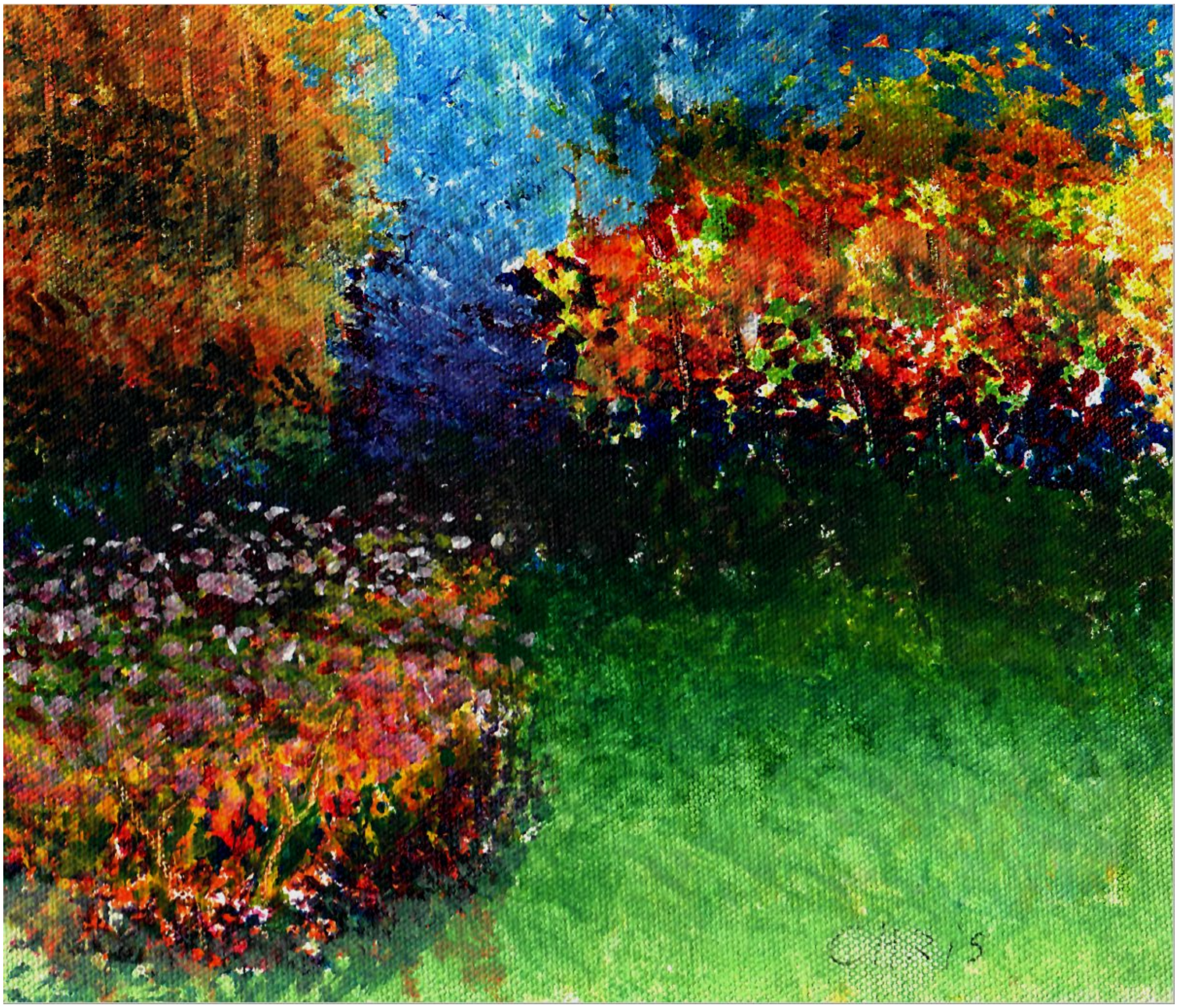
Department of Developmental Services

Fact Book
Fiscal Year 2019 – 2020
Eighteenth Edition



Prepared by DDS Information Technology Division
2022

Department of Developmental Services
1215 O Street, MS 8-10
Sacramento, CA 95814

PREFACE

The Fact Book presents data about the individuals served by the Department of Developmental Services (DDS) 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 (RCs), and, as of January 2020, three state-operated facilities (two developmental centers and one community facility). In this publication, community facility consumer counts and percentages are included with the developmental centers.

Infants and toddlers from birth through two years may be eligible for early intervention services through Early Start if, through documented evaluation and assessment, they meet one of these criteria:

- have a developmental delay of at least 33% in one or more areas of cognitive, communication, social or emotional, adaptive, or physical and motor development including vision and hearing; or
- have an established risk condition of known etiology, with a high probability of resulting in delayed development; or
- be considered at high risk of having a substantial developmental disability due to a combination of biomedical risk factors which are diagnosed by qualified personnel.

To be eligible for Lanterman services at age 36 months or older, 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 *Section 4512 of the California Welfare and Institutions Code*. Eligibility is established through diagnosis and assessment performed by regional centers. The data presented in this Fact Book includes only those individuals with developmental disabilities who are eligible for and have requested regional center services.

A developmental disability is a condition that constitutes a substantial impairment in three or more areas of major life activity.[1] Developmental disabilities include Intellectual Disability (ID), Autism, Epilepsy, Cerebral Palsy (CP), and disabling conditions (referred to as Fifth Category) closely related to, or requiring treatment similar to, that of a person with Intellectual Disability. The service delivery system, which offers personalized supports, includes individuals with developmental disabilities, their families and/or legal

[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.

representatives, DDS, regional centers, advocacy and professional organizations, the State Council on Developmental Disabilities, direct service providers, and developmental centers.

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 DDS website. Additional information about DDS consumer characteristics and caseload is on the Facts and Stats webpage, which also includes DDS consumer demographic information for prior years.

Cover Art: The Joy of Spring – artist Chris France

TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

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

Artist: Tanuja Giri

Tanuja Giri is a painter and printmaker that gathers inspiration from everyday life, music, and movies. Although she has only been studying printmaking for under a year, she has shown tremendous skill and has guided others along the way with it. She finds happiness in color and incorporates it into all of her work with subjects such as flowers, animals, and people.

DDS CONSUMER INFORMATION

The consumer information charts display Client Master File (CMF) data. Regional centers add consumers to the 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 through age two with a developmental delay or 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 state-operated facility.
- **State-Operated (Status Code 8):** People with a diagnosed developmental disability served in a state-operated facility.
- **Prevention (Status Code P):** Children birth through age two 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.

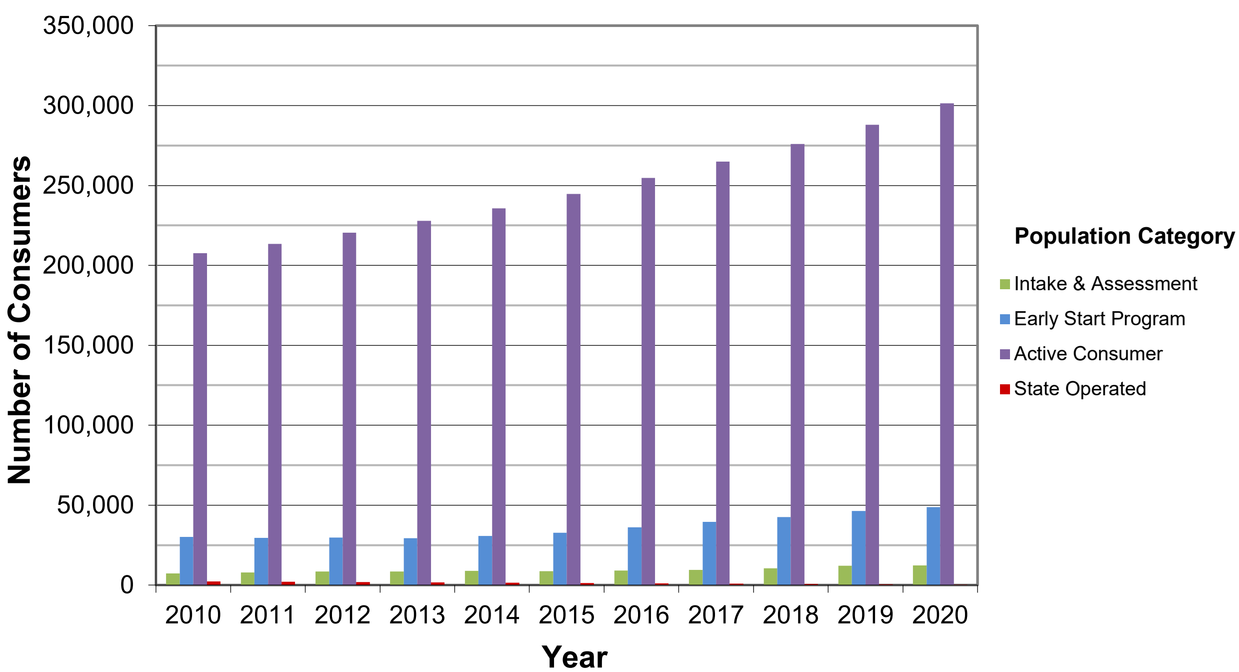
CONSUMER POPULATION CATEGORIES

The number of DDS consumers in the Intake and Assessment, Early Start Program, Active Consumer, and State-Operated categories increased by 46.8% between January 1, 2010 and January 1, 2020. According to Department of Finance estimates, California's general population grew 6.5% between January 2010 and January 2020. DDS provided services to approximately 0.91% of California's population as of January 1, 2020.

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

Population Category	January 2010		January 2020	
	Number of Consumers	Percentage of Total Consumers	Number of Consumers	Percentage of Total Consumers
Intake & Assessment*	7,244	2.9%	12,203	3.4%
Early Start Program**	30,183	12.2%	48,806	13.5%
Active Consumer	207,605	84.0%	301,498	83.1%
State-Operated	2,183	0.9%	285	0.1%
Total	**247,215**	**100.0%**	**362,792**	**100.0%**

Figure 1: Number of Consumers by Population Category



*Only Table 1 includes Intake and Assessment consumers whereas the following tables do not.
**Early Start Program counts include those with a Prevention status, which lasted from October 2009 through September 2012.

CONSUMER DEMOGRAPHICS

Consumer demographic information for Early Start, Active, and State-Operated consumers as of January 1, 2010, as compared to January 1, 2020, is displayed by residence type, age, ethnicity, gender, and primary language. The numbers do not include consumers who are being assessed for eligibility (Status Code 0).

Consumer Residence Type

While 74.6% of consumers resided in the home of a parent or guardian in January 2010, 80.7% had this residence type in January 2020. During this same period, decreases continued in the proportion of people living in community care settings (11.4% to 8.8%) and state-operated facilities (0.9% to 0.1%).

