



APRIL
2015

A Report on the Increasing Autism Rates in California

This report is an attempt to enrich community understanding of California's increasing autism rates by bringing to light important data from our public agencies.

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1. Executive Summary

This report is an attempt to enrich community understanding of California's increasing autism rates by bringing to light important data, primarily from California's Department of Developmental Services (DDS), the state agency that provides services to residents with developmental disabilities, mainly through the system of 21 nonprofit regional centers located throughout the state. As explained in the next section, autism cases entered into the DDS system (what the report terms "DDS autism") represent just a portion of the overall clinically-defined population, and typically encompasses the more substantially disabled end of the spectrum.

Because of the entitlements and case-finding provisions of its unique Lanterman Act¹, California is routinely acknowledged as maintaining the most robust and reliable statewide population autism and developmental disability data in the country. While the data is not perfect — consensus holds that the DDS system omits a portion of the state's overall clinically-defined autism population² and that eligibility criteria vary slightly by region — the case information in DDS databases is detailed, subject to ongoing review, and based on probing eligibility assessments that have grown more stringent over time. While the DDS data may not provide exact reflections of autism growth patterns, they paint a sufficiently thorough picture from which reasonable people can draw reasonable conclusions about growth and implications for public policy³.

A summary of key data is as follows:

- **DDS autism cases now surpass 76,000.** The DDS autism caseload stood at 2,701 in 1987, but in late 2014 surpassed 75,000 cases, and as of the date of this report, 76,000. This represents a 28-fold increase over 28 years. Sixteen years ago, DDS had considered 1998's autism caseload of slightly more than 11,000 a number of considerable concern, but now the volume nears seven times that level.
- **DDS intake is now reflecting nearly 5,000 DDS autism births per year.** Prior to the 1980s, DDS autism cases reflected an underlying count of 200 or fewer autism births per year. Today the number is nearing 5,000 such births per year feeding into the DDS system, a 25-fold increase over birth rates three decades ago. In addition, about 1.2% of all male births (2008 birth year sample) in California now result in DDS autism. In 1987, that rate was .017%.

- **DDS autism cases run at a rate about 59% of autism cases identified by special education.** Based on a comparison of DDS autism cases by birth year to California special education autism cases of the same birth year, it appears that DDS autism rates represent a population of approximately 59% of the size of the population identified in special education.
- **Autism occupies an increasing portion of the overall DDS caseload.** Autism intakes now represent about 70% of all DDS intakes. By contrast, in 1987, autism represented just 4.85% of the entire DDS caseload.
- **Adult DDS autism cases are poised to double in the next five years and triple in the next ten.** The DDS autism population aging out of school at age 22 is of particular importance to DDS, since the costs for support generally shift from school districts to the regional centers at that time. DDS autism 22+ caseload, if projected over time, will double over the next five years and triple over the next ten years, to about 42,000 cases at the end of 2025.
- **Regional center costs to support DDS adults with autism will soar.** Based on the most conservative estimates, that is, current averages for purchase of services for DDS autism adults, regional center annual costs to serve DDS autism adults (aged 22+) will nearly triple over the next ten years, to about \$1.2 billion.
- **The greater Bay Area experienced a more than 15-fold increase in its counties' DDS autism caseload between 1990 and 2014.** The Bay Area is now home to about 12,000 DDS autism cases, up from 754 in 1990.
- **Currently, about 94% of DDS autism cases statewide reside at home** with parents or family.

Implications:

- In light of the expected tripling of our more-severe adult autism population over the next decade, current efforts to strengthen California's faltering developmental services system⁴ are urgent.
- As autism extends to occupy an ever-growing portion of the DDS caseload, day programs and supports that serve adults with autism, particularly those with complex behavioral needs, must be developed or expanded.

- Policymakers should also understand the enormous wave of autism growth in the state means a substantial boost in community-based supported housing will be necessary to serve this burgeoning population incapable of caring or providing for itself.
- California's public health resources, including surveillance, reporting, and research efforts, should be immediately directed to further illuminate growth trends, to help project future service needs, and to help ascertain possible causes of this debilitating and costly neurodevelopmental disorder.

2. Definitions

This report focuses primarily on the neurodevelopmental disorder of autism as it exists within California's DDS system. DDS-defined autism involves substantial levels of impairment that may not be present in all individuals clinically diagnosed with autism.

