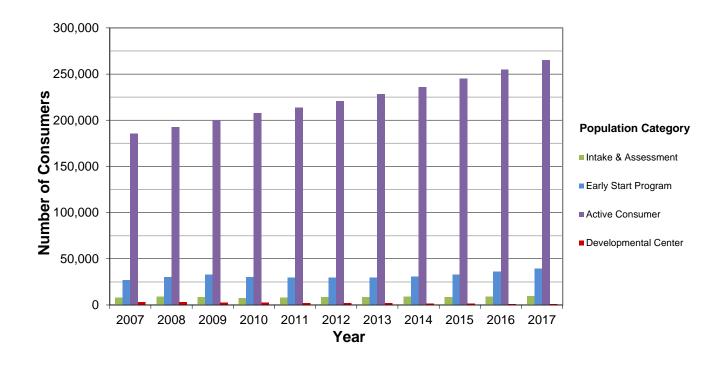
CONSUMER POPULATION CATEGORIES

The number of DDS consumers in the Intake and Assessment, Early Start Program, Active Consumer, and Developmental Center categories increased by 41.3% between January 1, 2007 and January 1, 2017. According to Department of Finance estimates, California's general population grew 9.4% between March 2007 and July 2017. DDS provided service to approximately 0.79% of California's population as of July 1, 2017.

 Table 1: Number of Consumers in each Population Category on the Client Master File

	Januar	y 2007	Januar	y 2017
		Percentage		Percentage
	Number of	of Total	Number of	of Total
Population Category	Consumers	Consumers	Consumers	Consumers
Intake & Assessment	7,656	3.4%	9,388	3.0%
Early Start Program*	26,598	11.9%	39,507	12.6%
Active Consumer	185,534	83.3%	264,842	84.2%
Developmental Center	2,914	1.3%	901	0.3%
Total	222,702	100.0%	314,638	100.0%

Figure 1: Number of Consumers by Population Category



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

^{**} Includes 43 consumers at Canyon Springs Community Facility.

CONSUMER DEMOGRAPHICS

Consumer demographic information for Early Start, Active, and Developmental Center consumers as of January 1, 2007, as compared to January 1, 2017 is displayed by residence type, age, ethnicity, gender, and primary language.

Consumer Residence Type

Changes in the residence types of the population are noteworthy. While 72.6% of consumers resided in the home of a parent or guardian in January 2007, 78.4% had this residence type in January 2017. During this same period, decreases continued in the proportion of people living in community care settings (12.4% to 9.6%) and developmental centers (1.3% to 0.3%).

Definitions of Residence Types

Own Home-Family: Home of a family member, guardian, or conservator

Community Care: Settings such as Foster Homes for Children, Family Home Agency (FHA) homes, and Community Care Facilities (CCF), including Adult Residential Facilities for Persons with Special Health Care Needs (ARFPSHN)

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 or community facility operated by DDS

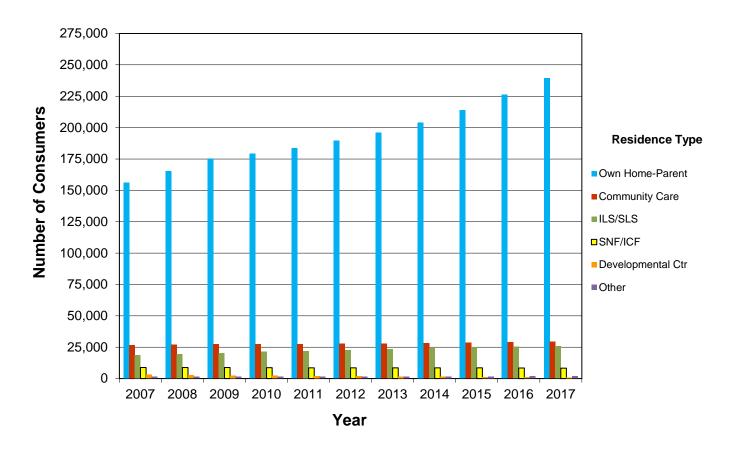
Other: Settings such as Hospitals, Community Treatment Facilities, Rehabilitation Centers, Psychiatric Treatment Centers, Correctional Institutions, and other settings in the community

Consumer Residence Type

Table 2: Residence Type of Consumers

	January	2007	January	2017
Residence Type	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Own Home-Parent	156,204	72.6%	239,221	78.4%
Community Care	26,744	12.4%	29,158	9.6%
ILS/SLS	18,802	8.7%	25,767	8.4%
SNF/ICF	8,811	4.1%	8,342	2.7%
Developmental Center	2,891	1.3%	901	0.3%
Other	1,594	0.7%	1,871	0.6%
Total	215,046	100.0%	305,260	100.0%

Figure 2: Number of Consumers by Residence Type



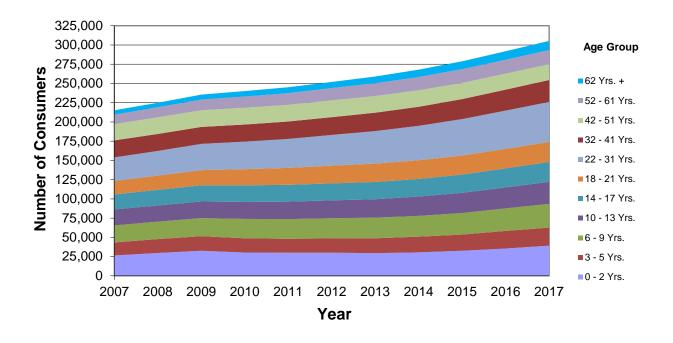
Consumer by Age

The DDS population continued to trend toward becoming slightly older. The average age of all consumers in January 2007 was 24.9 years of age as compared to January 2017, when the average was 25.2 years of age.

Table 3: Age Group of Consumers Served by DDS

	January 2007		January 2017
Age Group	Number of Consumers	Percentage of Total	Number of Percentage Consumers of Total
0- 2 Yrs.	26,514	12.3%	39,196 12.8%
3 - 5 Yrs.	16,951	7.9%	23,491 7.7%
6 - 9 Yrs.	22,097	10.3%	30,820 10.1%
10 - 13 Yrs.	20,594	9.6%	28,592 9.4%
14 - 17 Yrs.	19,644	9.1%	25,874 8.5%
18 - 21 Yrs.	17,333	8.1%	26,034 8.5%
22 - 31 Yrs.	30,720	14.3%	51,937 17.0%
32 - 41 Yrs.	22,146	10.3%	28,551 9.4%
42 - 51 Yrs.	21,244	9.9%	20,507 6.7%
52 - 61 Yrs.	12,183	5.7%	18,579 6.1%
62 Yrs. +	5,620	2.6%	11,680 3.8%
Total	215,046	100.0%	305,261 100.0%

Figure 3: Number of Consumers by Age Group



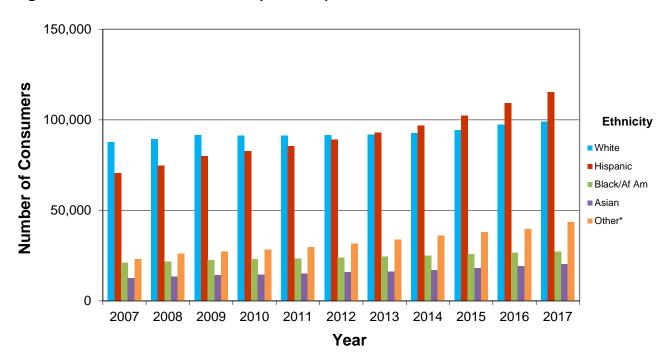
Ethnicity

Hispanics continue to be the fastest growing segment of the DDS population, increasing from 32.8% in January 2007 to 37.8% in January 2017. Over this same period, the White population decreased from 40.8% to 32.4% of the total DDS population.

