

# **ANNUAL REPORT TO THE LEGISLATURE ON AUTISM**

Created by the California Department of Developmental Services  
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# SECTION 1: BACKGROUND

Under the Lanterman Developmental Disabilities Services Act (Lanterman Act), the California Department of Developmental Services (DDS) serves individuals with intellectual and developmental disabilities and oversees the services and supports needed for individuals to lead more independent and productive lives in the community of their choice. DDS contracts with 21 regional centers (RCs) to identify and coordinate services to individuals in the community.

**Autism Spectrum Disorder (ASD)** is a developmental disability characterized by social, communication, and behavioral challenges. Autism is one of the developmental disabilities that qualifies for services and supports in accordance with the Lanterman Act (Welfare & Institutions Code 4512(a)(1)).

The California Budget Act of 2023 established the Autism Services Branch within DDS. The Budget Bill included a requirement that DDS report outcomes related to this investment:

*Of the funds appropriated in Schedule (2), \$1,032,000 is appropriated for the creation of an Autism Services Branch within the State Department of Developmental Services. Of the reimbursements appropriated in Schedule (4), \$206,000 is available for support of these purposes. By April 1, 2024, and at least annually thereafter, the department shall provide written reporting to the Legislature on outcomes and impacts associated with this expenditure, including updates on autism caseload data, and associated intake, ethnicity, age of eligibility determination, transitions out of secondary education, services and supports, and racial and ethnic inequities. This information shall be provided using historical data, yielding trend data over time, to the maximum extent feasible. As part of this written reporting, the department shall provide observations and analysis on the trends as demonstrated in the data related to autism, including information on areas of the system where there is a demonstration of unmet need.*

Provision 9 under Section 60. Item 4300-001-001 of Section 2.00 of the Budget Act of 2023

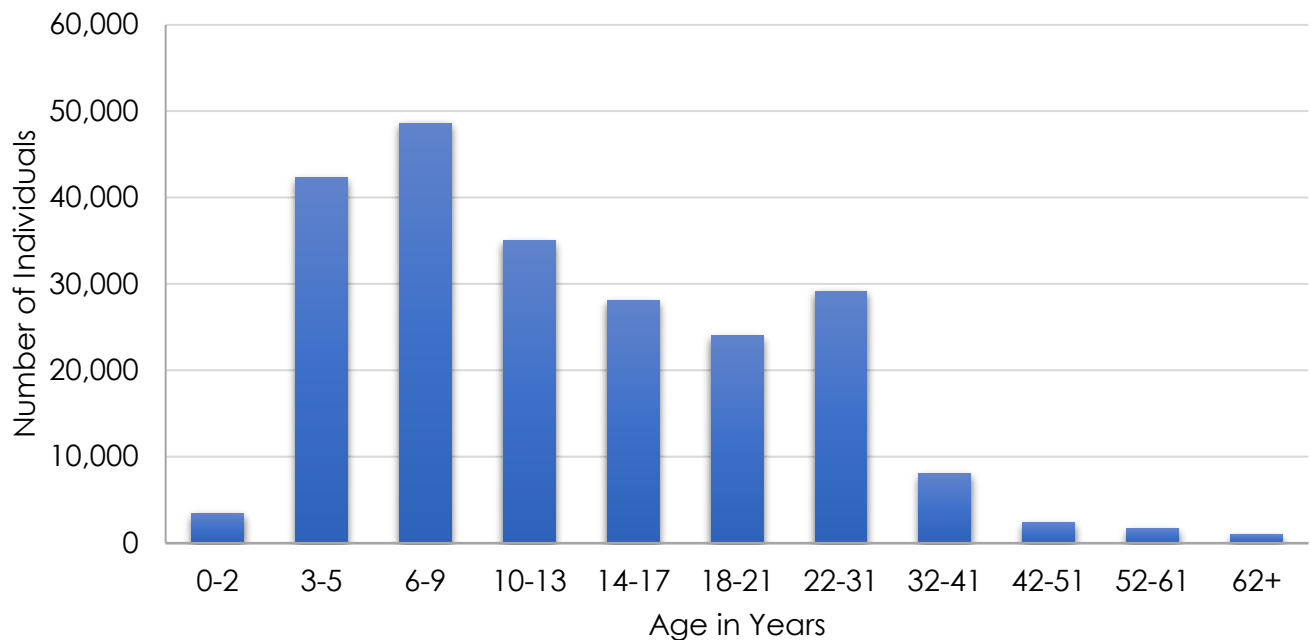
The associated allocated funds allowed the Department to hire a team of staff to support research, programs, outreach, and initiatives focused on ASD. This report provides updates on DDS ASD caseload and services data and the projects of the Autism Services Branch.