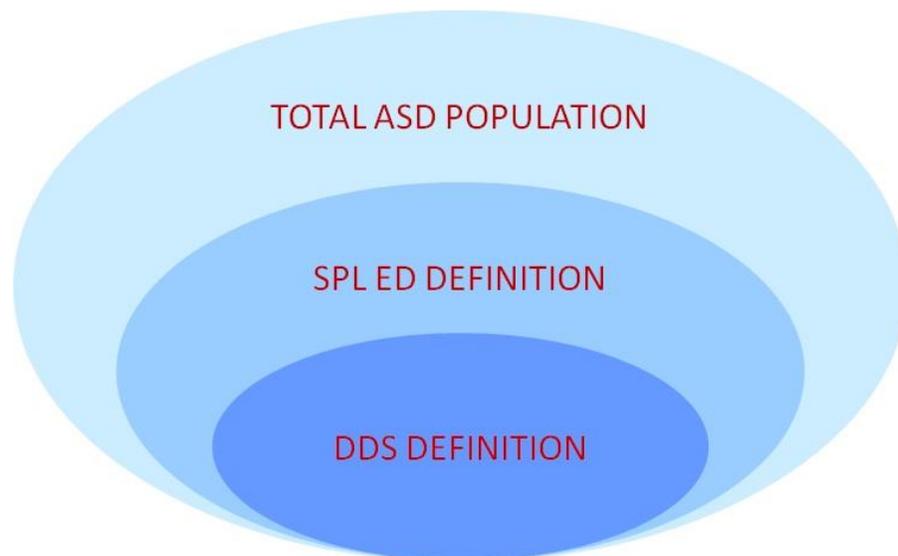


Figure 1: This report focuses on autism as it exists within California's DDS system rather than the more broadly defined clinical or special education populations. This image is a conceptual representation of the DDS subset and does not reflect comparative incidence.

Definition of DDS Autism. DDS provides services to persons with developmental disabilities who fall under five eligibility categories: cerebral palsy, epilepsy, autism, intellectual disability, and other conditions closely related to intellectual disability. Aside from meeting diagnostic criteria for autism, the applicant must also have a level of impairment that rises to the level of a "developmental disability," which is defined as a non-physical disability that originates before an

individual attains 18 years of age, is expected to continue indefinitely, and constitutes a substantial disability. (Welfare & Institutions Code sec. 4512(a)) As of August of 2003, the bar for “substantial disability” was heightened to require that the person must also exhibit significant functional limitations in at least three of these areas (previously it had been one area), as determined by a regional center, and as appropriate to the age of the person: (1) Self-care; (2) Receptive and expressive language; (3) Learning; (4) Mobility; (5) Self-direction; (6) Capacity for independent living; and (7) Economic self-sufficiency. (Id. sec. 4512(l))

Definition of Autism in Special Education. The special education definition of autism is generally acknowledged to encompass a broader array of disabilities, including impairments considered to be milder than those in the DDS system. For purposes of establishing eligibility for special education services in California, autism is defined as follows:

Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, and adversely affecting a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. (34 CFR 300.8(c)(1)(i))

Definition of autism in clinical application. For the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) diagnostic criteria, please refer to the Autism Speaks website at: <https://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria>

It is unknown at this time what percentage of clinically-defined autism is included within the DDS system.

3. DDS autism caseload, 1987-2014

DDS Autism Caseload	
1987	2,701
1988	2,944
1989	3,262
1990	3,629
1991	4,026
1992	4,446
1993	4,825
1994	5,446
1995	6,179
1996	7,006
1997	8,179
1998	9,587
1999	11,233
2000	13,054
2001	15,441
2002	18,460
2003	22,040
2004	25,020
2005	28,046
2006	31,012
2007	34,656
2008	38,656
2009	46,686
2010	52,900
2011	57,900
2012	63,126
2013	68,631
2014	75,221
Source: CA DDS	