Table 4: Ethnicity of Consumers

	January	y 2007	January	2017
Ethnicity	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
White	87,726	40.8%	98,999	32.4%
Hispanic	70,517	32.8%	115,326	37.8%
Black/Af Am	21,235	9.9%	27,287	8.9%
Asian	12,544	5.8%	20,209	6.6%
Other*	23,024	10.7%	43,440	14.2%
Total**	215,046	100.0%	305,261	100.0%

Figure 4: Number of Consumers by Ethnicity



^{*} Includes multiple ethnicities

^{**} Related table, Table 27, includes consumers engaged in the Intake and Assessment process (status code 0), while Table 4 does not.

Consumer Gender

The trend in the DDS consumer gender distribution of DDS consumers continued in 2017 with males increasing in numbers relative to females. In January 2007, 60.9% of the people served were male as compared to 39.1% female. In January 2017, the gap widened to 64.6% male compared to 35.4% 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 2007			January 2017		
Gender	Number of Percentage Consumers of Total		Number of Consumers	Percentage of Total		
Female	84,042	39.1%	107,953	35.4%		
Male	131,004	60.9%	197,308	64.6%		
Total	215,046	100.0%	305,261	100.0%		

Consumer Primary Language

English continues to be the most prevalent primary language of DDS consumers. English was the primary language for 76.3% of consumers in January 2007 and 75.2% in January 2017.

Table 6: Primary Language (English and Non-English) of Consumers

	January	January	January 2017		
Primary Language	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total	
English	164,113	76.3%	229,598	75.2%	
Non-English	50,933	23.7%	75,663	24.8%	
Total	215,046	100.0%	305,261	100.0%	

CONSUMER RESIDENCE TYPE BY AGE GROUP JANUARY 2007 AND JANUARY 2017

During the period from January 1, 2007 to January 1, 2017, DDS has followed the Lanterman Act's direction to promote "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." ². The overall percentage of consumers in both the "Birth through 17" and "18 and Older" age groups residing in the home of a parent, guardian, or conservator (labeled "Own Home-Family" in the tables below), a community care setting, or supported living or independent setting, increased. Meanwhile, the percentage of consumers residing in skilled nursing facilities (SNF), intermediate care facilities (ICF), and developmental centers decreased. 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.

Table 7: Number of Consumers by Residence Type and Age Group - Birth to 17

	January 2007		January	/ 2017
Residence Type	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Own Home-Parent	100,258	94.8%	143,137	96.7%
Community Care	4,487	4.2%	4,340	2.9%
ILS/SLS	0	0.0%	0	0.0%
SNF/ICF	456	0.4%	166	0.1%
Developmental Center	37	0.0%	0	0.0%
Other	559	0.5%	330	0.2%
Total	105,797	100.0%	147,973	100.0%

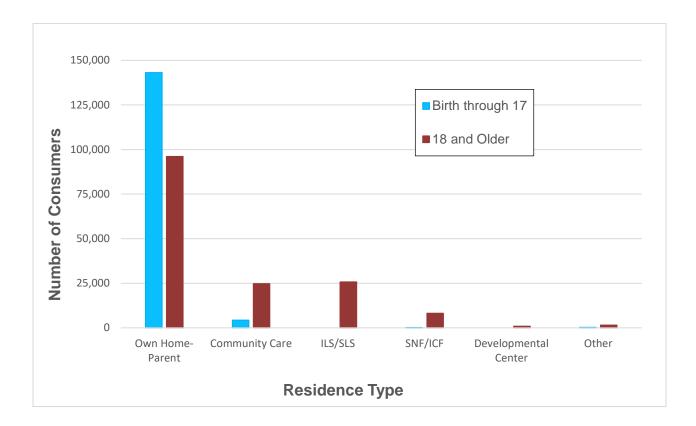
Table 8: Number of Consumers by Residence Type and Age Group - 18 and Older

	January 2007		January	2017
Residence Type	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Own Home-Parent	55,946	51.2%	96,084	61.1%
Community Care	22,257	20.4%	24,818	15.8%
ILS/SLS	18,802	17.2%	25,767	16.4%
SNF/ICF	8,355	7.6%	8,176	5.2%
Developmental Center	2,854	2.6%	901	0.6%
Other	1,035	0.9%	1,542	1.0%
Total	109,249	100.0%	157,288	100.0%

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² Welfare and Institutions Code, Division 4.5, Chapter 1, Section 4501.

Figure 5: Number of Consumers by Residence Type and Age Group - January 2017



CONSUMER GENDER AND AGE AT TIME OF INTAKE AND ASSESSMENT PROCESS

In January 2017 9,388 individuals received intake and assessment services (intake is based on the initial CMF entry date). Of these individuals, 28.4% were determined eligible to receive Early Start Program services, 31.9% were eligible to receive services as Active Consumers, and the remaining individuals were determined ineligible to receive regional center services.

Consumer Gender

The percentage of males in the population engaged in intake increased from 67.3% in January 2007 to 69.6% in January 2017, while the percentage of females decreased from 32.7% to 30.4%.

Table 9: Gender of Consumers Engaged in the Intake and Assessment Process

January 2007			January	January 2017		
Gender	Number of Percentag Consumers of Total		Number of Consumers	Percentage of Total		
Female	2,504	32.7%	2,855	30.4%		
Male	5,152	67.3%	6,533	69.6%		
Total	7,656	100.0%	9,388	100.0%		

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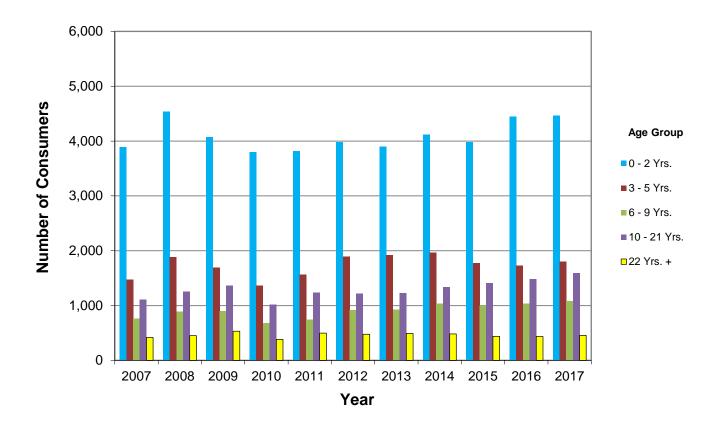
Consumer Age

The proportion by age group of the intake population is stable over time. The 10-21 years age group was the segment of this population with the largest increase, growing from 14.6% in January 2007 to 16.9% in January 2017. The age groups including age 10 and older increased from 20.0% in January 2007 to 21.8% in January 2017.

Table 10: Age Group of Consumers Engaged in the Intake and Assessment Process

	Januar	y 2007	Januar	January 2017		
Age Group	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total		
0 - 2 Yrs.	3,890	50.8%	4,460	47.5%		
3 - 5 Yrs.	1,477	19.3%	1,803	19.2%		
6 - 9 Yrs.	758	9.9%	1,082	11.5%		
10 - 21 Yrs.	1,114	14.6%	1,587	16.9%		
22 Yrs. +	417	5.4%	456	4.9%		
Total	7,656	100.0%	9,388	100.0%		

Figure 6: Number of Consumers by Age Group at Time of Intake and Assessment



CONSUMERS RESIDING IN A DEVELOPMENTAL CENTER

Based on the principles in the Lanterman Act³ and the Supreme Court *Olmstead*⁴ decision, the total developmental center population has declined from a high of over 13,300 residents in 1968 to 901 residents in January 2017. Over the last five years, the total population served in DDS-operated facilities has decreased by 920 residents.