# SECTION 2: AUTISM CASELOAD INFORMATION

## 2.1 AUTISM CASELOAD TRENDS

In December 2023, the DDS caseload included 360,070 individuals eligible for Lanterman Act services, and 178,210 of those individuals had a diagnosis of ASD. Within the ASD caseload, the majority of individuals served (approximately 80%) are under 22 years-of-age. Children 6-9 years-of-age represent the largest proportion of the ASD population (22%).

Figure 1. The DDS ASD Caseload by age group in Calendar Year (CY) 2023.



Source: DDS Client Master File and Client Development Evaluation Report for Lanterman-eligible individuals with a diagnosis of ASD in CY 2023. Data extracted March 1, 2024.

The population numbers and share of individuals with a diagnosis of ASD have been steadily rising over time, while the share of all other diagnostic categories (Intellectual Disability, Cerebral Palsy, Epilepsy, and Other) have declined or remained stable. Over the last ten years (CY 2013-2023), the ASD caseload has grown by 156%. Over that time, the ASD caseload has grown in share of the Lanterman-eligible caseload from 29% in 2013 to 50% in 2023 (Table 1).

The share of individuals with a diagnosis of ASD varies by RC. Golden Gate Regional Center has the lowest share at 32%, while Frank D. Lanterman Regional Center has the highest share at 60% (Table 2).

Table 1. Shares of Each Lanterman Act Services Developmental Disability Category from CY 2013-2023.

Calendar Year	Autism	Intellectual Disability	Cerebral Palsy	Epilepsy	Other
2013	29%	67%	15%	16%	11%
2014	31%	66%	15%	16%	10%
2015	33%	64%	14%	15%	10%
2016	35%	63%	14%	15%	10%
2017	37%	61%	13%	14%	10%
2018	39%	59%	13%	14%	10%
2019	41%	57%	12%	13%	11%
2020	43%	55%	12%	13%	11%
2021	45%	54%	11%	12%	11%
2022	48%	52%	10%	11%	11%
2023	50%	50%	10%	11%	11%

Source: DDS Client Master File and Client Development Evaluation Report for Lanterman-eligible individuals from CY 2013-2023. Data extracted March 1, 2024; Note: An individual may have more than one diagnosis and may be counted under multiple diagnoses (i.e., duplicated counts).

Table 2. Lanterman-Eligible Caseload and ASD Caseload Shares by RC in CY 2023.

Regional Center	ASD Caseload	Total Caseload	ASD Share
Alta California	14,090	28,274	50%
Central Valley	9,892	23,471	42%
Eastern Los Angeles	7,323	12,935	57%
Frank D. Lanterman	6,655	11,032	60%
Far Northern	4,324	9,031	48%
Golden Gate	2,892	9,115	32%
Harbor	9,751	16,480	59%
Inland	16,426	41,217	40%
Kern	5,635	11,636	48%
North Bay	4,047	9,291	44%
North Los Angeles County	17,787	30,099	59%
East Bay	11,984	22,831	52%
Orange County	10,421	22,030	47%
Redwood Coast	1,912	4,311	44%
San Andreas	7,272	16,549	44%
South Central Los Angeles	9,441	18,590	51%
San Diego	20,223	35,624	57%
San Gabriel/Pomona	6,381	13,968	46%
Tri Counties	7,519	15,469	49%
Valley Mountain	8,502	16,724	51%
Westside	5,114	9,513	54%

Source: DDS Client Master File and Client Development Evaluation Report for Lanterman-eligible individuals from CY 2023. Data extracted March 1, 2024; Note: If an individual transferred between regional centers during CY 2023, they may be counted under more than one regional center (i.e., duplicated counts).