Figure 2: DDS autism caseload, 1987-2014

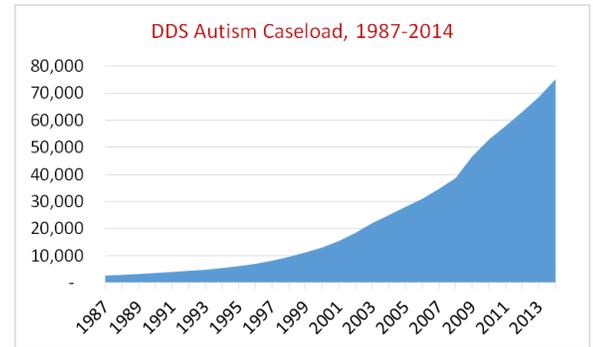


Figure 3: DDS autism caseload, 1987-2014

Autism was first included as an eligible category served by California's developmental services system in 1971. By 1987, DDS counted 2,701 autism cases. At the end of 2014, the caseload surpassed 75,000. Today, the number exceeds 76,000, representing a 28-fold increase from 1987 counts. In other words, for every one Californian identified with DDS-eligible autism in 1987, there are about 28 today. Sixteen years ago, DDS had considered 1998's autism caseload of slightly more than 11,000 a number of considerable concern, but now the volume nears seven times that level.⁵

4. DDS autism current cases, by birth year, 1931-2010

Current DDS Autism Cases, by Birth Year 1931-2010							
1931	1	1951	33	1971	141	1991	1,476
1932	1	1952	48	1972	129	1992	1,741
1933	1	1953	55	1973	150	1993	1,768
1934	4	1954	64	1974	173	1994	1,967
1935	1	1955	87	1975	178	1995	2,122
1936	2	1956	70	1976	199	1996	2,187
1937	2	1957	109	1977	189	1997	2,326
1938	4	1958	116	1978	246	1998	2,474
1939	2	1959	102	1979	256	1999	2,525
1940	3	1960	124	1980	243	2000	2,854
1941	10	1961	133	1981	324	2001	3,128
1942	3	1962	143	1982	347	2002	3,338
1943	14	1963	147	1983	381	2003	3,699
1944	11	1964	143	1984	443	2004	3,789
1945	13	1965	152	1985	511	2005	3,904
1946	15	1966	164	1986	585	2006	4,051
1947	24	1967	149	1987	684	2007	4,335
1948	30	1968	172	1988	797	2008	4,625
1949	36	1969	139	1989	1,033	2009	4,444
1950	39	1970	172	1990	1,227	2010	4,395

Source: California Dept. of Developmental Services, data as of January 2015

Figure 4: DDS autism current cases, by birth year, 1931-2010

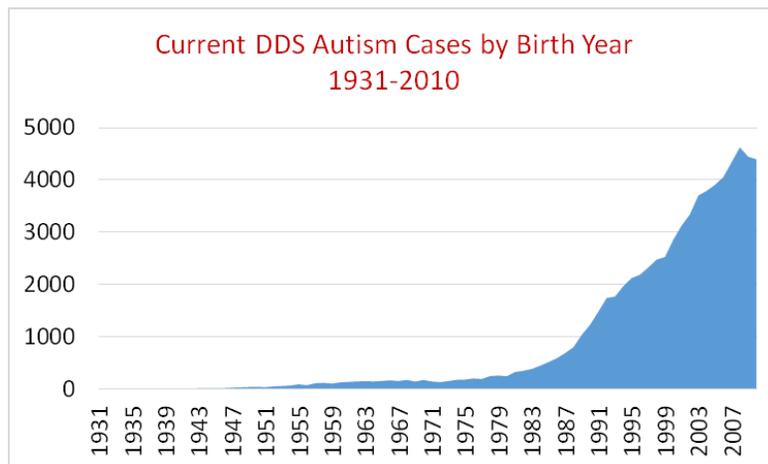


Figure 5: DDS autism current cases, by birth year, 1931-2010

Births of individuals later deemed to have DDS-eligible autism have been increasing sharply every year since the early 1980s. Typically intake into the system occurs between 2 and 7 years of age. The data reflects about 200 DDS autism births per year into the 1980s, but now the system is reflecting nearly 5,000 such births per year. The drop off in cases after birth year 2008 is likely attributable to usual delay in cases entering the system, and likely does not represent an actual decrease in DDS-eligible autism cases.