Table 11 provides the number of consumers and percentage of consumers residing in each developmental center and community facility (Canyon Springs and Sierra Vista) as reflected in monthly CMF updates.

Table 11: Number of Consumers Residing in Each Developmental Center

		January 2012		January 2017	
Developmental Center	Closure Date	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Canyon Springs	N/A ⁵	46	2.6%	43	5.0%
Fairview	Dec 2021	389	21.9%	196	22.8%
Lanterman	Dec 2014	297	16.7%	0	0.0%
Porterville ⁶	Dec 2021	527	29.7%	335	39.0%
Sierra Vista	Dec 2009	4	0.2%	0	0.0%
Sonoma	Dec 2018	558	31.4%	327	38.1%
Total		1,821	100.0%	901	100.0%

³ 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.

⁴ In 1999, the United States Supreme Court issued a ruling in the *Olmstead* case that required decreased dependency on institutional services.

⁵ Canyon Springs is not scheduled to close.

⁶ Closure date is for the General Treatment Area only.

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 developmental disability categories (Intellectual Disability, Autism, Epilepsy, Cerebral Palsy, or 5th Category) of consumers served by DDS from January 1, 2007 to January 1, 2017. Only people with a Client Development Evaluation Report (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 consumer development evaluation. All individuals age 3 and over who have been diagnosed with a developmental disability are included in the CDER file. For children under 3 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 in both 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, as of November 2008. In the previous CDER, Autism included consumers with Autism-Full Syndrome, Autism-Residual State, Autism Suspected or Not Diagnosed; in the revised CDER, Autism includes 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 used to describe 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 18.

5th **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, thereby making the data more accurate, useful, and likely to be fully reported.

CONSUMER DEVELOPMENTAL DISABILITY CATEGORY TRENDS

The composition of the population by type of developmental disability shows some significant shifts from January 1, 2007 to January 1, 2017:

- The percentage of persons with "No Intellectual Disability" recorded in their CDER file grew from 24.0% to 37.1%.
- The percentage of persons reported to have "Moderate", "Severe" or "Profound" Intellectual Disability declined from 31.0% to 22.1%.
- The percentage of persons with Autism increased from 18.7% to 34.6%.
- The percentage of persons with Epilepsy declined over this period from 20.1% to 14.9%
- The percentage of persons with Cerebral Palsy also declined, from 18.4% to 13.7%.
- The percentage of persons with 5th Category remained steady at 10.2%.



Winter Fox (relief printmaking) - Shawyna Mays

Shawyna has studied printmaking for a year and has worked with Southside Unlimited since 2012. She is also skilled in watercolor, mosaic, and mixed media, drawing inspiration from wildlife, nature, and landscapes.

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Table 12: Number of Consumers with Intellectual Disability

January 2007			January 2017	
Level of Intellectual Disability	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
No ID	44,832	24.0%	97,974	37.1%
Mild	71,366	38.3%	87,654	33.2%
Moderate	31,912	17.1%	34,858	13.2%
Severe	14,966	8.0%	14,524	5.5%
Profound	11,007	5.9%	8,852	3.4%
Unspecified	12,360	6.6%	19,923	7.6%
Total	186,443	100.0%	263,785	100.0%

Figure 7: Number of Consumers with Intellectual Disability

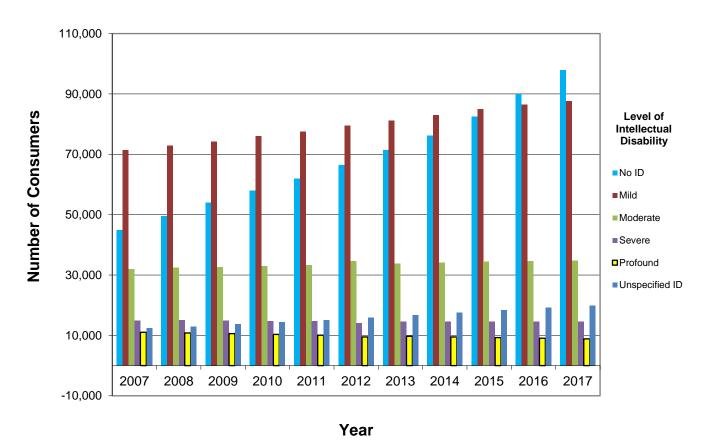


Table 13: Number of Consumers with Autism

	January	y 2007	January	January 2017		
Has Autism	Number of Percentage Consumers of Total		Number of Consumers	Percentage of Total		
Yes	34,903	18.7%	91,312	34.6%		
No	151,540	81.3%	172,473	65.4%		
Total	186,443	100.0%	263,785	100.0%		

Figure 8: Number of Consumers with Autism

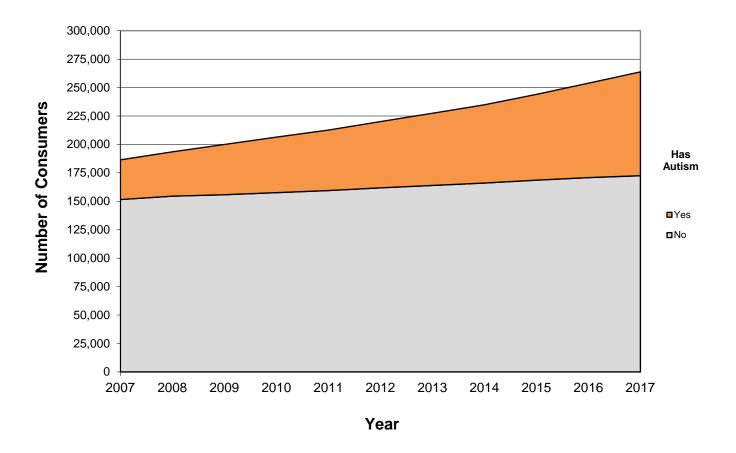


Table 14: Number of Consumers with Epilepsy

	January	y 2007	Januar	January 2017		
Has Epilepsy	Number of Percentage Consumers of Total		Number of Consumers	Percentage of Total		
Yes	37,553	20.1%	39,195	14.9%		
No	148,890	79.9%	224,590	85.1%		
Total	186,443	100.0%	263,785	100.0%		

Figure 9: Number of Consumers with Epilepsy

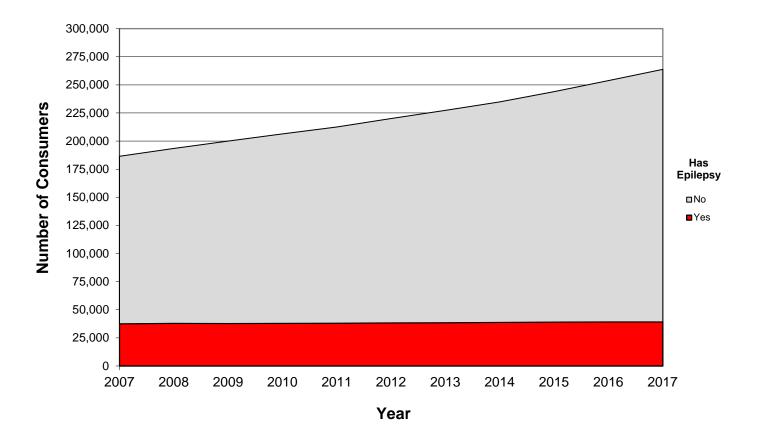
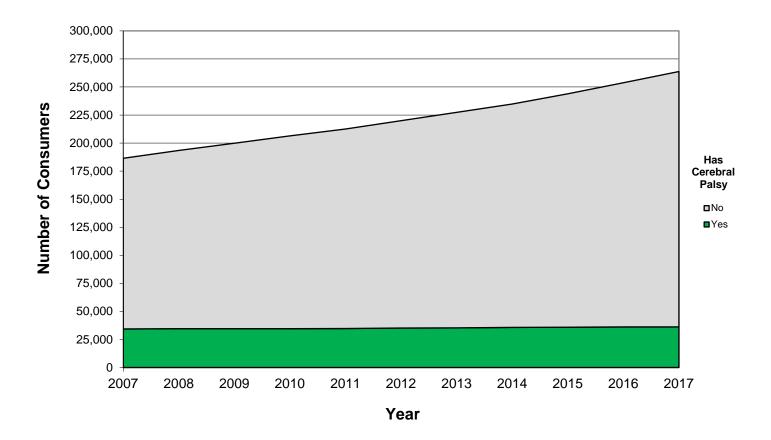