## 2.2 POPULATION CHARACTERISTICS AND DEMOGRAPHICS

Within the statewide Lanterman-eligible ASD caseload, 79% of individuals are male and 21% are female (ratio = 3.76:1). Approximately 19% of the ASD caseload has co-occurring Intellectual Disability, while 81% do not have co-occurring Intellectual Disability.

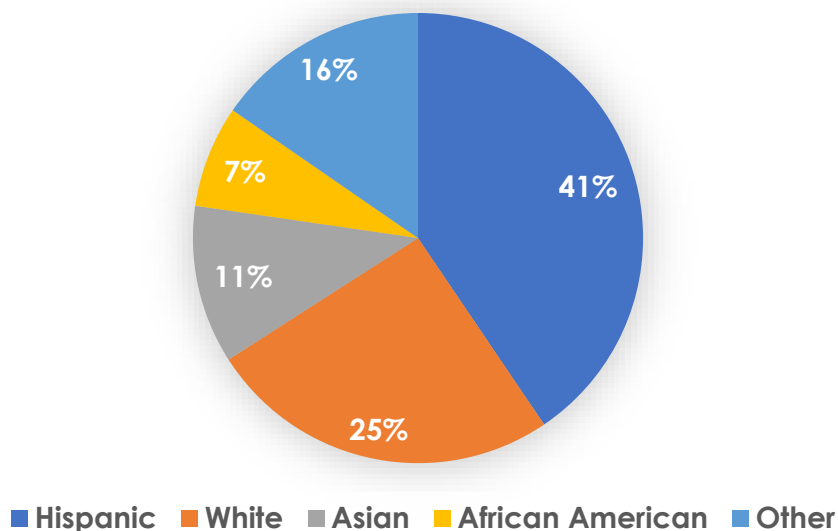
Figure 2. Left: share of DDS ASD caseload identifying as male and female; Right: share of DDS ASD caseload with and without co-occurring Intellectual Disability.



Source: DDS Client Master File and Client Development Evaluation Report for Lanterman-eligible individuals with a diagnosis of ASD from CY 2023. Data extracted March 1, 2024.

Among individuals with a diagnosis of ASD, 41% identify as Hispanic, 25% identify as White, 11% identify as Asian, 7% identify as African American, and 16% identify as any other race/ethnicity (including mixed race).

Figure 3. DDS ASD caseload by shares of each race/ethnicity group.



Source: DDS Client Master File and Client Development Evaluation Report for Lanterman-eligible individuals with a diagnosis of ASD from CY 2023. Data extracted March 1, 2024.

The five most common primary languages spoken by individuals with a diagnosis of ASD include English (81%), Spanish (16%), Vietnamese (1%), Mandarin Chinese (<1%), and Cantonese Chinese (<1%).

### 2.3 AGE AT ELIGIBILITY DETERMINATION

To evaluate system entry trends, individuals' ages were examined at the time of their transition from intake to eligibility determination for Early Start or Lanterman Act services (for individuals first entering the DDS service system between July 1, 2017 and January 31, 2024). Statewide, 41% of individuals with ASD became eligible for services from birth through 2 years-of-age, 38% became eligible between 3 and 8 years-of-age, and 21% became eligible at 9 years-of-age and older.

Across racial and ethnic groups, there were larger shares of children identifying as Hispanic, Asian and Other Race/Ethnicity entering the system under 3 years-of-age compared to children identifying as African American or White. Individuals identifying as White had the largest share of individuals becoming eligible at 9 years-of-age and older.

Table 3. Shares of Individuals Becoming Eligible for Early Start and Lanterman Services by Age and Race/Ethnicity.