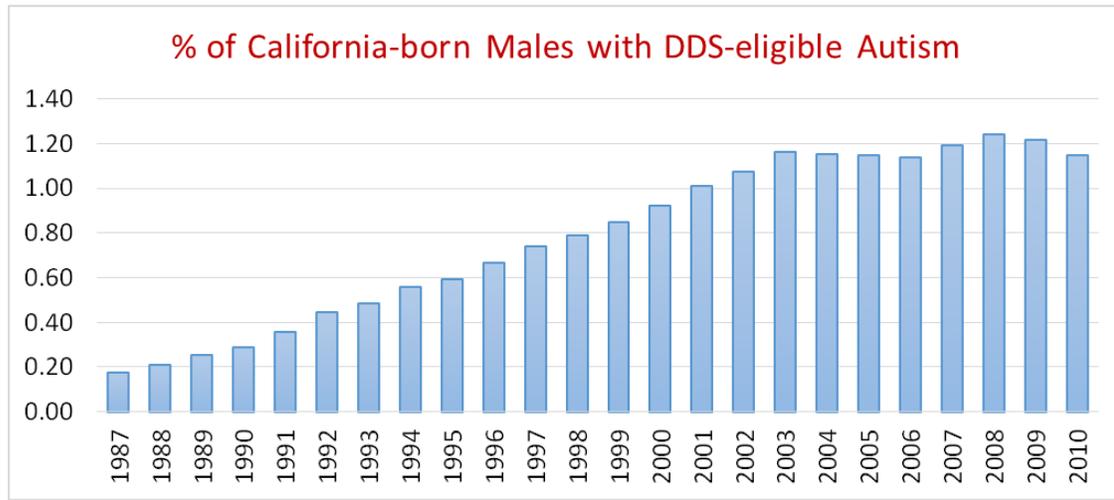


Figure 6: Percentage of California-born males with DDS-eligible autism (Source: California Department of Public Health)

Comparing California-born DDS male autism cases by birth year (birth year 2008) to all live male births (excluding perinatal deaths) in the state, we see a male autism rate of more than 1.2%. For females, the rate is approximately .3%. For all births, approximately .8% yielded eligible autism cases. To compare, for birth year 1987, the rate of California male births resulting in DDS autism was .017%, .004% of females, and .01% all cases.

5. DDS autism cases as percent of total DDS caseload

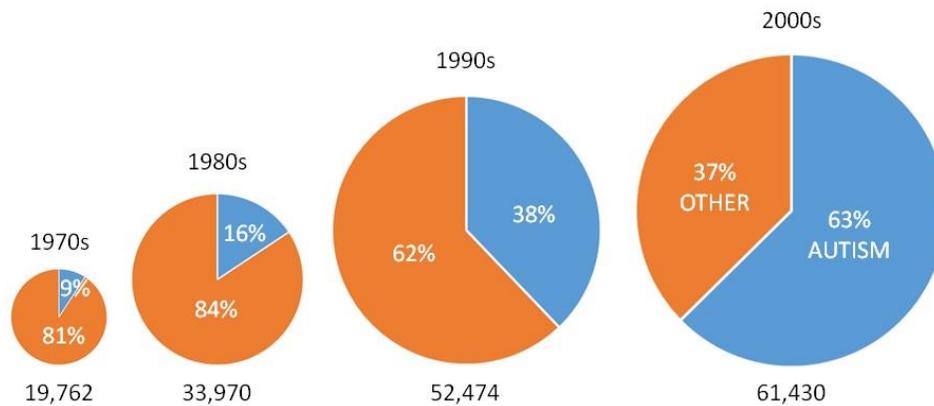


Figure 7: DDS autism cases as percent of total DDS caseload, by decade.

Before the 1980s, autism was a rare disorder occupying less than 5% of the developmental services caseload. Of the intakes in the 2000s, however, 63% were autism. Today, autism intakes into the DDS system represent about 70% of all DDS intakes, and have grown to occupy more than 30% of the overall DDS caseload.