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), Enhanced Behavior Supports Homes (EBSH), and Community Crisis Homes (CCH)

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)

State-Operated Facility: Developmental Center or community facility operated by DDS

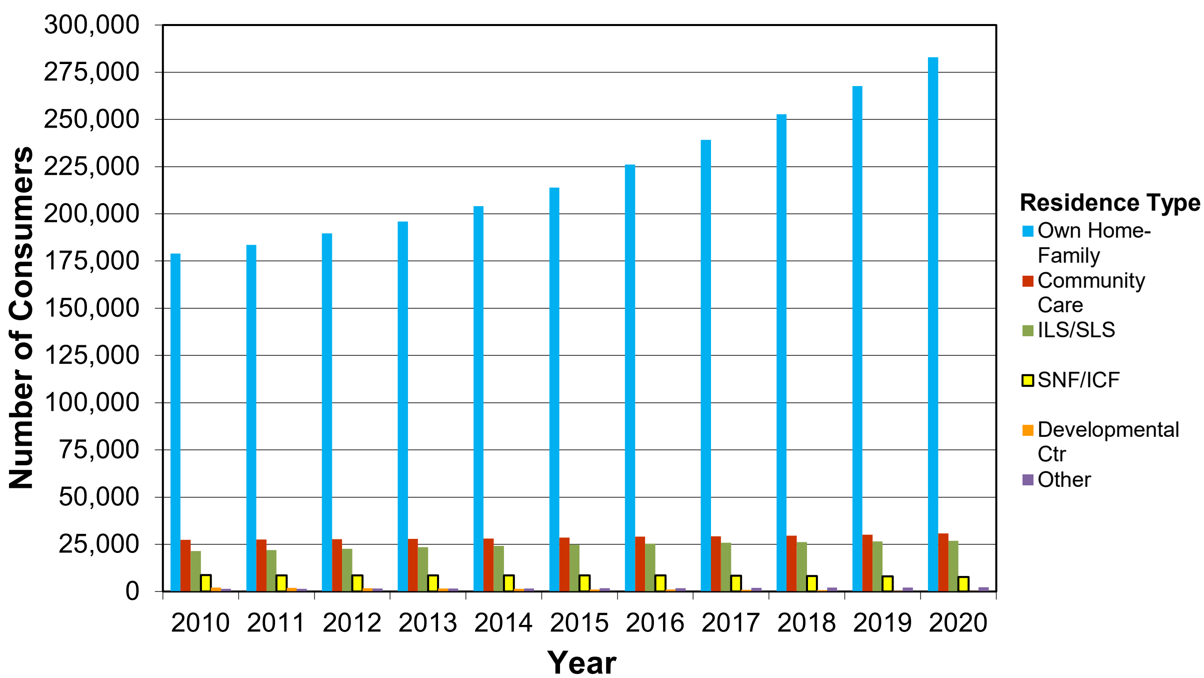
Other: Settings such as Hospitals, Community Treatment Facilities, Rehabilitation Centers, Psychiatric Treatment Centers, Institutions for Mental Disease, Correctional Institutions, and other settings in the community

Consumer Residence Type

Table 2: Residence Type of Consumers

Residence Type	January 2010		January 2020	
	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Own Home-Family	179,031	74.6%	282,878	80.7%
Community Care	27,299	11.4%	30,690	8.8%
ILS/SLS	21,359	8.9%	26,772	7.6%
SNF/ICF	8,644	3.6%	7,771	2.2%
State-Operated Facility	2,183	0.9%	285	0.1%
Other	1,455	0.6%	2,193	0.6%
Total	**239,971**	**100.0%**	**350,589**	**100.0%**

Figure 2: Number of Consumers by Residence Type



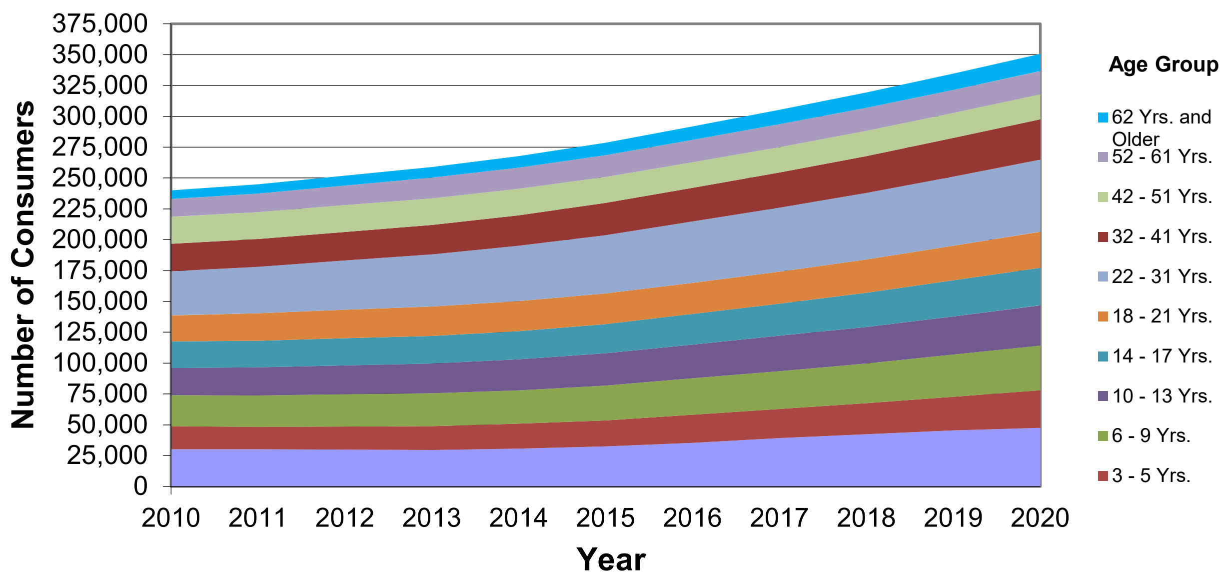
Consumer Age

The average age of the DDS population has been mostly unchanged over the last 10 years. The average age of all consumers in January 2010 was 25.0 years as compared to January 2020, when the average was 24.7 years of age. The only age group to see a decrease in population over this time period was 42 – 51 years, which was 21,807 in January 2010 and 20,308 in January of 2020, a decrease of 6.9%. The remaining 10 age groups had an average increase of 53.3%, with 62 and older seeing the largest growth at 100.7%. As a share of all consumers, the age groups with the largest increases from January 2010 to January 2020 were 0-2, 3-5, 22-31 and 62 and older.

Table 3: Age Group of Consumers Served by DDS

Age Group	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
0 - 2 Yrs.	30,270	12.6%		47,592	13.6%
3 - 5 Yrs.	18,620	7.8%		30,419	8.7%
6 - 9 Yrs.	25,004	10.4%		36,276	10.3%
10 - 13 Yrs.	22,041	9.2%		32,475	9.3%
14 - 17 Yrs.	21,671	9.0%		30,470	8.7%
18 - 21 Yrs.	21,091	8.8%		29,186	8.3%
22 - 31 Yrs.	35,727	14.9%		58,400	16.7%
32 - 41 Yrs.	22,331	9.3%		32,740	9.3%
42 - 51 Yrs.	21,807	9.1%		20,308	5.8%
52 - 61 Yrs.	14,442	6.0%		18,743	5.3%
62 Yrs. and Older	6,967	2.9%		13,980	4.0%
Total	**239,971**	**100.0%**		**350,589**	**100.0%**

Figure 3: Number of Consumers by Age Group



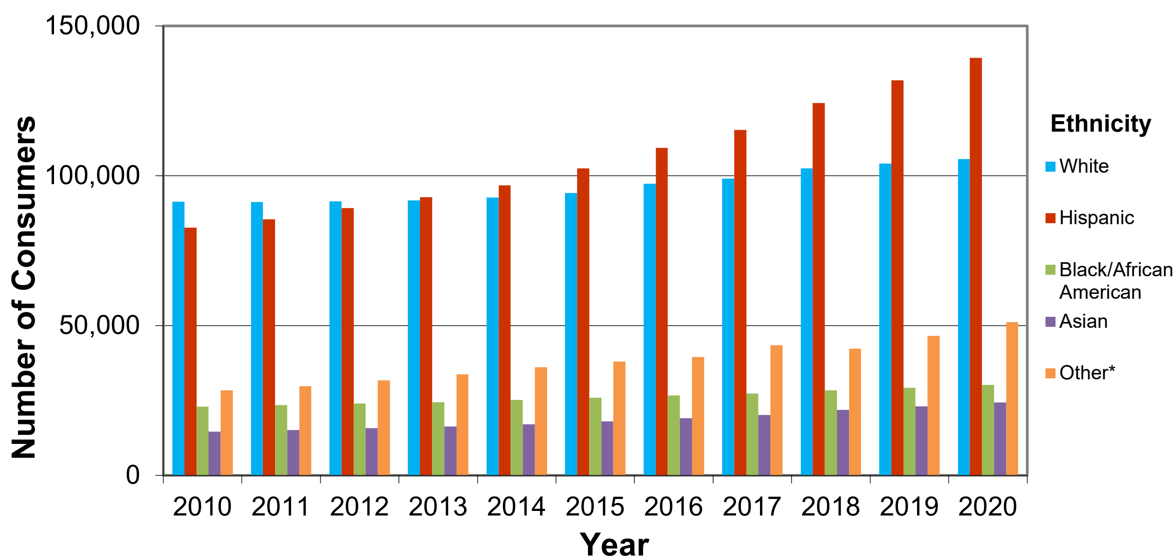
Consumer Ethnicity/Race

Blacks and Whites had the smallest population growth (31.4% and 15.6% respectively) from January 2010 to January 2020. The Hispanic population increased 68.6% over this 10-year period. The Asian and Other populations had population growth of 66.3% and 80.2% respectively. Blacks and Whites were the only Ethnicity/Race populations to see a decrease in the share of the DDS population (1% and 8.0% reductions respectively). Hispanics had the largest gain in percent share of 5.4%.

Table 4: Ethnicity of Consumers

Ethnicity/Race	January 2010		January 2020	
	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
White	91,333	38.1%	105,564	30.1%
Hispanic	82,656	34.4%	139,377	39.8%
Black/African American	22,973	9.6%	30,180	8.6%
Asian	14,644	6.1%	24,356	6.9%
Other*	28,365	11.8%	51,112	14.6%
Total**	**239,971**	**100.0%**	**350,589**	**100.0%**

Figure 4: Number of Consumers by Ethnicity



*Includes multiple ethnicities and individuals with no recorded ethnicity.

Consumer Gender

The trend in the DDS consumer gender distribution continued in 2020 with males increasing in numbers relative to females. In January 2010, 62.3% of the people served were male as compared to 37.7% female. In January 2020, the gap widened to 65.7% male compared to 34.3% 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

Gender*	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
Female	90,350	37.7%		120,352	34.3%
Male	149,621	62.3%		230,237	65.7%
Total	**239,971**	**100.0%**		**350,589**	**100.0%**

Consumer Primary Language

English continues to be the most prevalent primary language of DDS consumers. English was the primary language for 75.6% of consumers in January 2010 and 75.9% in January 2020.