Age in Years	African American	Asian	Hispanic	Other	White	Total Share by Age
0	3%	1%	2%	2%	2%	2%
1	11%	13%	16%	16%	11%	14%
2	22%	25%	25%	29%	19%	25%
3	15%	13%	14%	13%	11%	13%
4	10%	10%	10%	9%	8%	9%
5	7%	8%	7%	6%	6%	6%
6	5%	5%	4%	4%	4%	4%
7	3%	3%	3%	3%	4%	3%
8	3%	2%	2%	2%	3%	3%
9+	22%	18%	16%	17%	32%	21%
<b>TOTAL</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

Source: History Status file and Client Developmental Evaluation report Data as of January 31, 2024, for individuals first entering the DDS system (transitioning from Intake to Early Start or Lanterman Act Services) from July 1, 2017 to January 31, 2024.

## 2.4 SERVICES AND SUPPORTS

For individuals with a diagnosis of ASD of all ages statewide, the most commonly used service type in 2023 was In-home Respite (service code 862). The next most commonly used service types vary by age group (Table 4).

Table 4. Top 10 Most Commonly Used Service Codes Among Individuals with ASD by Age Group in CY 2023.

Service Code & Name	0-13	Rank	14-17	Rank	18-21	Rank	22+	Rank
862-IN-HOME RESPITE SERVICE AGENCY	35,854	1	9,963	1	6,924	1	7,862	1
051-PERSONAL EMERGENCY RESPONSE	8,119	2	1,354	4	756	8		
643-TRANSLATOR	6,612	3	1,443	3	994	6		
028-SOCIALIZATION TRAINING PROGRAM	4,128	4	1,218	5	509	10		
062-PERSONAL ASSISTANCE	3,754	5	1,543	2	1,713	2	2,688	10
102-INDIVIDUAL OR FAMILY TRAINING	3,612	6	897	6	1,079	5		
103-SPECIALIZED HEALTH TREATMENT & TRAINING	3,497	7	813	7	706	9		
024-PURCHASE REIMBURSEMENT	3,108	8	564	10				
660-RETAIL/WHOLESALE STORES	2,878	9						
490-FINANCIAL MANAGEMENT SERVICES	2,737	10	615	9				
605-ADAPTIVE SKILLS TRAINERS			745	8	774	7		
520-INDEPENDENT LIVING PROGRAM					1,710	3	4,825	4
055-COMMUNITY INTEGRATION TRAINING PROGRAM					1,278	4	6,492	2
880-TRANSPORTATION - ADDITIONAL COMPONENT							6,037	3
510-ADULT DEVELOPMENT CENTER							4,287	5
515-BEHAVIOR MANAGEMENT PROGRAM							3,688	6
915-RESIDENTIAL FACILITY - ADULTS							3,536	7
895-TRANSPORTATION - PUBLIC/RENTAL/TAXI							3,077	8
875-TRANSPORTATION COMPANY							3,018	9

Source: State Claims File for individuals with Status 2, 3, and U as of CY 2023. Data extracted March 18, 2024.



For individuals with a diagnosis of ASD falling into the 14-17 and 18-21 age groups, In-home Respite (service code 862) services accounted for the largest amount of purchase of service (POS), followed by Personal Assistance (service code 062). For adults 22 years-of-age and older, Residential Facilities Serving Adults (service code 915) accounted for the largest amount of POS, followed by Supported Living Services (service code 896) (Table 5).

Table 5. Top 10 Service Codes with Highest Total POS Among Individuals with ASD by Age Group in CY 2023.