6. DDS autism adult population projected increase and projected costs

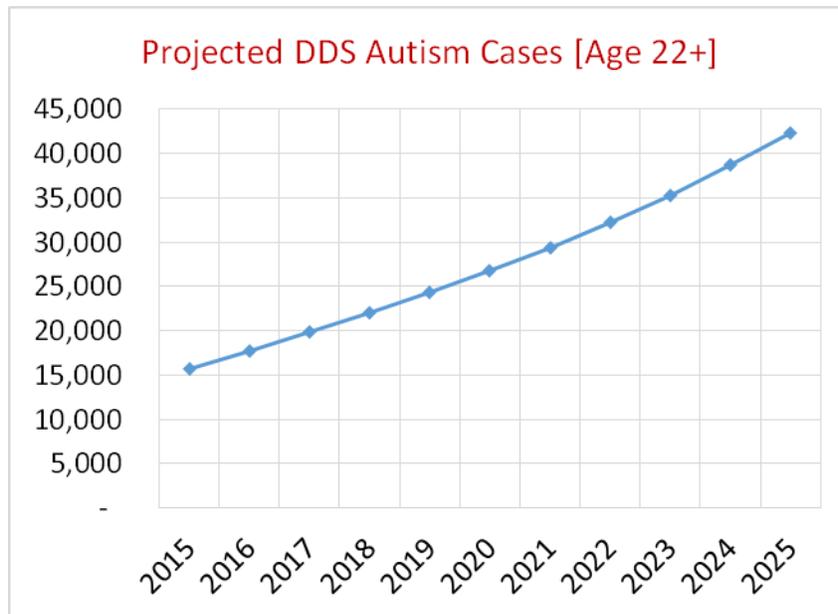


Figure 8: Projected DDS adult autism cases through 2025, 22+ years old, based on current caseload counts.

For practical purposes this report defines “adult” at the 22nd birthday, the time at which individuals with autism age out of the school system, pursuant to IDEA, the Individuals with Disabilities Education Act. At age 22, California’s regional center services become the primary source of programs and support for individuals with autism. The DDS adult autism population was about 14,000 at end of 2014. Based on projecting current DDS cohorts over the next ten years, we can see that DDS adult autism cases will double over next five years, and will triple over next ten years, to about 42,000 cases in 2025. Currently, California is nearing 2,000 DDS autism age-outs every year; this will near 4,000 annual age-outs by 2025, based on current caseload numbers.

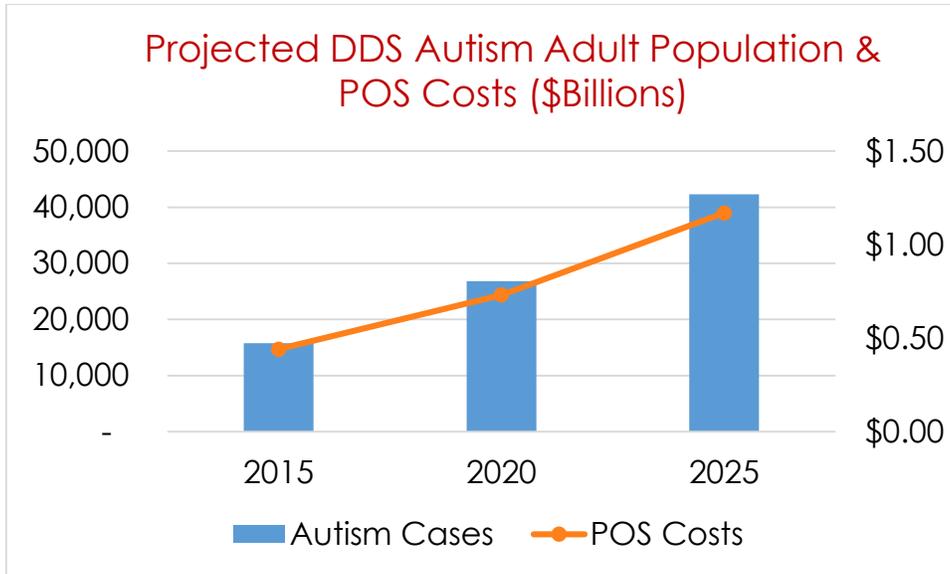


Figure 9: Projected DDS POS costs for adult autism caseload supports.

Regional center costs to support DDS adults with autism will surpass \$1 billion based on the most conservative estimates grounded in current dollars spent on adult autism cases. Based on current averages for purchase of services for DDS autism adults, regional center annual costs to serve DDS autism adults (aged 22+) will nearly triple over the next ten years, from about \$441 million today to about \$1.2 billion. These costs do not include non-regional center costs such as parent out-of-pocket expenses, In-Home Support Services (IHSS), Social Security, or housing assistance. Actual regional center costs will likely surge beyond current averages as parents age and as increasing portions of the DDS autism adult population move outside the family home, requiring housing and ongoing support, and as cost of living increases.