Table 6: Primary Language of Consumers

Primary Language	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
English	181,420	75.6%		266,165	75.9%
Spanish	46,771	19.5%		69,026	19.7%
Vietnamese	2,378	1.0%		3,134	0.9%
Chinese	2,322	1.0%		3,208	0.9%
Tagalog	1,014	0.4%		1,263	0.4%
Other	6,066	2.5%		7,793	2.2%
Total	**239,971**	**100.0%**		**350,589**	**100.0%**

**Non-binary gender data will be available for inclusion in future Fact Books.

CONSUMER RESIDENCE TYPE BY AGE GROUP
JANUARY 2010 AND JANUARY 2020

From January 1, 2010 to January 1, 2020, DDS 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] In both the "Birth through 17" and "18 and Older" age groups, the percentage of consumers residing in community settings (the home of a parent, guardian, or conservator [labeled "Own Home-Family" in the tables below]; a community care setting; or, for 18 and older, a supported living or independent setting) increased. Meanwhile, the percentage of consumers residing in skilled nursing facilities, intermediate care facilities, and state-operated facilities 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 through 17

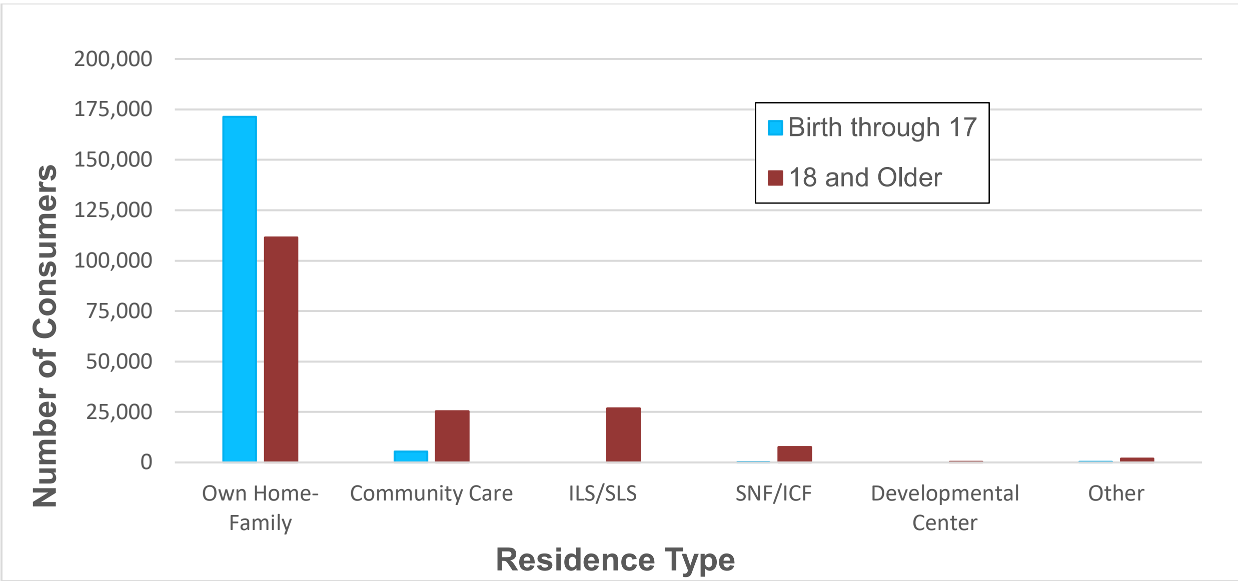
Residence Type	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
Own Home-Family	113,091	96.2%		171,377	96.7%
Community Care	3,751	3.2%		5,378	3.0%
SNF/ICF	375	0.3%		119	0.1%
State-Operated Facility	*	0.0%		0	0.0%
Other	**	**		358	0.2%
Total	**117,606**	**100.0%**		**177,232**	**100.0%**

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

Residence Type	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
Own Home-Family	65,940	53.9%		111,501	64.3%
Community Care	23,548	19.2%		25,312	14.6%
ILS/SLS	21,359	17.5%		26,772	15.4%
SNF/ICF	8,269	6.8%		7,652	4.4%
State-Operated Facility	2,162	1.8%		277	0.2%
Other	1,087	0.9%		1,843	1.1%
Total	**122,365**	**100.0%**		**173,357**	**100.0%**

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

Figure 5: Number of Consumers by Residence Type and Age Group – January 2020



CONSUMER GENDER AND AGE AT TIME OF INTAKE AND ASSESSMENT PROCESS

In the month of January 2020, 12,199 individuals received intake and assessment services. Of these individuals, 28.3% were determined eligible to receive Early Start Program services, 29.3% were eligible to receive services as Active Consumers, and the remaining individuals were determined ineligible to receive regional center services or did not complete the eligibility determination process.

Consumer Gender

The percentage of males in the population engaged in intake decreased from 68.9% in January 2010 to 67.6% in January 2020, while the percentage of females increased from 31.1% to 32.4%.

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

Gender**	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
Female	2,256	31.1%		3,952	32.4%
Male	4,988	68.9%		8,247	67.6%
Total	**7,244**	**100.0%**		**12,199**	**100.0%**

**Non-binary gender data will be available for inclusion in future Fact Books.

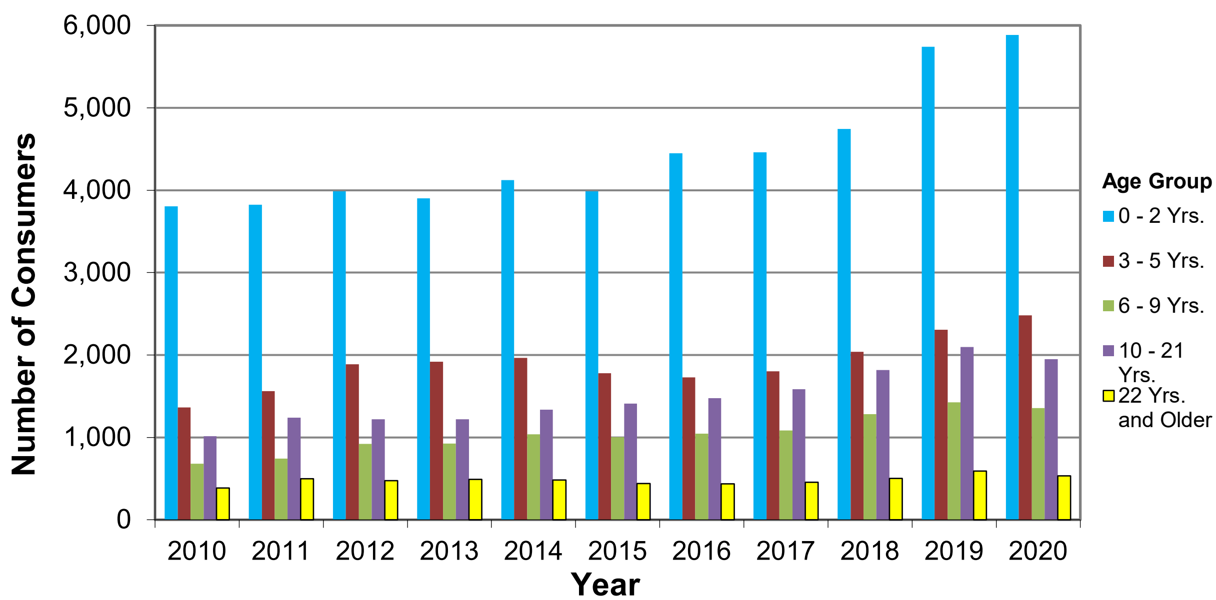
Consumer Age

The proportion by age group of the intake population has been relatively stable over the last 10 years. The 10-21 year old group was the segment of this population with the largest increase, growing from 14.0% in January 2010 to 16.0% in January 2020. The age group birth through two years decreased the most, from 52.5% to 48.2%.

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

Age Group	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
0 – 2 Yrs.	3,805	52.5%		5,885	48.2%
3 – 5 Yrs.	1,363	18.8%		2,479	20.3%
6 – 9 Yrs.	679	9.4%		1,356	11.1%
10 – 21 Yrs.	1,013	14.0%		1,949	16.0%
22 Yrs. and Older	384	5.3%		534	4.4%
Total	**7,244**	**100.0%**		**12,203**	**100.0%**

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



CONSUMERS RESIDING IN A STATE-OPERATED FACILITY

Based on the principles in the Lanterman Act[3] and the Supreme Court *Olmstead*[4] decision, the total state-operated facility population has declined from a high of over 13,300 residents in 1968 to 277 residents in January 2020. Over the last five years, the total population served in state-operated facilities has decreased by 881 residents as four developmental centers and one community facility have been closed.

Table 11 provides the number of consumers and percentage of consumers residing in each developmental center and community facility (Canyon Springs).

Table 11: Number of Consumers Residing in Each State-Operated Facility

State-Operated Facility	Last Person Transitioned to Community	January 2015		January 2020	
		Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Canyon Springs	N/A [5]	**	**	42	15.2%
Fairview	Feb 2020	299	25.8%	**	**
Lanterman	Dec 2014	*	*	0	0.0%
Porterville [6]	Feb 2020	378	32.6%	222	80.1%
Sonoma	Dec 2018	423	36.5%	*	*
Total		**1,158**	**95.7%**	**277**	**84.8%**

[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 dependence on institutional services.

[5]Canyon Springs is not scheduled to close.

[6]Closure date is for the General Treatment Area only.

*Cell suppressed for small numbers.

**Cell suppressed for complementary cell.

Developmental Disability Category Definitions

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, 2010 to January 1, 2020. 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. Most 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

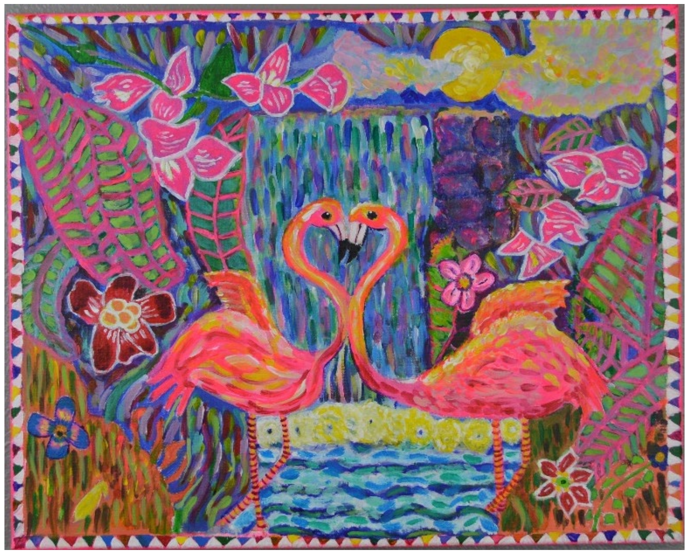
Intellectual Disability is characterized by significant limitations in both intellectual functioning (i.e., an IQ of approximately 70 or below) and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. Levels of Intellectual Disability are reported here as mild, moderate, 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 with revisions made in November 2008 and November 2014. In the CDER before November 2008, Autism included consumers with Autism-Full Syndrome, Autism-Residual State, Autism Suspected or Not Diagnosed. In the 2008 revised CDER, Autism includes consumers with Autistic Disorder, Asperger Disorder, or Pervasive Developmental Disorder. In the 2014 revised CDER, Autism includes consumers with Autism Spectrum 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 of individuals with intellectual disabilities.