Table 15: Number of Consumers with Cerebral Palsy

January 2007			Januar	January 2017		
Has Cerebral Palsy	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total		
Yes	34,359	18.4%	36,110	13.7%		
No	152,084	81.6%	227,675	86.3%		
Total	186,443	100.0%	263,785	100.0%		

Figure 10: Number of Consumers with Cerebral Palsy

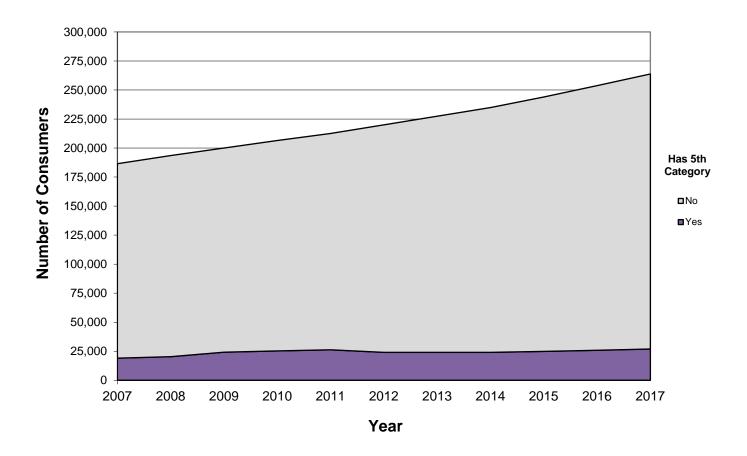


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Table 16: Number of Consumers with 5th Category

January 2007			Januar	January 2017		
Has 5 th Category	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total		
Yes	19,041	10.2%	26,939	10.2%		
No	167,402	89.8%	236,846	89.8%		
Total	186,443	100.0%	263,785	100.0%		

Figure 11: Number of Consumers with 5th Category



Day 00

COMBINATIONS OF DEVELOPMENTAL DISABILITIES

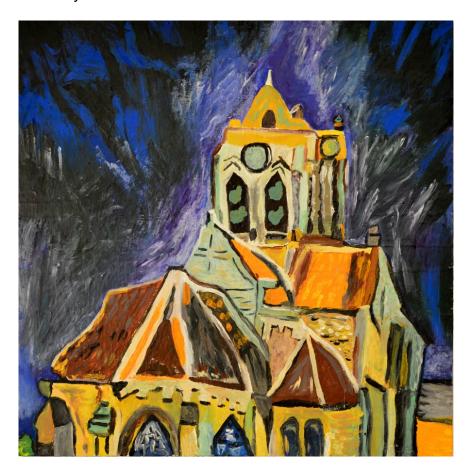
It is common for a consumer to have a combination of two or more developmental disabilities (Intellectual Disability, Autism, Epilepsy, Cerebral Palsy, or 5th Category) recorded on their CDER.

The majority of consumers with Intellectual Disability have only Intellectual Disability (58.6%) recorded on their CDER as of January 2017. However, the percentage of consumers with Intellectual Disability who also have Autism increased from 9.0% to 13.3% from January 2007 to January 2017.

An even larger percentage of consumers with Autism have only Autism (71.0%) recorded on their CDER as of January 2017. The percentage of consumers with Autism who also have Intellectual Disability decreased from 36.7% to 24.1% from January 2007 to January 2017.

A small percentage of consumers have only Epilepsy (7.1%) or Cerebral Palsy (16.3%) as of January 2017. Most consumers with Epilepsy (79.9%) or Cerebral Palsy (72.8%) also have Intellectual Disability.

Consumers with 5th Category have only 5th Category recorded on their CDER 54.3% of the time as of January 2017.



House - Artist unknown

Table 17: Number of Consumers with Intellectual Disability with a Combination of Developmental Disabilities

	January 2007		Januar	y 2017
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*
Total Number of				
Consumers with ID	141,611		165,811	
ID Only	82,644	58.4%	97,094	58.6%
Autism	12,814	9.0%	22,025	13.3%
Epilepsy	31,245	22.1%	31,306	18.9%
Cerebral Palsy	26,039	18.4%	26,284	15.9%
5 th Category	5,993	4.2%	6,172	3.7%

^{*}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

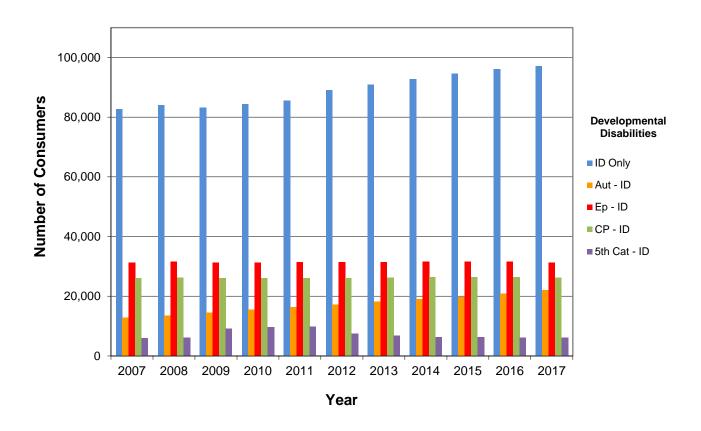


Table 18: Number of Consumers with Autism and another Developmental Disability

	Januar	y 2007	January 2017	
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*
Total Number of				
Consumers with				
Autism	34,903		91,312	
Autism Only	20,495	58.7%	64,788	71.0%
ID	12,814	36.7%	22,025	24.1%
Epilepsy	2,392	6.9%	3,792	4.2%
Cerebral Palsy	679	1.9%	1,061	1.2%
5 th Category	1,332	3.8%	3,428	3.8%

^{*}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 and another Developmental Disability

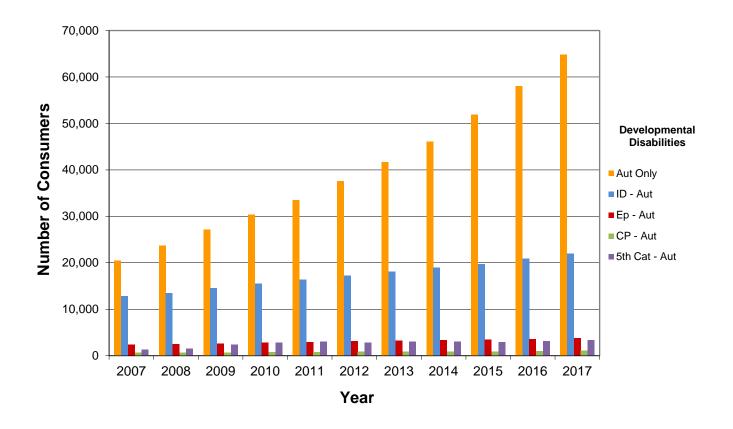


Table 19: Number of Consumers with Epilepsy and another Developmental Disability

	Januar	y 2007	Januar	January 2017	
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*	
Total Number of					
Consumers with					
Epilepsy	37,553		39,195		
Epilepsy Only	2,691	7.2%	2,781	7.1%	
ID ,	31,245	83.2%	31,306	79.9%	
Autism	2,392	6.4%	3,792	9.7%	
Cerebral Palsy	15,083	40.2%	14,862	37.9%	
5 th Category	2,590	6.9%	3,052	7.8%	