Service Code & Name	0-13	Rank	14-17	Rank	18-21	Rank	22+	Rank
862-IN-HOME RESPITE SERVICE AGENCY	\$255,807,971	1	\$71,898,648	1	\$52,574,934	1	\$74,852,058	7
062-PERSONAL ASSISTANCE	\$59,749,459	2	\$27,189,893	2	\$34,571,529	2	\$96,778,229	5
605-ADAPTIVE SKILLS TRAINERS	\$13,632,955	3	\$6,904,957	6	\$12,180,223	7		
028-SOCIALIZATION TRAINING PROGRAM	\$11,486,977	4	\$5,408,300	7				
331-COMMUNITY INTEGRATION SUPPORTS	\$9,443,133	5	\$4,956,989	8				
465-RESPITE (PARTICIPANT-DIRECTED)	\$8,872,136	6						
115-SPECIALIZED THERAPEUTIC SERVICES	\$8,786,904	7	\$4,342,719	9				
805-INFANT DEVELOPMENT PROGRAM	\$8,321,943	8						
860-HOMEMAKER SERVICE	\$7,489,104	9						
612-BEHAVIOR ANALYST	\$7,398,657	10						
113-SPECIAL RESIDENTIAL FACILITY HABILITATION			\$10,311,488	4	\$12,608,147	6	\$140,104,950	3
320-COMMUNITY LIVING SUPPORTS			\$4,318,873	10				
901-ENHANCED BEHAVIORAL SUPPORTS HOME			\$13,088,802	3			\$46,913,114	10
920-RESIDENTIAL FACILITY - CHILDREN			\$7,210,756	5	\$7,717,791	10		
055-COMMUNITY INTEGRATION TRAINING PROGRAM					\$17,626,150	4	\$139,181,385	4
109-PROGRAM SUPPORT - RESIDENTIAL					\$8,914,263	9	\$56,155,466	9
520-INDEPENDENT LIVING PROGRAM					\$8,940,668	8		
896-SUPPORTED LIVING SERVICES					\$13,248,079	5	\$213,467,135	2
915-RESIDENTIAL FACILITY - ADULTS					\$29,869,026	3	\$320,522,649	1
510-ADULT DEVELOPMENT CENTER							\$56,376,677	8
515-BEHAVIOR MANAGEMENT PROGRAM							\$93,725,576	6

Source: State Claims File for individuals with Status 2, 3, and U as of CY 2023. Data extracted March 18, 2024.

Among individuals with ASD, there are differences in POS across racial and ethnic groups, however the trends in POS differ depending on the age groups and respective types of service. For example, for individuals with a diagnosis of ASD living in the family home, there are some POS disparities across race/ethnicity groups (Table 6). For young adults (18-21 years-of-age), Hispanic, Asian, and White groups had similar average POS, while African Americans had higher POS and individuals of any other race/ethnicity had lower POS on average.

The POS values presented below include the mean and median values for each age group and race/ethnicity group. The average (mean) and median (middle score) are statistical methods used to examine the center of a dataset. Often the mean can be used to represent the most common measure of POS, however, in cases where a small number of outliers skew the overall distribution of data for a group, the median may be a better representation. For example, in cases where a few individuals have very high POS (like individuals residing in specialized residential homes), the mean can become inflated.

Table 6. Mean and Median POS of Individuals with a Diagnosis of ASD Living In the Family Home by Race/Ethnicity in CY 2023.

	<b>Mean</b>	<b>Median</b>
<b>Ages 0-13 years</b>		
African American	\$5,148	\$4,656
Asian	\$4,517	\$3,825
Hispanic	\$4,235	\$3,652
Other	\$3,920	\$3,403
White	\$4,712	\$3,523
<b>Ages 14-17 years</b>		
African American	\$6,914	\$6,870
Asian	\$5,806	\$5,019
Hispanic	\$6,074	\$5,491
Other	\$5,007	\$4,545
White	\$5,551	\$4,497
<b>Ages 18-21 years</b>		
African American	\$10,220	\$9,072
Asian	\$8,583	\$7,055
Hispanic	\$8,528	\$7,471
Other	\$6,511	\$5,679
White	\$8,543	\$6,249
<b>Ages 22+ years</b>		
African American	\$22,707	\$20,334
Asian	\$22,557	\$20,180
Hispanic	\$17,912	\$15,318
Other	\$19,149	\$15,453
White	\$20,352	\$16,361

Source: Client Master File and State Claims File for individuals with Status 2, 3, and U as of Calendar Year 2023. In-home is defined as individuals with residence type code of 11 (home of parent/family/guardian), 78 (foster home), 79 (family home under a family home agency), and 80 (certified foster home) as of each month in the CY. Data were extracted March 18, 2024.