Artist: Maria Bustillos

Maria Bustillos is best known for her large-scale collages and paintings inspired by ancient and classical art and architecture, religious iconography, and historical royal portraiture. She is attracted to subjects that display pattern, symmetry, and balance and which embody Classical ideals of proportion and beauty. Maria's artwork often deals with themes of divinity and the sublime, or even the surreal. Maria's affinity for architectural subjects is an expression of her reverence for elegance, harmony, and ornamentation

CONSUMER DEVELOPMENTAL DISABILITY CATEGORY TRENDS

The composition of the population by type of developmental disability shows some significant shifts from January 1, 2010 to January 1, 2020*:

- **Table 12**: The percentage of persons with Intellectual Disability recorded in their CDER file decreased from 71.9% to 57.2%.
- **Table 13:** The percentage of persons with Autism increased from 23.7% to 41.2%.
- **Table 14**: The percentage of persons with Epilepsy declined over this period from 18.4% to 13.1%.
- **Table 15:** The percentage of persons with Cerebral Palsy also declined, from 16.8% to 12.1%.
- **Table 16:** The percentage of persons with a 5th Category diagnosis decreased from 12.2% to 10.4%.

*Category trends do not include consumers in the Early Start Program

Table 12: Number of Consumers with Intellectual Disability

Level of Intellectual Disability	January 2010		January 2020	
	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
No ID	57,993	28.1%	127,965	42.8%
Mild	76,011	36.8%	91,133	30.5%
Moderate	32,983	16.0%	35,409	11.8%
Severe	14,756	7.1%	14,265	4.8%
Profound	10,366	5.0%	8,044	2.7%
Unspecified	14,352	7.0%	22,335	7.5%
ID Diagnosis Subtotal	148,468	71.9%	171,186	57.2%
Overall Total	**206,461**	**100.0%**	**299,151**	**100.0%**

Figure 7: Number of Consumers with Intellectual Disability

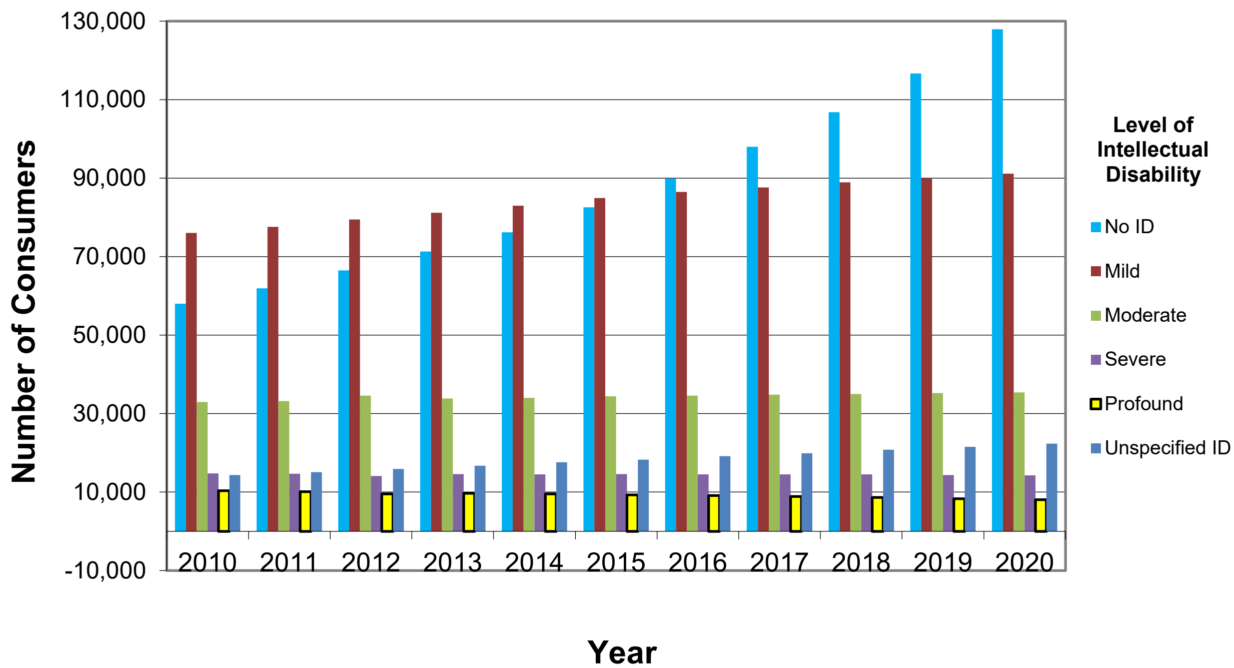


Table 13: Number of Consumers with Autism

Has Autism	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
Yes	48,888	23.7%		123,190	41.2%
No	157,573	76.3%		175,961	58.8%
Total	**206,461**	**100.0%**		**299,151**	**100.0%**

Figure 8: Number of Consumers with Autism

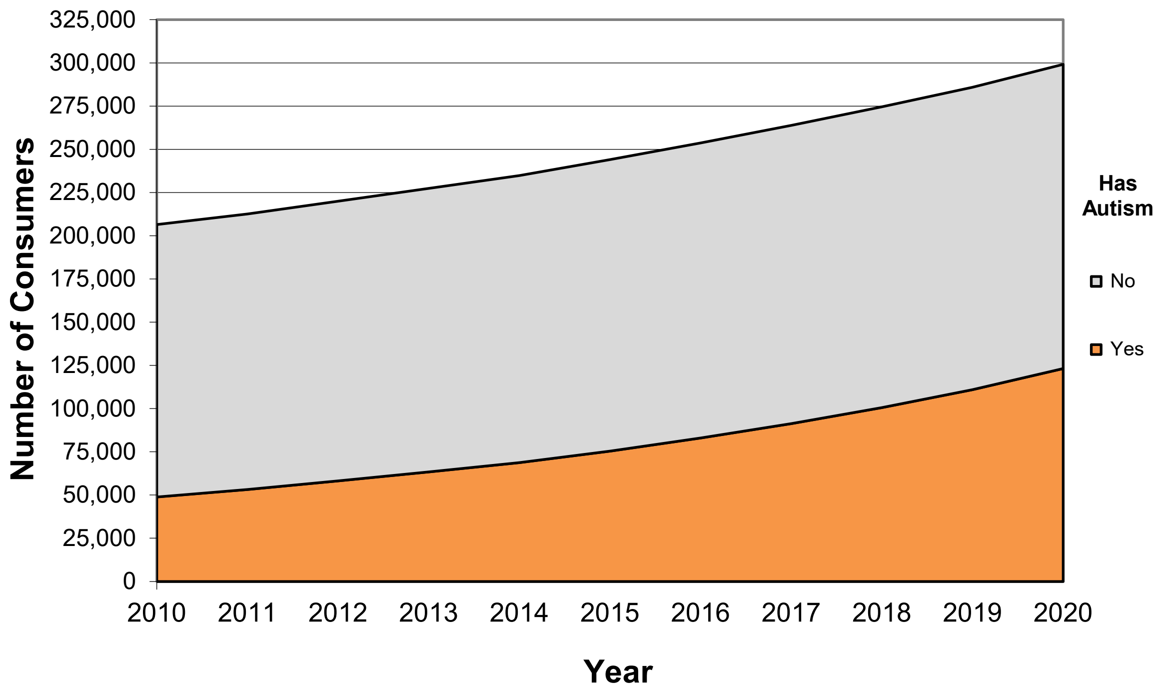


Table 14: Number of Consumers with Epilepsy

Has Epilepsy	January 2010		January 2020	
	Number of Consumers	Percentage of Total	Number of Consumers	Percentage of Total
Yes	37,961	18.4%	39,070	13.1%
No	168,500	81.6%	260,081	86.9%
Total	**206,461**	**100.0%**	**299,151**	**100.0%**

Figure 9: Number of Consumers with Epilepsy

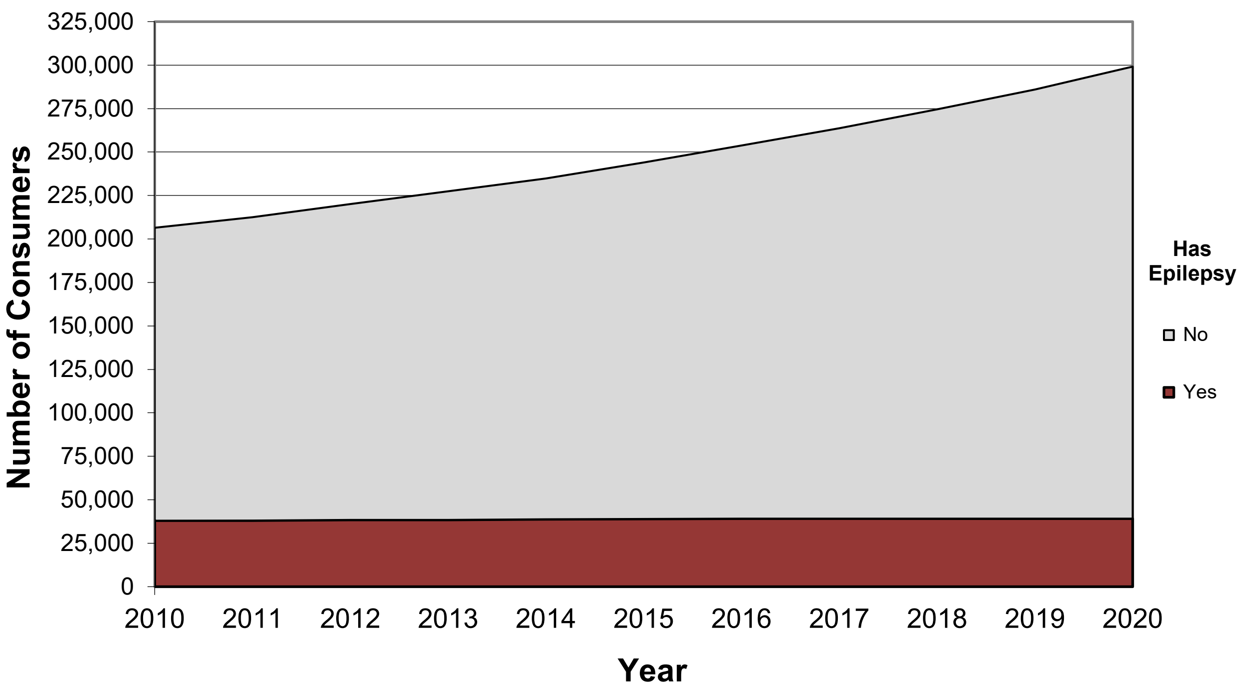


Table 15: Number of Consumers with Cerebral Palsy

Has Cerebral Palsy	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
Yes	34,638	16.8%		36,061	12.1%
No	171,823	83.2%		263,090	87.9%
Total	**206,461**	**100.0%**		**299,151**	**100.0%**