^{*}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 and another Developmental Disability

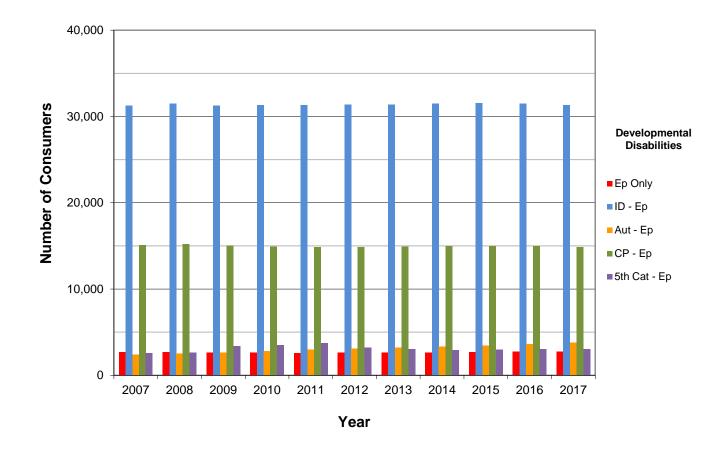


Table 20: Number of Consumers with Cerebral Palsy and another Developmental Disability

	Januar	y 2007	Januar	y 2017
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*
Total Number of				
Consumers with				
Cerebral Palsy	34,359		36,110	
Cerebral Palsy Only	5,305	15.4%	5,879	16.3%
ID	26,039	75.8%	26,284	72.8%
Autism	679	2.0%	1,061	2.9%
Epilepsy	15,083	43.9%	14,862	41.2%
5 th Category	2,089	6.1%	2,562	7.1%

^{*}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 and another Developmental Disability

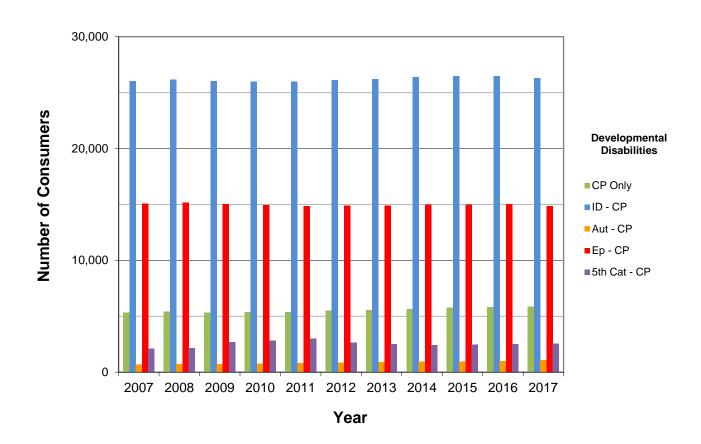
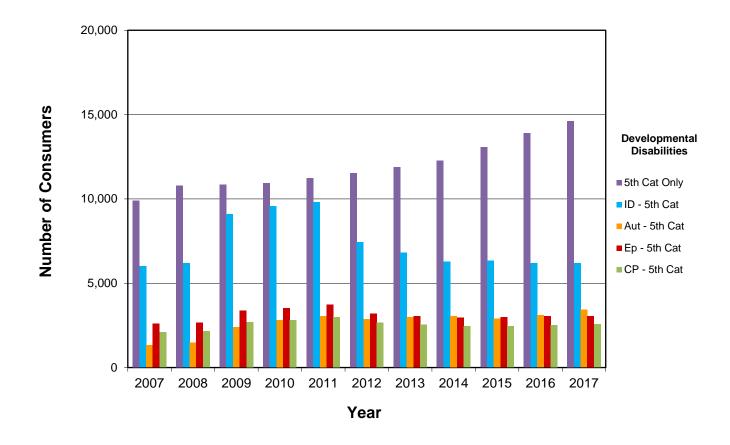


Table 21: Number of Consumers with 5th Category Diagnosis and another Developmental Disability

	Januar	y 2007	January 2017		
	Number of Consumers	Percentage of Total*	Number of Consumers	Percentage of Total*	
Total Number of					
Consumers with 5th					
Category	19,041		26,939		
5 th Category Only	9,907	52.0%	14,622	54.3%	
ID	5,993	31.5%	6,172	22.9%	
Autism	1,332	7.0%	3,428	12.7%	
Epilepsy	2,590	13.6%	3,052	11.3%	
Cerebral Palsy	2,089	11.0%	2,562	9.5%	

^{*}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^{th} Category Diagnosis and another Developmental Disability



SECTION 2: WHAT CONSUMERS RECEIVE



Ferris Wheel - Yelena Zhukova

Yelena has been with Southside Unlimited since 2011. She has excelled at a variety of art mediums including ceramics, painting, mixed media, and digital art.

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PERCENT OF CONSUMERS BY AGE GROUP RECEIVING REGIONAL CENTER-FUNDED SERVICES OF ALL CONSUMERS SERVED BY DDS IN THE COMMUNITY FY 2006-07 TO FY 2016-17

All consumers served by DDS receive case management services through their local regional center, regardless of whether they receive purchased services. Regional centers are legally required to provide or secure services in the most cost-effective way possible, including referral to 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 number of consumers of all ages who receive regional center funded services as a percentage of all DDS consumers served in the community (Early Start and Active consumers) fluctuated moderately from FY 2006-07 to FY 2016-17, decreasing from 78.4% of consumers served in the community to 78.0%. The share of consumers of all ages receiving regional center funded services decreased 0.7 percentage points between FY 2015-16 and FY 2016-17.

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, as data is finalized.

Table 22: Percentage of Consumers (Prevention*, Early Start Program, Active Consumer) Receiving Regional Center-Funded Services, by Age Group

FY 2006-07 to FY 2016-17

Fiscal			22-61	62 Yrs	All Ages
Year	0-2 Yrs	3-21 Yrs	Yrs	and Up	(Total)
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%	65.7%	86.1%	91.3%	78.0%
14/15	94.3%	66.2%	85.9%	91.8%	78.3%
15/16	94.6%	66.5%	86.2%	91.5%	78.7%
16/17	94.9%	65.0%	85.8%	91.6%	78.0%

^{*} Prevention consumers are included in FY 09-10, FY 10-11, and FY 12-13 only.

Purchase of Services Growth vs. DDS CaseLoad - FY 2006-07 to FY 2016-17

The community caseload (Prevention, Early Start Program, and Active Consumers on the Client Master File as of the end of each FY) grew by 94,346 consumers from FY 2006-07 to FY 2016-17, or 43.4%. By comparison, cumulative growth for Purchase of Service (POS) expenditures increased by \$2,339.3 million, or 85.7%, over this period. Total POS expenditures leveled off from FY 2008-09 to FY 2010-11, reflecting state budget cuts.