For respite services, which are the most commonly used service type for individuals with a diagnosis of ASD across all age groups, there are small differences in POS across race/ethnicity groups.

Table 7. Mean POS and Median POS of Individuals with ASD with Respite Usage by race and ethnicity in CY 2023

	<b>Mean</b>	<b>Median</b>
<b>Ages 0-13 years</b>		
African American	\$7,683	\$6,611
Asian	\$6,646	\$5,219
Hispanic	\$7,548	\$6,340
Other	\$6,777	\$5,354
White	\$6,548	\$5,014
<b>Ages 14-17 years</b>		
African American	\$7,654	\$5,943
Asian	\$6,675	\$4,985
Hispanic	\$7,601	\$5,988
Other	\$6,689	\$5,000
White	\$6,822	\$5,045
<b>Ages 18-21 years</b>		
African American	\$7,260	\$5,643
Asian	\$7,683	\$5,783
Hispanic	\$7,950	\$6,316
Other	\$7,430	\$5,505
White	\$6,961	\$5,381
<b>Ages 22+ years</b>		
African American	\$9,593	\$7,936
Asian	\$9,442	\$7,891
Hispanic	\$9,214	\$8,031
Other	\$9,505	\$7,341
White	\$10,063	\$7,332

Source: Client Master File and State Claims File for individuals with Status 2, 3, and U as of Calendar Year 2023. Respite is defined as service codes: 420, 864 and 862. Data were extracted March 18, 2024.

Personal assistance (service code 062) is the second highest ranked service type by POS for individuals under the age of 22. For this service type, there are large differences between the mean and median values for each group, indicating there may be small numbers of individuals with very high utilization of the service (Table 8).

Table 8. Mean POS and Median POS of Individuals with ASD with Personal Assistance Usage by Race/Ethnicity in CY 2023

	<b>Mean</b>	<b>Median</b>
<b>Ages 0-13 years</b>		
African American	\$14,335	\$8,508
Asian	\$17,638	\$13,884
Hispanic	\$15,426	\$11,287
Other	\$14,356	\$8,713
White	\$18,458	\$12,631
<b>Ages 14-17 years</b>		
African American	\$15,799	\$10,283
Asian	\$14,562	\$10,050
Hispanic	\$17,740	\$11,536
Other	\$16,860	\$11,877
White	\$19,559	\$9,311
<b>Ages 18-21 years</b>		
African American	\$19,779	\$15,283
Asian	\$15,891	\$10,832
Hispanic	\$17,453	\$13,387
Other	\$21,561	\$12,122
White	\$27,914	\$12,877
<b>Ages 22+ years</b>		
African American	\$30,748	\$26,068
Asian	\$32,329	\$27,065
Hispanic	\$27,705	\$20,228
Other	\$43,446	\$25,684
White	\$47,266	\$22,515

Source: Client Master File and State Claims File for individuals with Status 2, 3, and U as of Calendar Year 2023. Personal Assistance is defined as service code 062. Data were extracted March 18, 2024.

# SECTION 3: AUTISM SERVICES BRANCH UPDATE

In addition to conducting research and data tracking related to ASD, the Autism Services Branch supports a variety of projects related to ASD. Updates on these projects, including completed deliverables, are provided below.

## 3.1 COMMUNICATIONS AND TECHNICAL ASSISTANCE

- In September 2023, DDS launched the **Autism Helpline** to respond to inquiries and requests for assistance coming to the Department and related to ASD. The helpline includes an email inbox and phone line that are available for anyone to contact at (833) 815-2337 or [autism@dds.ca.gov](mailto:autism@dds.ca.gov). The Department is also tracking data on the types of communications received through the Autism Helpline, in order to follow emerging trends and to inform the development of informational materials (like FAQs).