Figure 10: Number of Consumers with Cerebral Palsy

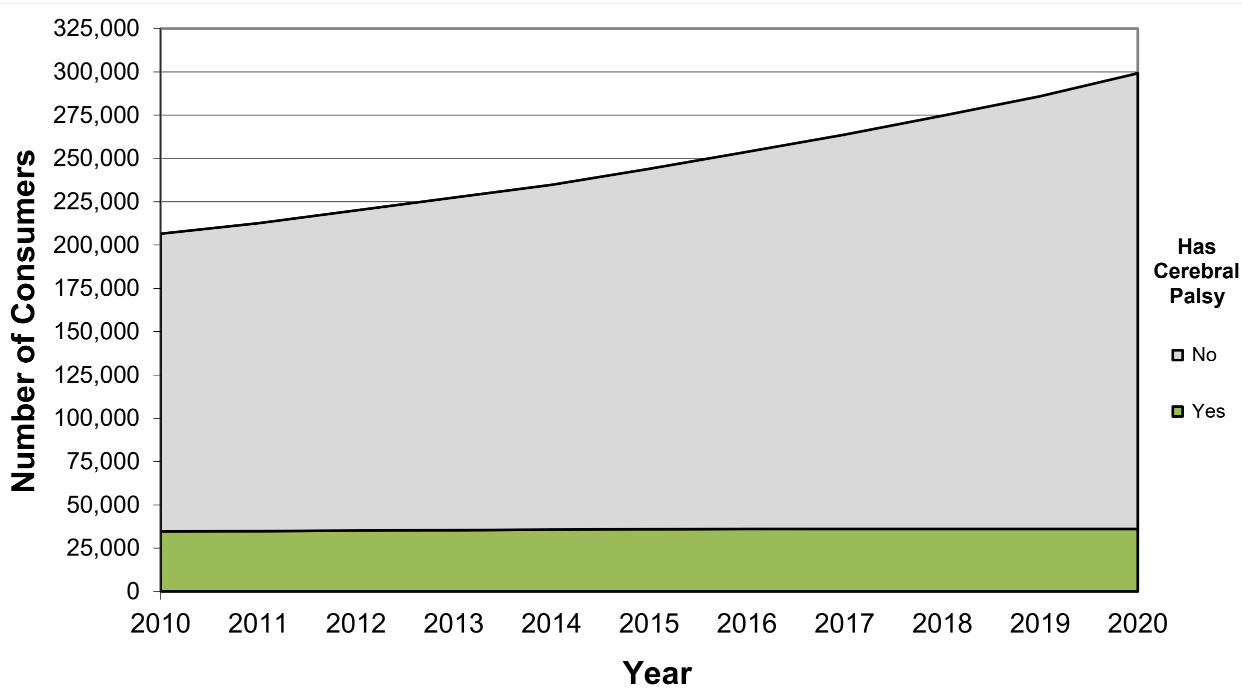
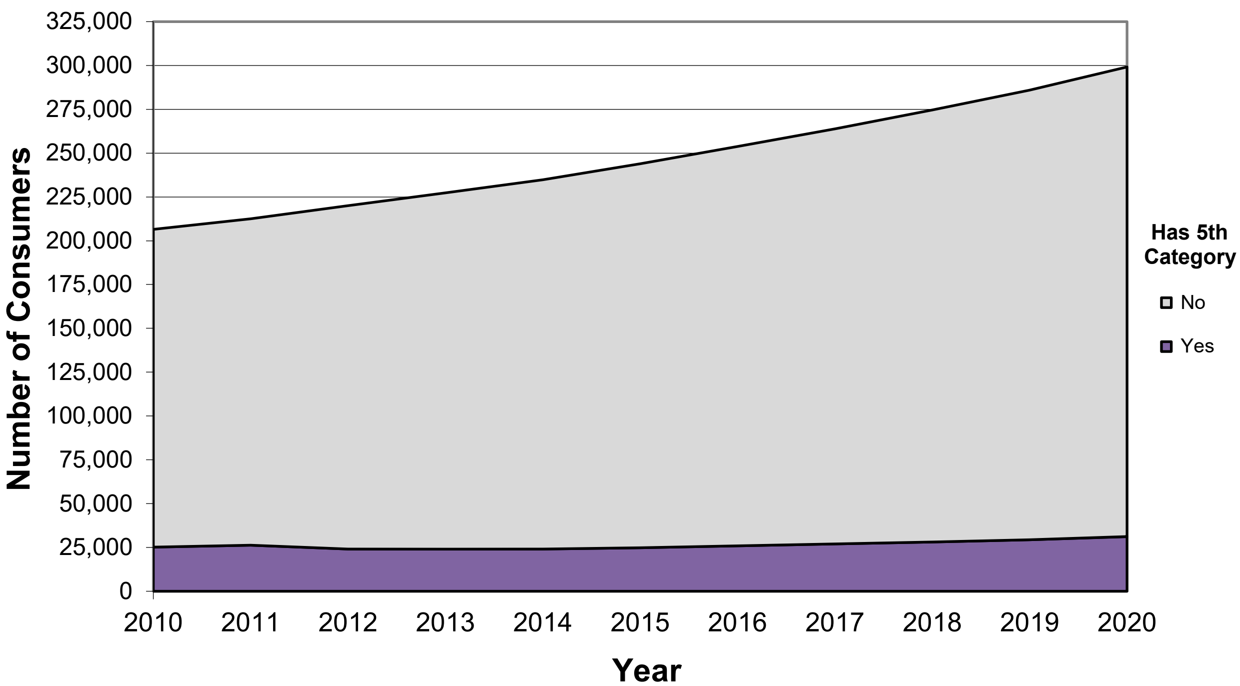


Table 16: Number of Consumers with 5th Category

Has 5th Category	January 2010			January 2020	
	Number of Consumers	Percentage of Total		Number of Consumers	Percentage of Total
Yes	25,247	12.2%		31,128	10.4%
No	181,214	87.8%		268,023	89.6%
Total	**206,461**	**100.0%**		**299,151**	**100.0%**

Figure 11: Number of Consumers with 5th Category



COMBINATIONS OF DEVELOPMENTAL DISABILITIES

It is common for a consumer to have a combination of two or more developmental disabilities recorded on their CDER.

The majority of consumers with an Intellectual Disability (57.8%) have only an Intellectual Disability recorded on their CDER as of January 2020. However, the percentage of consumers with an Intellectual Disability who also have Autism increased from 10.4% to 15.4% between January 2010 and January 2020.

An even larger percentage of consumers with Autism (73.2%) have only Autism recorded on their CDER as of January 2020. The percentage of consumers with Autism who also have an Intellectual Disability decreased from 31.7% to 21.5% between January 2010 and January 2020. A small percentage of consumers have only Epilepsy (7.3%) or Cerebral Palsy (16.6%) as of January 2020. Most consumers with Epilepsy (78.6%) or Cerebral Palsy (71.5%) also have an Intellectual Disability. Consumers with a 5th Category diagnosis have only 5th Category recorded on their CDER 53.7% of the time as of January 2020.

Artist: Suzie Saldana

Suzie Saldana is a mixed media painter who dives into collage and paint. A significant attribute to her work is that it is bold and can be textural, linear, and colorful. Identifiable themes in Suzie's work include ocean life, animals, and religious figures and iconography. It is a visual documentation of her faith, life experience, and her love and passion for the arts. Her faith has led Suzie into a love for stained glass windows; she is inspired by the separation of color through line work. When losing herself in her pieces she is happiest. Suzie experiences the world through emotion and states, "Creativity is always coming from my heart and my mind too...it is feelings that must be let out and shared." Suzie's style is distinct. It is honest and intentional. When creating, she states, "I am in touch with my faith most when I create. I am not sad. I am happy." The imagery she presents becomes a vehicle for self-expression. She believes that the world is beautiful, and its imagery should be shared.

SECTION 2: WHAT CONSUMERS RECEIVE

Brush Strokes – Lindsay Platz

Artist Lindsay Platz has been drawing, painting, and creating ceramic and mosaic art since she was 18. She has a strong desire to explore many art forms and is extremely experimental in her approach. For Lindsay it is important to express texture in any media.

PERCENT OF CONSUMERS BY AGE GROUP RECEIVING REGIONAL CENTER-FUNDED SERVICES OF ALL CONSUMERS SERVED BY DDS IN THE COMMUNITY FY 2009-10 TO FY 2019-20

All consumers served by DDS receive case management services through their local regional center, regardless of whether they receive purchased regional center 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 share of consumers of all ages who receive regional center-funded services as a percentage of all DDS consumers served in the community (Early Start, Active, and Prevention Program consumers) fluctuated minimally from FY 2009-10 to FY 2019-20, decreasing from 79.4% of consumers served in the community to 78.2%. Of note, the share of consumers ages birth through age 2 receiving regional center-funded services increased from 88.4% to 96.0% between FY 2009-10 and FY 2019-20.

Purchase of service reports 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 are finalized.

Table 17: Percentage of Consumers (Prevention*, Early Start Program and Active Consumers) Receiving Regional Center-Funded Services, by Age Group for FY 2009-10 to FY 2019-20

Fiscal Year	0-2 Years	3-21 Years	22-61 Years	62 Years and Up	All Ages (Total)
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%	90.5%	**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	94.3%	66.2%	85.9%	91.8%	**78.3%**
15/16	94.6%	66.5%	86.2%	91.5%	**78.7%**
16/17	95.0%	65.1%	85.8%	91.6%	**78.1%**
17/18	95.3%	65.4%	85.9%	92.0%	**78.3%**
18/19	95.8%	66.6%	86.0%	92.4%	**79.0%**
19/20	96.0%	66.4%	85.3%	92.4%	**78.2%**

*Prevention consumers are included in FY 2009-10 through FY 2012-13 only as the program has been phased out.