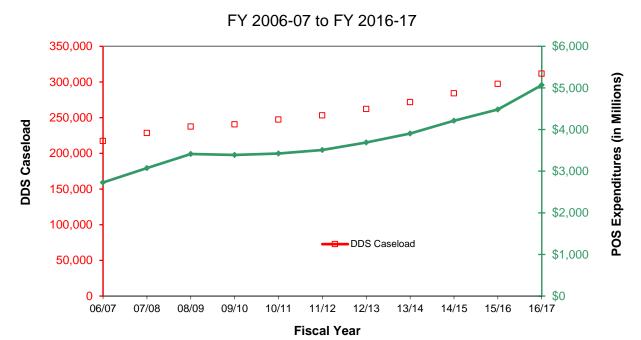
Table 23: DDS Caseload Number and POS Expenditure Amount (in Millions)

FY 2	006-0	7 to	FY	2016	3-17
------	-------	------	----	------	------

Fiscal Year	DDS Caseload	POS Expenditures** (in Millions)
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	\$3,906.1
14/15	284,169	\$4,212.7
15/16	297,333	\$4,481.1
16/17	311,679	\$5,068.0

^{*}Prevention consumers are included in FY 09-10, FY 10-11, and FY 12-13 only.

Figure 17: DDS Caseload Number and POS Expenditure Amount (in Millions)



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^{**}Includes contract POS.

EXPENDITURES AND COUNTS BY SERVICE CATEGORY FY 2012-13 TO FY 2016-17

Tables 24, 25, and 26 provide a comprehensive, detailed view of regional center funded services by service category based on 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 2012-13 to FY 2016-17, along with POS changes from FY 2015-16 to FY 2016-17.

Overall, POS expenditures increased \$586.9 million (13.1%) from FY 2015-16 through FY 2016-17. All but four service categories show an increase in POS expenditures from FY 2015-16 to FY 2016-17.

The service categories with the largest POS expenditure increase from FY 2015-16 to FY 2016-17 were *Residential Services*, which increased by \$217.1 million (19.7%), and *Supported Living & Related Svcs*, which increased by \$150.3 million (20.6%).

Beginning February 1, 2016, responsibility for Medi-Cal beneficiaries under 21 years of age with an Autism Spectrum Disorder who received Behavioral Health Treatment (BHT) services provided through the regional centers began transitioning to the Department of Health Care Services Medi-Cal managed care and fee-for-service delivery systems.

DHCS will provide BHT as it is defined by <u>Section 1374.73</u> of the Health and Safety Code. In consultation with stakeholders as required by Section 14132.56 of the W&I Code, the Department developed and defined eligibility criteria, provider participation criteria, utilization controls, and the delivery system for BHT services, subject to the limitations allowed under federal law. See http://www.dhcs.ca.gov/services/medical/Pages/BehavioralHealthTreatment.aspx for more information.

Table 24: POS Expenditures* (in Millions) by Service Category

FY 2012-13 to FY 2016-17

Service Category	FY 12-13	FY 13-14	FY 14-15	FY 15-16	FY 16-17	Change from FY 15-16 to FY 16-17
Residential Services	\$912.2	\$946.3	\$1,035.2	\$1,103.9	\$1,321.0	\$217.1
Adult Day Program	\$821.4	\$876.0	\$922.7	\$984.8	\$1,112.5	\$127.7
Adult Development Center	\$327.2	\$342.8	\$356.9	\$373.6	\$400.6	\$27.0
Behavior Mgmt. Program	\$195.3	\$209.5	\$217.4	\$227.9	\$247.3	\$19.5
Other Look-Alike Programs	\$165.5	\$186.1	\$206.4	\$230.7	\$285.5	\$54.9
Independent Living Program	\$80.5	\$82.6	\$85.1	\$92.6	\$113.1	\$20.5
Activity Center	\$48.6	\$50.1	\$51.4	\$53.2	\$57.3	\$4.1
Social Recreation Program	\$4.3	\$4.9	\$5.5	\$6.8	\$8.6	\$1.8
Supported Living & Related Svcs.	\$562.0	\$610.1	\$662.9	\$729.7	\$880.0	\$150.3
Behavioral Services**	\$282.8	\$286.6	\$311.2	\$285.5	\$199.9	-\$85.6
Transportation	\$236.7	\$251.3	\$267.0	\$284.7	\$326.0	\$41.3
Respite	\$206.3	\$225.4	\$259.3	\$290.9	\$361.4	\$70.5
Infant Development Program	\$151.3	\$162.7	\$168.8	\$178.9	\$206.6	\$27.7
Medical Care & Services	\$95.4	\$102.6	\$115.9	\$116.5	\$121.6	\$5.2
Supported Employment Program	\$89.9	\$92.3	\$94.4	\$97.0	\$117.6	\$20.7
Supplemental Program Support	\$66.3	\$74.3	\$82.4	\$90.8	\$105.7	\$14.9
Work Activity Program	\$57.1	\$57.4	\$55.7	\$53.5	\$48.9	-\$4.6
Day Care	\$33.7	\$33.6	\$29.9	\$29.2	\$31.1	\$2.0
Social-Recreational Activities	\$27.4	\$28.1	\$29.6	\$30.9	\$32.1	\$1.2
Non-Medical Therapy Services	\$4.9	\$5.0	\$4.6	\$4.7	\$5.0	\$0.3
Medical & Adaptive EquipSupplies	\$5.7	\$6.2	\$6.0	\$6.6	\$7.1	\$0.5
Camps	\$1.3	\$1.4	\$1.7	\$2.1	\$2.4	\$0.3
Environmental & Vehicle Mod.	\$3.4	\$3.2	\$4.0	\$5.7	\$7.4	\$1.7
Mobility Training	\$0.5	\$0.4	\$0.4	\$0.4	\$0.4	\$0.0
All Other Services	\$131.3	\$143.3	\$160.9	\$185.4	\$181.5	-\$4.0
Total	\$3,689.4	\$3,906.1	\$4,212.7	\$4,481.1	\$5,068.0	\$586.9

^{*}POS is the monthly data through December following each FY end. In the last three fiscal years, figures for the same fiscal year will differ slightly from one annual Fact Book to the next, as data is finalized.

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^{**}Decrease is mostly due to the transition of authorization and payment of Behavioral Health Treatment services as regional center consumers to services as Medi-Cal beneficiaries. See previous page.

NUMBER OF CONSUMERS RECEIVING POS

Table 25 presents the number of consumers receiving services by service category from FY 2012-13 through FY 2016-17, along with the changes in the number of consumers from FY 2015-16 to FY 2016-17.

Overall, the number of consumers receiving POS increased by 14,151 (4.9%) from FY 2015-16 to FY 2016-17. Most service categories (20 of 25) showed an increase in the number of consumers receiving the service from FY 2015-16 to FY 2016-17.

Individual service categories with the largest increase in the number of consumers receiving the service from FY 2015-16 to FY 2016-17 were *Respite*, which increased by 6,471 consumers (7.2%), and the *Infant Development Program* category, which increased by 5,056 consumers (10.6%).

The service category with the largest decrease in the number of consumers receiving the service from FY 2015-16 to FY 2016-17 was *Behavioral Services*, which decreased by 4,665 consumers (10.9%).

Beginning February 1, 2016, responsibility for Medi-Cal beneficiaries under 21 years of age with an Autism Spectrum Disorder who receive Behavioral Health Treatment (BHT) services provided through the regional centers (RC) began transitioning to the Department of Health Care Services (DHCS) Medi-Cal managed care and fee-for-service (FFS) delivery systems.

DHCS will provide BHT as it is defined by <u>Section 1374.73</u> of the Health and Safety Code. In consultation with stakeholders as required by Section 14132.56 of the W&I Code, the Department developed and defined eligibility criteria, provider participation criteria, utilization controls, and the delivery system for BHT services, subject to the limitations allowed under federal law. See http://www.dhcs.ca.gov/services/medi-cal/Pages/BehavioralHealthTreatment.aspx for more information.