Figure 4. Types of Communications Received by the Autism Helpline from September 1, 2023 through February 20, 2024.

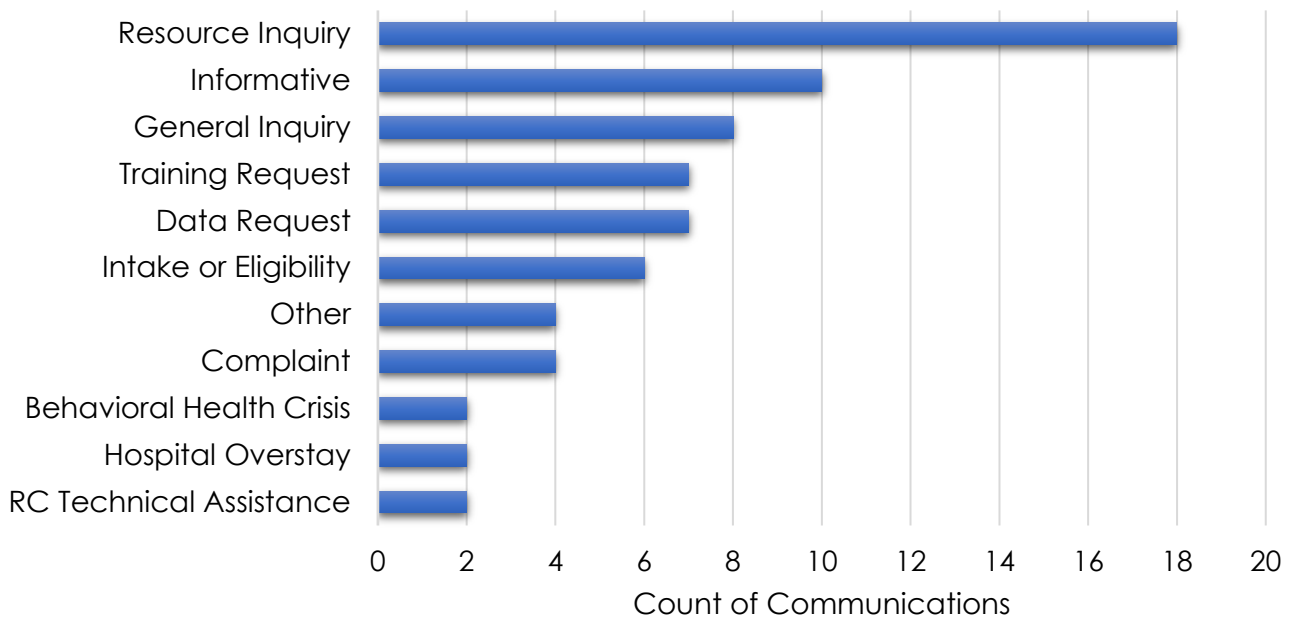
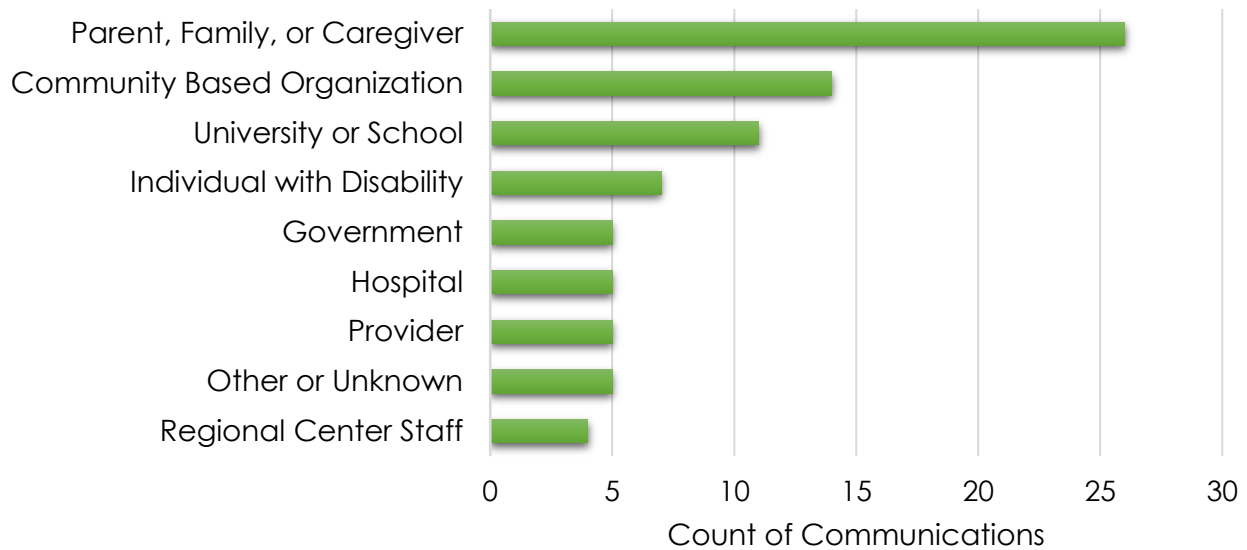