Purchase of Services (POS) Growth vs. DDS Caseload - FY 2009-10 to FY 2019-20

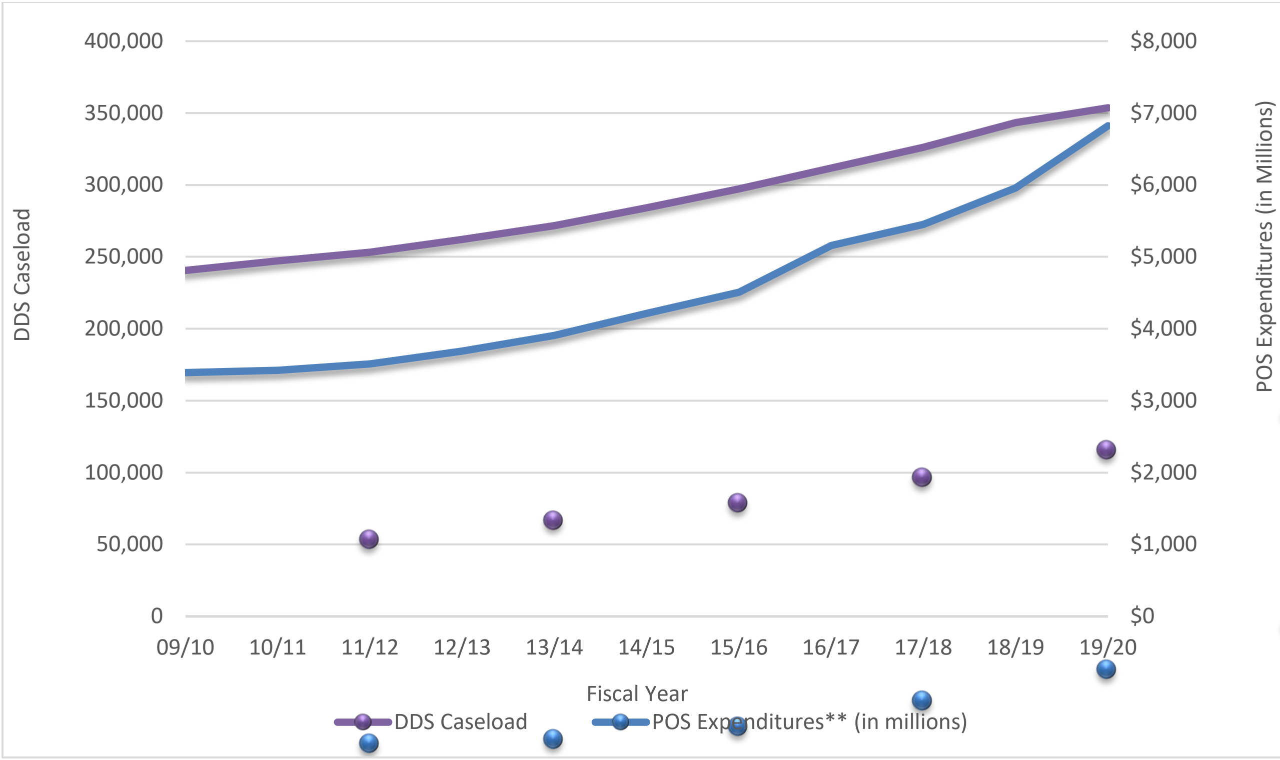
The community caseload (Early Start, Active, and Prevention Program consumers on the Client Master File as of the end of each FY) grew by 113,088 consumers from FY 2009-10 to FY 2019-20, or 47.0%. By comparison, annual POS expenditures increased by $3,433.0 million, or 101.3%, over this period.

Table 18: DDS Caseload Number and POS Expenditure Amount (in Millions) for FY 2009-10 to FY 2019-20

Fiscal Year	DDS Caseload	Percentage Change Caseload	POS Expenditures** (in millions)	Percentage Change Expenditures
09/10	**240,568**	--	**$3,390.1**	--
10/11	**247,310**	2.80%	**$3,424.2**	1.01%
11/12	**253,235**	2.40%	**$3,510.7**	2.53%
12/13	**262,149**	3.52%	**$3,689.4**	5.09%
13/14	**271,724**	3.65%	**$3,906.1**	5.87%
14/15	**284,169**	4.58%	**$4,212.7**	7.85%
15/16	**297,333**	4.63%	**$4,506.1**	6.97%
16/17	**311,679**	4.82%	**$5,158.4**	14.48%
17/18	**326,162**	4.65%	**$5,451.4**	5.68%
18/19	**343,309**	5.26%	**$5,960.5**	9.34%
19/20	**353,656**	3.01%	**$6,823.1**	14.47%

*Prevention consumers are included in FY 2009-10 through FY 2013-13 only as the program has been phased out.
**Includes contract POS.

Figure 12: DDS Caseload Number and POS Expenditure Amount (in Millions) for FY 2009-10 to FY 2019-20



**Includes contract POS.

EXPENDITURES AND COUNTS BY SERVICE CATEGORY
FY 2015-16 TO FY 2019-20

Tables 19, 20, and 21 provide a comprehensive, detailed view of regional center-funded services by service category for the past five years.

PURCHASE OF SERVICES EXPENDITURES

Table 19 presents POS expenditures by service category from FY 2015-16 to FY 2019-20, along with POS changes from FY 2018-19 to FY 2019-20.

Overall, POS expenditures increased $862.5 million (14.5%) from FY 2018-19 to FY 2019-20. All but six service categories show an increase in POS expenditures from FY 2018-19 to FY 2019-20.

The service categories with the largest increase in POS expenditure from FY 2018-19 to FY 2019-20 were *Residential Services*, which increased by $279.4 million (17.5%), and *Supported Living & Related Services*, which increased by $164.0 million (15.3%).

The Work Activity Program category had the largest POS expenditure decrease from FY 2018-19 to FY 2019-20, by -$8.1 million (-21.9%).

Table 19: POS Expenditures* (in Millions) by Service Category for FY 2015-16 to FY 2019-20

Service Category	FY 15-16	FY 16-17	FY 17-18	FY 18-19	FY 19-20	Change from FY 18-19 to FY 19-20
Residential Services	$1,104.3	$1,323.0	$1,416.0	$1,596.3	$1,875.7	**$279.4**
Adult Day Program	$984.9	$1,118.3	$1,166.2	$1,214.4	$1,346.0	**$131.6**
• Adult Development Center	$373.6	$402.8	$402.2	$399.1	$416.3	**$17.1**
• Behavior Mgmt. Program	$227.8	$248.3	$250.0	$251.6	$266.9	**$15.3**
• Other Look-Alike Programs	$230.7	$287.6	$323.8	$360.6	$447.5	**$86.8**
• Independent Living Program	$92.6	$113.2	$123.9	$135.7	$149.9	**$14.3**
• Activity Center	$53.2	$57.8	$57.3	$57.9	$56.0	**-$1.8**
• Social Recreation Program	$6.8	$8.6	$9.1	$9.5	$9.4	**-$0.1**
Supported Living & Related Services	$730.7	$882.9	$971.6	$1,073.6	$1,237.6	**$164.0**
Behavioral Services	$285.8	$202.1	$197.0	$174.0	$190.3	**$16.3**
Transportation	$285.0	$329.4	$342.2	$359.8	$384.9	**$25.1**
Respite	$290.8	$362.2	$408.0	$513.9	$651.9	**$138.0**
Infant Development Program	$178.9	$206.8	$222.2	$239.5	$249.3	**$9.8**
Medical Care & Services	$117.3	$123.5	$138.2	$159.9	$183.7	**$23.8**
Supported Employment Program	$97.0	$118.0	$119.3	$120.3	$123.3	**$2.9**
Supplemental Program Support	$90.8	$106.8	$115.6	$130.0	$202.2	**$72.2**
Work Activity Program	$53.5	$50.9	$44.1	$37.5	$29.3	**-$8.1**
Day Care	$29.2	$31.3	$30.9	$31.3	$30.4	**-$0.9**
Social-Recreational Activities	$30.9	$32.2	$33.4	$34.0	$37.2	**$3.2**
Non-Medical Therapy Services	$4.7	$5.0	$5.2	$5.4	$6.1	**$0.8**
Medical & Adaptive Equip.-Supplies	$6.6	$7.2	$7.5	$8.1	$9.0	**$0.9**
Camps	$2.1	$2.4	$3.2	$4.2	$3.6	**-$0.6**
Environmental & Vehicle Mod.	$5.7	$7.4	$9.3	$10.4	$11.5	**$1.1**
Mobility Training	$0.4	$0.4	$0.4	$0.3	$0.3	**-$0.1**
All Other Services	$207.5	$248.7	$221.0	$247.5	$250.7	**$3.2**
Total	**$4,506.1**	**$5,158.4**	**$5,451.3**	**$5,960.5**	**$6,823.1**	**$862.5**

*Data as of December following each FY end.

NUMBER OF CONSUMERS RECEIVING POS

Table 20 presents the number of consumers receiving services by service category from FY 2015-16 through FY 2019-20, along with the changes in the number of consumers from FY 2018-19 to FY 2019-20.

Overall, the number of consumers receiving POS increased by 4,787 (1.5%) from FY 2018-19 to FY 2019-20. Some service categories (11 of 25) showed an increase in the number of consumers receiving the service from FY 2018-19 to FY 2019-20.

Individual service categories with the largest increase in the number of consumers receiving the service from FY 2018-19 to FY 2019-20 were *Supplemental Program Support,* which increased by 10,407 consumers (132.8%), and the *Respite* category, which increased by 5,281 consumers (6.0%).

The service category with the largest decrease in the number of consumers receiving the service from FY 2018-19 to FY 2019-20 was *Behavioral Services,* which decreased by 4,332 consumers (-14.5%). The decrease is mostly attributable to a change in responsibility for some Medi-Cal beneficiaries from DDS to the Department of Health Care Services. Beginning February 1, 2016, responsibility for Medi-Cal beneficiaries under 21 years of age with an Autism Spectrum Disorder who receive regional center-funded BHT services began transitioning to the DHCS Medi-Cal managed care and Fee for Service (FFS) delivery systems. In March of 2018, consumers with other diagnoses meeting the same criteria also began transitioning to DHCS FFS delivery systems. Consumers with other diagnoses with Medi-Cal managed care started transitioning in July 2018.