Table 25: Number of Consumers Receiving Services by Service Category

FY 2012-13 to FY 2016-17

Service Category	FY 12-13	FY 13-14	FY 14-15	FY 15-16	FY 16-17	Change from FY 15-16 to FY 16-17
Residential Services	30,037	30,625	31,240	31,533	31,517	-16
Adult Day Program*	70,296	73,461	76,848	80,439	83,766	3,327
Adult Development Center	29,902	31,218	32,414	33,586	34,020	434
Behavior Mgmt. Program	13,869	14,667	15,279	15,533	15,836	303
Other Look-Alike Programs	12,578	13,681	14,844	15,980	18,234	2,254
Independent Living Program	13,519	13,755	14,603	16,311	17,869	1,558
Activity Center	6,684	6,768	6,827	7,032	7,061	29
Social Recreation Program	1,197	1,281	1,406	1,614	1,741	127
Supported Living & Related Svcs.	38,986	40,398	44,864	49,250	53,368	4,118
Behavioral Services**	39,134	41,289	42,836	42,771	38,106	-4,665
Transportation	75,557	80,890	83,148	85,885	87,653	1,768
Respite	68,137	72,708	83,581	90,187	96,658	6,471
Infant Development Program	37,867	39,838	42,888	47,690	52,746	5,056
Medical Care & Services	57,684	61,012	60,524	63,530	64,724	1,194
Supported Employment Program	10,807	10,809	11,038	11,271	11,686	415
Supplemental Program Support	5,865	6,650	7,088	7,396	7,582	186
Work Activity Program	10,960	10,688	10,303	9,757	8,391	-1,366
Day Care	6,138	5,932	5,799	5,409	5,483	74
Social-Recreational Activities	5,470	5,468	5,750	6,068	6,109	41
Non-Medical Therapy Services	2,813	2,579	2,392	2,050	1,900	-150
Medical & Adaptive EquipSupplies	4,260	4,631	4,840	4,997	5,220	223
Camps	1,114	1,279	1,554	1,691	1,882	191
Environmental & Vehicle Mod.	482	484	591	667	796	129
Mobility Training	345	342	317	332	318	-14
All Other Services	93,661	97,139	103,080	110,763	119,697	8,934
Total*	252,101	262,205	275,443	291,472	305,623	14,151

^{*}Total counts are unduplicated by consumer to avoid double counting consumers receiving multiple types 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, as data is finalized.

Page

^{**}Decrease is mostly due to the transition of authorization and payment of Behavioral Health Treatment services as regional center consumers to services as Medi-Cal beneficiaries. See previous page.

NUMBER OF VENDORS PROVIDING SERVICES

Table 26 presents the number of vendors providing services by service category from FY 2012-13 through FY 2016-17, along with the changes in the number of vendors from FY 2015-16 to FY 2016-17.

Overall, the number of vendors providing services decreased by 482 (1.1%) from FY 2015-16 to FY 2016-17. Just over half of the service categories (13 of 25) showed a decrease in the count of vendors providing the service from FY 2015-16 to FY 2016-17.

Service categories with the largest decrease in the number of vendors providing services from FY 2015-16 to FY 2016-17 were *Respite*, which decreased by 125 vendors (6.7%), and *Medical Care and Services*, which decreased by 93 vendors (4.4%).

The service category with the largest increase in the number of vendors providing services from FY 2015-16 to FY 2016-17 was *Supported Living & Related Services*, which increased by 104 vendors (4.5%).

Vendor counts for Transportation, Respite, and Day Care services began decreasing in FY 2011/12 with implementation of a new requirement to use a Financial Management Service (FMS) in conjunction with participant-directed vouchered services. Many consumer families who were individually vendorized for these services when using vouchers switched to using vendorized agencies for coordination of services. As a result, these consumer families are no longer vendorized and are no longer reflected in the vendor counts. The decline of vendors in these service categories continues to drive the overall decrease in vendors.

Table 26: Number of Vendors Providing Services by Service Category

FY 2012-13 to FY 2016-17

Service Category	FY 12-13	FY 13-14	FY 14-15	FY 15-16	FY 16-17	Change from FY 15-16 to FY 16-17
Residential Services	5,912	5,941	5,862	5,874	5,825	-49
Adult Day Program*	2,021	2,076	2,126	2,215	2,272	57
Adult Development Center	599	624	633	647	640	-7
Behavior Mgmt. Program	320	336	344	346	351	5
Other Look-Alike Programs	571	575	595	631	665	34
 Independent Living Program 	396	403	416	454	478	24
Activity Center	142	142	145	144	142	-2
 Social Recreation Program 	21	22	21	22	22	0
Supported Living & Related Svcs.	2,174	2,216	2,242	2,298	2,402	104
Behavioral Services	1,018	1,028	1,071	1,086	1,084	-2
Transportation**	6,565	5,476	5,168	5,072	5,007	-65
Respite**	4,511	2,164	1,966	1,874	1,749	-125
Infant Development Program	457	451	454	485	496	11
Medical Care & Services	2,282	2,231	2,178	2,125	2,032	-93
Supported Employment Program	369	375	372	367	372	5
Supplemental Program Support	1,570	1,671	1,737	1,798	1,807	9
Work Activity Program	116	115	110	109	103	-6
Day Care**	2,301	1,369	1,132	584	544	-40
Social-Recreational Activities	164	159	162	159	154	-5
Non-Medical Therapy Services	215	188	174	149	126	-23
Medical & Adaptive EquipSupplies	1,614	1,590	1,585	1,594	1,560	-34
Camps	50	49	46	39	47	8
Environmental & Vehicle Mod.	65	57	64	68	73	5
Mobility Training	31	30	27	23	25	2
All Other Services	26,136	25,695	25,198	24,586	24,286	-300
Total*	49,872	45,321	44,471	43,355	42,873	-482

^{*}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, as data is finalized.

^{**}The vendor counts for these services began decreasing in FY 2011/12. See previous page.

POPULATION AND PER CAPITA COST BY DEVELOPMENTAL DISABILITY AND AGE GROUP

As of July 2017, the majority of consumers with Intellectual Disability (64.5%), Epilepsy (72.3%), Cerebral Palsy (65.3%), or 5th Category (54.0%) were age 22 years or older, whereas the majority of consumers with Autism (80.1%) were 3-21 years of age.

The average per capita cost of consumers with each developmental disability category increases considerably after age 21. Autism is the most expensive developmental disability per capita for age groups 32-41 years and older compared with Intellectual Disability, Epilepsy, Cerebral Palsy, or 5th Category.

Expenditures for consumers typically rise after age 21 when Department of Education-funded 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.



Untitled - Michael Ramirez

Michael participated at Southside until last year, specializing in mixed media painting.