Figure 5. Types of individuals or groups contacting the Autism Helpline from September 1, 2023 through February 20, 2024.



- DDS is currently engaged in building the **Autism Resource Hub** on the DDS website. This site will house resources and information related to ASD and supports and services, as well as FAQs, and informational materials developed in collaboration with system partners.

### 3.2 COMMUNITY ENGAGEMENT

- In 2023, DDS hosted four quarterly meetings of the **Autism Focus Group**. This group is comprised of 14 autistic self-advocates served by RCs across the state, ranging in age from 18 to 49. The primary function of this workgroup is to identify priority areas for evaluation and make recommendations on how to reduce barriers to community inclusion. The meetings in 2023 centered around topics identified as priorities by the group, which included services to support an individual, employment services, and education and transitions. The group reconvened on March 9, 2024 and will continue to meet quarterly throughout the year.
- DDS is planning to host **Family Focus Groups** across the state in 2024 that will bring together families of individuals with developmental disabilities and high support needs. Discussions will center on families' lived experiences and their identification of potential focus areas for service development.
- The Autism Services Branch staff are continuously engaging with the autism community and providing trainings related to ASD statewide. Since July 2023, staff have participated in 8 disability community events and resource fairs and led 10 presentations on ASD for approximately 1,269 attendees. Presentation audiences

have varied from individuals and families, regional centers, other state departments, university trainees and clinicians, and providers.

### **3.3 BUILDING SYSTEM-WIDE EXPERTISE**

- DDS secured an interagency agreement with the UC Davis MIND Institute University Center for Excellence in Developmental Disabilities (UCEDD) to host an ongoing **ECHO Autism** for California professionals, partners, and families. Project ECHO (Extension for Community Healthcare Outcomes) was developed at the University of New Mexico, and is a learning and guided practice model for increasing workforce capacity to provide specialty care and reduce health disparities. The ECHO Autism builds an interdisciplinary learning network across California to train on evidence-based practices through presentations and case-based discussion. The UC Davis MIND Institute and Autism Services Branch staff collaborate to identify topics for each 6-session curriculum that will rotate throughout each year. Example topics include Early Intervention, Mental Health, and Co-occurring Medical Conditions. The ECHO Autism is offered to participants free of charge.
- In summer 2023, the Autism Services Branch and Clinical Services Branch teams began meeting with the ARCA Psychology Collaborative clinicians to update the **Autism Spectrum Disorders: Best Practices Guidelines for Screening, Diagnosis, and Assessment** (2002) publication. This publication will provide detailed best practice recommendations for screening, evaluating and assessing individuals for a diagnosis of ASD. The project is ongoing in 2024, in partnership with regional center psychologists and clinical experts from the UCEDDs and other California university autism centers.