Table 20: Number of Consumers Receiving Services by Service Category for FY 2015-16 to FY 2019-20

Service Category	FY 15-16	FY 16-17	FY 17-18	FY 18-19	FY 19-20	Change from FY 18-19 to FY 19-20
Residential Services	30,660	30,836	31,259	30,907	28,869	**-2,038**
Adult Day Program*	77,476	80,556	83,596	87,094	88,332	**1,238**
• Adult Development Center	32,273	32,612	32,744	32,973	31,854	**-1,119**
• Behavior Mgmt. Program	14,969	15,246	15,486	15,550	15,178	**-372**
• Other Look-Alike Programs	15,055	17,204	18,974	21,615	25,610	**3,995**
• Independent Living Program	15,326	16,675	18,279	19,952	20,881	**929**
• Activity Center	6,757	6,766	6,735	6,815	6,229	**-586**
• Social Recreation Program	1,254	1,348	1,330	1,385	1,288	**-97**
Supported Living & Related Services	45,621	49,094	51,201	55,402	60,392	**4,990**
Behavioral Services**	37,441	31,995	30,081	29,972	25,640	**-4,332**
Transportation	77,377	78,674	80,569	82,197	80,448	**-1,749**
Respite	70,411	74,430	80,875	87,794	93,075	**5,281**
Infant Development Program	45,237	49,895	53,979	58,619	58,068	**-551**
Medical Care & Services	57,409	58,465	61,491	66,650	66,460	**-190**
Supported Employment Program	10,375	10,848	11,291	11,800	11,866	**66**
Supplemental Program Support	6,941	7,125	7,517	7,837	18,244	**10,407**
Work Activity Program	9,130	7,824	6,932	6,122	4,873	**-1,249**
Day Care	4,863	4,856	4,802	4,878	4,597	**-281**
Social-Recreational Activities	5,158	5,262	5,509	5,634	5,508	**-126**
Non-Medical Therapy Services	1,717	1,614	1,656	1,625	1,661	**36**
Medical & Adaptive Equip.-Supplies	4,192	4,407	4,842	5,199	5,991	**792**
Camps	1,492	1,681	1,779	1,944	1,815	**-129**
Environmental & Vehicle Mod.	577	684	769	745	823	**78**
Mobility Training	245	236	247	239	171	**-68**
All Other Services	104,404	112,587	120,449	128,774	128,942	**168**
Total*	**275,727**	**287,306**	**302,304**	**320,657**	**325,444**	**4,787**

*Total counts are unduplicated by consumer to avoid double-counting consumers receiving multiple types of service. Counts are based on January POS data of each year as of April 2021.

**Decrease reflects the transition of authorization and payment of Behavioral Health Treatment services from regional center-funding to Medi-Cal funding as described on the previous page.

NUMBER OF VENDORS PROVIDING SERVICES

Table 21 presents the number of vendors providing services by service category from FY 2015-16 through FY 2019-20, along with the change in the number of vendors from FY 2018-19 to FY 2019-20.

Overall, the number of vendors providing services increased by 112 (0.3%) from FY 2018-19 to FY 2019-20. Over half of the service categories (15 of 25) showed a decrease in the count of vendors providing the service from FY 2018-19 to FY 2019-20.

Service categories with the largest decrease in the number of vendors providing services from FY 2018-19 to FY 2019-20 were *Transportation,* which decreased by 143 vendors (-3.0%), and *Respite,* which decreased by 111 vendors (-6.9%).

The service category with the largest increase in the number of vendors providing services from FY 2018-19 to FY 2019-20 was *Supplemental Program Support*, which increased by 2,115 vendors (102.7%).

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 vendored for these services when using vouchers switched to using vendored agencies for coordination of services. As a result, these consumer families are no longer reflected in the vendor counts.

Table 21: Number of Vendors Providing Services by Service Category for FY 2015-16 to FY 2019-20

Service Category	FY 15-16	FY 16-17	FY 17-18	FY 18-19	FY 19-20	Change from FY 18-19 to FY 19-20
Residential Services	5,733	5,710	5,937	6,093	6,198	**105**
Adult Day Program*	2,171	2,235	2,307	2,411	3,042	**631**
• Adult Development Center	638	629	639	629	626	**-3**
• Behavior Mgmt. Program	344	350	350	353	355	**2**
• Other Look-Alike Programs	616	653	702	793	1,416	**623**
• Independent Living Program	442	470	490	503	520	**17**
• Activity Center	139	137	135	135	129	**-6**
• Social Recreation Program	20	19	17	18	16	**-2**
Supported Living & Related Services	2,205	2,314	2,302	2,005	1,996	**-9**
Behavioral Services	1,021	1,003	1,006	1,048	1,038	**-10**
Transportation	4,632	4,563	4,619	4,713	4,570	**-143**
Respite	1,715	1,599	1,560	1,602	1,491	**-111**
Infant Development Program	463	479	497	497	518	**21**
Medical Care & Services	1,858	1,761	1,759	1,815	1,832	**17**
Supported Employment Program	355	354	352	359	368	**9**
Supplemental Program Support	1,703	1,710	1,879	2,059	4,174	**2115**
Work Activity Program	107	99	94	91	74	**-17**
Day Care	541	503	493	486	455	**-31**
Social-Recreational Activities	147	141	139	146	135	**-11**
Non-Medical Therapy Services	130	111	105	103	98	**-5**
Medical & Adaptive Equip.-Supplies	1,193	1,189	1,213	1,203	1,163	**-40**
Camps	35	43	36	35	31	**-4**
Environmental & Vehicle Mod.	62	66	71	73	77	**4**
Mobility Training	19	18	19	17	13	**-4**
All Other Services	23,593	23,527	23,787	23,768	23,280	**-488**
Total*	**41,026**	**40,806**	**41,339**	**41,434**	**41,546**	**112**

*Total counts are unduplicated by vendor to avoid double counting vendors providing multiple services. Counts are based on January POS data of each year as of April 2021.

POPULATION AND PER CAPITA POS BY DEVELOPMENTAL DISABILITY AND AGE GROUP

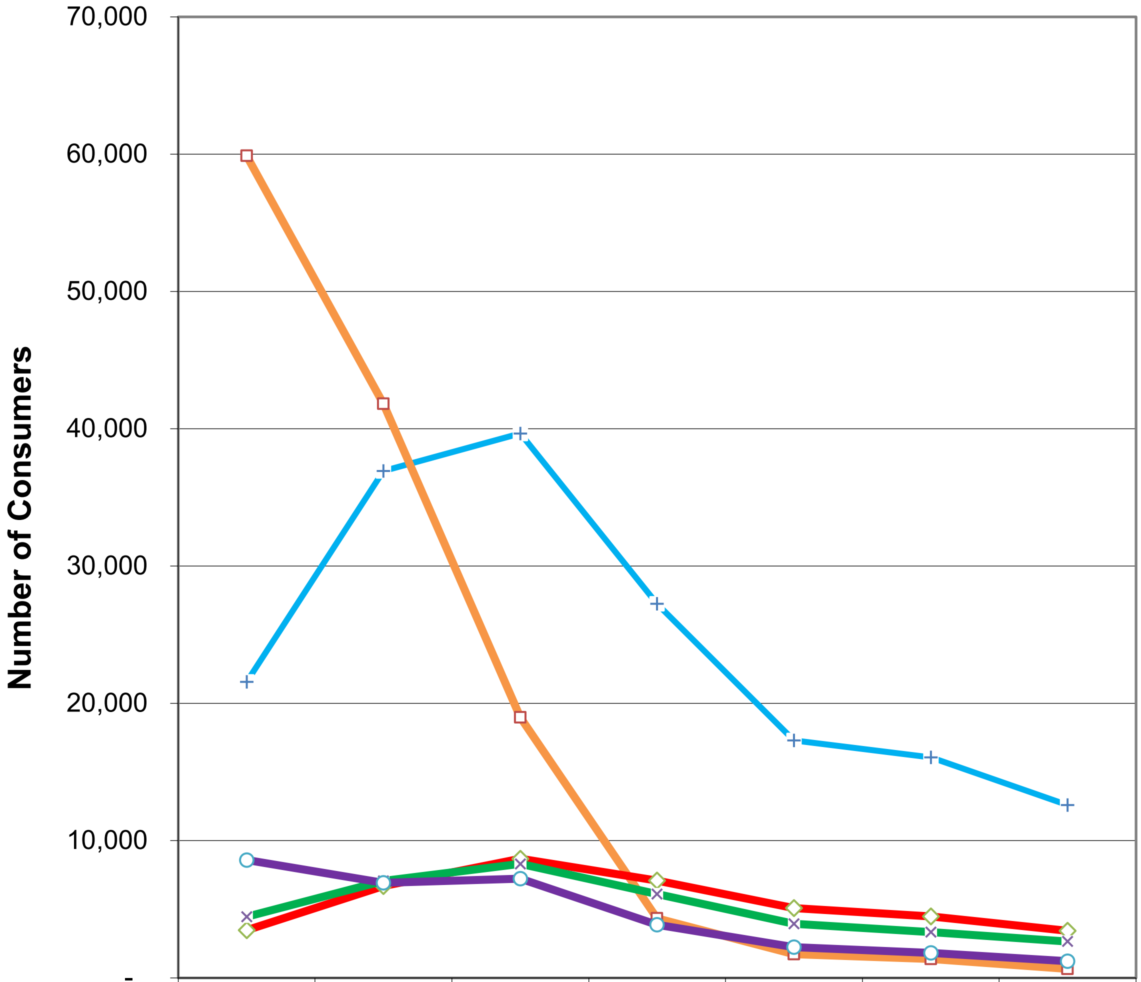
As of July 2020, the majority of consumers with Intellectual Disability (65.9%), Epilepsy (73.9%), Cerebral Palsy (67.9%), or 5th Category (51.4%) were age 22 years or older, whereas the majority of consumers with Autism (79.0%) were 3-21 years of age.

After age 21, the average per capita POS of consumers with each developmental disability category increases considerably when Department of Education-funded services are no longer available and out-of-home placement and day services are needed. Consumers ages 32 and older, per capita expenditures for Autism are higher than the other four developmental disability categories (Intellectual Disability, Epilepsy, Cerebral Palsy, and 5th Category).