Figure 18: Number of Consumers (Early Start Program, Active Consumer, Developmental Center) by Developmental Disability and Age Group

as of July 2017

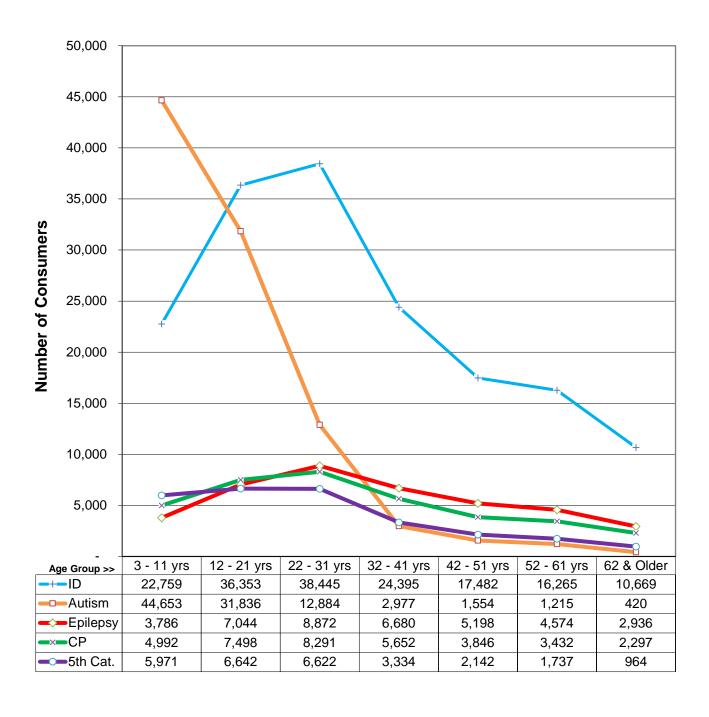
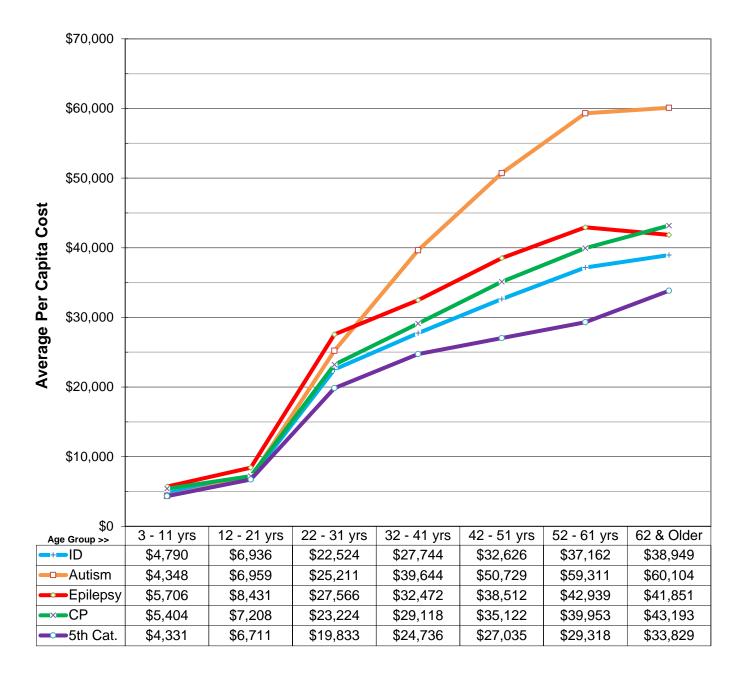


Figure 19: Average Per Capita Expenditures (Early Start Program, Active Consumer, Developmental Center) by Developmental Disability and Age Group

as of July 2017

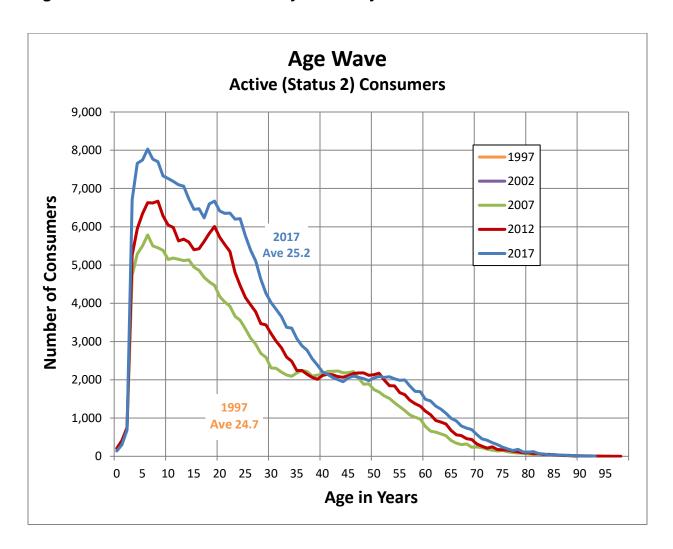


DEMOGRAPHIC TRENDS: AGE WAVE OVER THE PAST 20 YEARS

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 choosing housing and other adult services provided by DDS.

The over-40 population has remained relatively stable. Note the rightward population shifts due to increased longevity, but otherwise modest growth. The pattern of decline in the consumer population due to mortality now occurs after 55 years of age, whereas in 1997 the decline started before age 40.

Figure 20: Consumer Count on July 1 of every 5th Year for the Past 20 Years



DEMOGRAPHIC TRENDS: ETHNICITY OVER THE PAST 10 YEARS

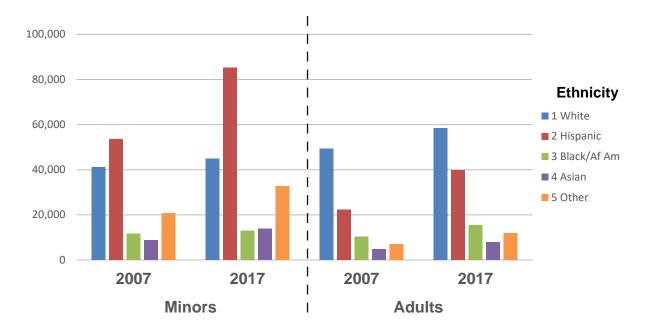
Over the past 10 years, the population of consumers of developmental services has grown by over 40%. Most of the growth has been in the Hispanic population, which rose by 49,214 consumers, or 64.8%. The White ethnic population group of DDS consumers grew the least by percentage, increasing by only 13,051 consumers, or 14.4%. This table includes consumers engaged in the Intake and Assessment process (status code 0), while a related table--Table 4--excludes them.

The minor and adult subpopulations trend very differently from each other due largely to the cessation of services funded through the Department of Education when consumers reach 22 years of age.

Table 27: Ethnicity - 2007 vs. 2017

	Minors (Ages 0-21 Years)			Adults (Ages 22 and Older)		
Ethnicity	2007	2017		2007	2017	
Ethnicity	Number of	Number of Consumers % Change		Number of C	% Change	
White	41,094	44,975	9.44%	49,317	58,487	18.59%
Hispanic	53,623	85,288	59.05%	22,315	39,864	78.64%
Black/Af Am	11,597	12,962	11.77%	10,345	15,466	49.50%
Asian	8,668	13,795	59.15%	4,690	7,840	67.16%
Other*	20,789	32,667	57.14%	6,978	11,871	70.12%
Total**	135,771	189,687	39.71%	93,645	133,528	42.59%

Figure 21: Ethnicity - 2007 vs. 2017



^{*}Includes multiple ethnicities.

SECTION 3: CONSUMER PERSONAL OUTCOMES HIGHLIGHTS

In 2008, DDS added the 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 highlights of the outcomes portion of the report as of January 1, 2018:

Education

57% of those in school have integrated classrooms

84% of those in school have contacts with persons without a developmental disability

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

Work and Day Services

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

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

47% of those working are paid minimum wage or over

Social Well-Being

87% of consumers have a community outing at least weekly

78% have one or more personal friends

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

99% 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

88% had dental care in the past year and had their needs met

94% of those with medical or dental conditions received full appropriate care

Living Situation – not living at family's home

89% like living at their community home

93% like the people they live with at their community home

87% wish to keep living at their community home

Day Activity – for those who attend a school, day program, or work-site

90% like their day activity

92% like the people at their day activity

91% of adult consumers choose to continue going to their day activity

Emotional Security

94% name someone with whom they can talk when unhappy

88% 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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