Stormy – Chris France

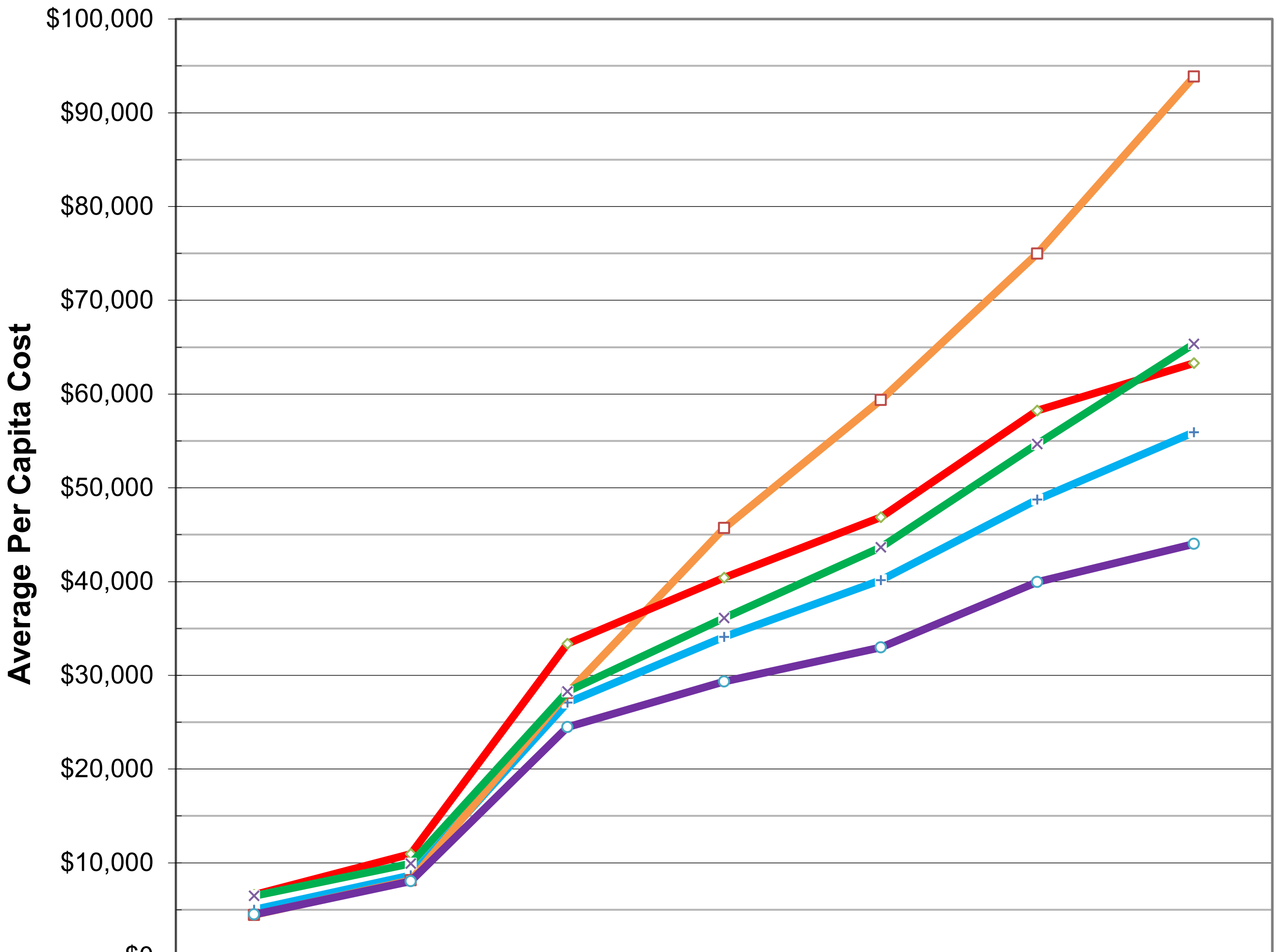
Artist Chris France has been an active painter for the last thirty years. When asked about his motivation to paint, Chris says it's not so much the idea of selling but showing the community that a disability does not mean he can't do things. Art has become a tool for advocacy and personal expression for Chris.

Figure 13: Developmental Disability by Age Group as of July 2020



Age Group >>	3 - 11 yrs	12 - 21 yrs	22 - 31 yrs	32 - 41 yrs	42 - 51 yrs	52 - 61 yrs	62 & Older
ID	21,558	36,919	39,659	27,260	17,296	16,058	12,590
Autism	59,876	41,828	18,977	4,339	1,719	1,376	659
Epilepsy	3,470	6,698	8,682	7,081	5,083	4,477	3,432
CP	4,462	7,073	8,309	6,121	3,938	3,342	2,650
5th Cat.	8,590	6,931	7,229	3,872	2,244	1,831	1,219

Figure 14: Average Per Capita Expenditures (Active Consumer and State-Operated) by Developmental Disability and Age Group as of July 2020

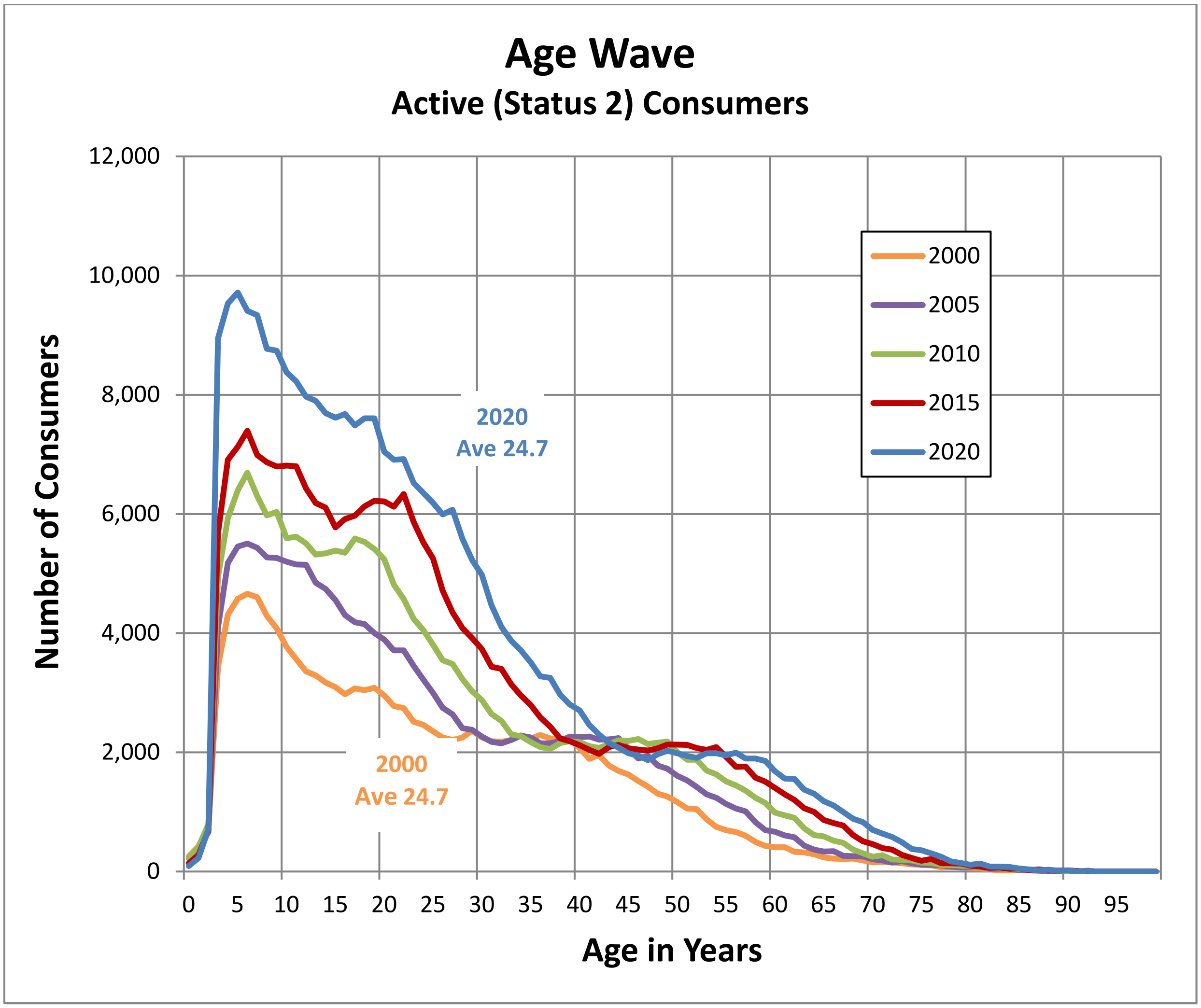


Age Group >>	3 - 11 yrs	12 - 21 yrs	22 - 31 yrs	32 - 41 yrs	42 - 51 yrs	52 - 61 yrs	62 & Older
ID	$5,009	$8,665	$27,099	$34,097	$40,148	$48,735	$55,932
Autism	$4,449	$8,142	$28,106	$45,697	$59,363	$74,966	$93,852
Epilepsy	$6,588	$10,961	$33,355	$40,424	$46,857	$58,246	$63,299
CP	$6,472	$9,918	$28,291	$36,113	$43,662	$54,660	$65,355
5th Cat.	$4,484	$8,042	$24,483	$29,331	$32,974	$39,964	$44,012

DEMOGRAPHIC TRENDS: AGE WAVE OVER THE PAST 20 YEARS

Over the past 20 years, the growing Early Start program and intake of school-aged children has resulted in a large overall growth in the 3-30 age group. The over-40 population has remained relatively stable, with a rightward population shift due to increased longevity, but otherwise modest growth. The decrease in the consumer population due to mortality now occurs after 55 years of age.

Figure 15: Consumer Count on July 1 of every 5th Year for the Past 20 Years



Demographic Trends: Average POS Wave Over the Past 20 Years

Table 22 presents the changes in average POS over the past 20 years broken down by age groups for FY1999-00, FY2009-10, and FY2019-20. The average POS data per consumer for age group 62 and older more than tripled over the years, while smaller increases were seen in younger age groups.

Table 22: POS Data per Consumer by Age Group and Fiscal Year for FY 1999-00, FY 2009-10, and FY 2019-20

Age Groups	FY 1999-00			FY 2009-10			FY 2019-20		
	Total POS	Population	Average POS	Total POS	Population	Average POS	Total POS	Population	Average POS
3-11	$91,006,653	24,847	$3,663	$401,698,851	38,287	$10,492	$353,978,092	59,997	$5,900
12-21	$131,940,535	18,723	$7,047	$340,638,045	34,002	$10,018	$641,031,160	54,995	$11,656
22-31	$249,425,218	18,762	$13,294	$638,075,254	29,981	$21,283	$1,521,394,404	50,070	$30,385
32-41	$261,272,069	18,399	$14,200	$460,531,140	19,618	$23,475	$1,075,148,589	29,376	$36,600
42-51	$185,109,132	12,643	$14,641	$496,034,184	19,423	$25,538	$795,293,640	18,633	$42,682
52-61	$81,991,908	5,541	$14,797	$347,656,534	12,757	$27,252	$885,488,519	17,561	$50,424
>62	$40,855,639	2,793	$14,628	$167,106,201	5,969	$27,996	$753,080,526	13,135	$57,334
Total	**$1,041,601,154**	**101,708**	**$82,271**	**$2,851,740,209**	**160,037**	**$146,054**	**$6,025,414,931**	**243,767**	**$234,980**

Note: In an earlier version of this report, the total average POS for all fiscal years were calculated incorrectly. It was previously calculated as the summation of average POS across all age groups instead of dividing the total POS by population for each fiscal year. The total average POS for each fiscal year above is correct.

SECTION 3: CONSUMER PERSONAL OUTCOMES HIGHLIGHTS

In 2009, DDS added the Personal Outcomes element to the CDER. 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 Personal Outcomes element from the CDER as of January 1, 2021:

Education
55% of those in school have integrated classrooms
85% 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 who speak the consumer's primary language
69% of those working are paid for over 10 hours of work per week
58% of those working are paid minimum wage or over

Social Well-Being
86% of consumers have a community outing at least weekly
76% 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
95% of those with medical or dental conditions received full appropriate care

Living Situation – not living in 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 in 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

Department of Developmental Services
Information Technology Division
1215 O Street, MS 8-10
Sacramento, CA 95814
Telephone: (916) 653-3329
E-mail: DataX@dds.ca.gov
Website: www.dds.ca.gov