7. DDS autism cases compared to special education autism cases

DDS vs SP. ED. Autism Cases by Birth Year				
Birth Year	Age in 2013	Sp. Ed. Cases	DDS Cases	% DDS of Sp. Ed.
2003	10	6,289	3,699	59%
2002	11	5,669	3,338	59%
2001	12	5,335	3,128	59%
2000	13	5,034	2,854	57%
1999	14	4,568	2,525	55%
1998	15	4,339	2,474	57%

Figure 10: DDS v Special Education autism cases, in year 2013, by birth year for ages 10-15. (Sources: California Department of Education Datquest and California DDS)

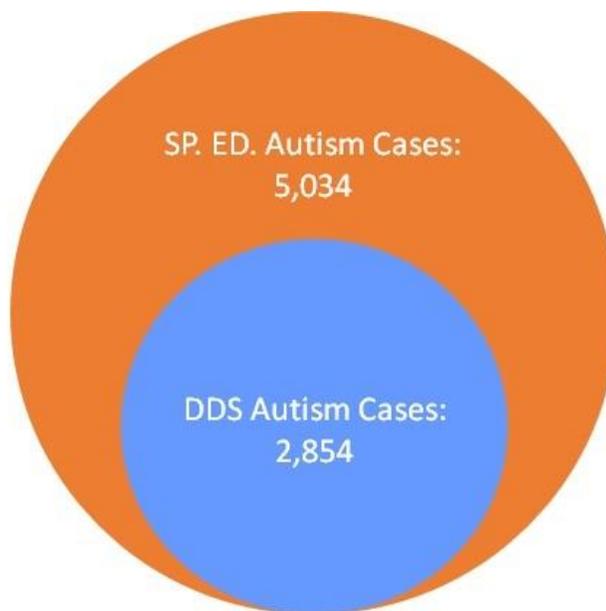
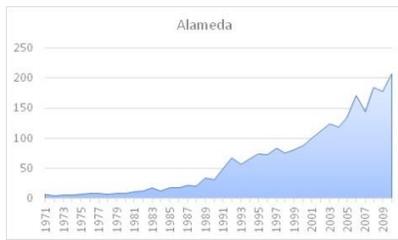


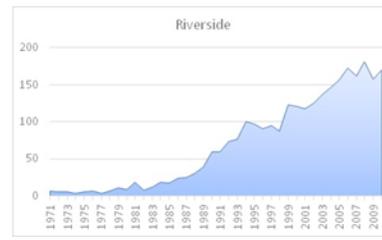
Figure 11: Sample: DDS v Special Education autism cases for birth year 2000.

Based on a comparison between DDS autism cases by birth year, and special education autism cases by the same birth years, about 59% of the number of special education autism cases are enrolled in the DDS system (note there may be some DDS autism cases not enrolled in the special education system). The most relevant years for ascertaining this comparison are ages 10-15, after the process of identification is largely complete and before students begin to exit the school system.

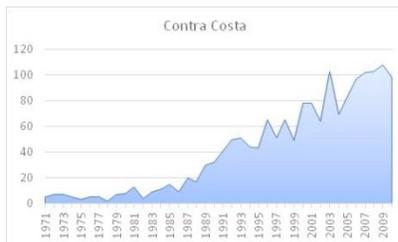
8. Current DDS autism cases, by birth year and current county of residence, with cumulative caseload



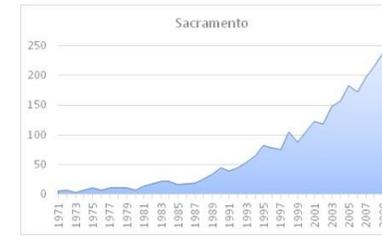
Alameda 2014 Caseload: 2,989.



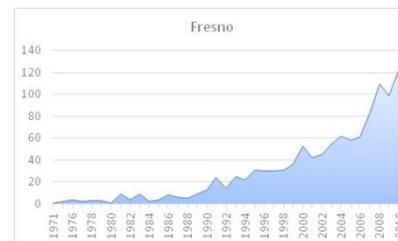
Riverside 2014 Caseload: 3,114.



Contra Costa 2014 Caseload: 2,027.



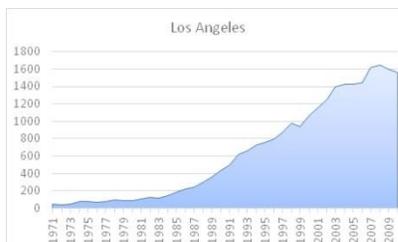
Sacramento 2014 Caseload: 3,041.



Fresno 2014 Caseload: 1,295.



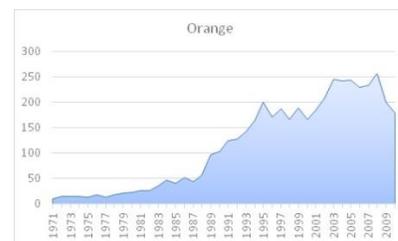
San Bernardino 2014 Caseload: 3,137.



Los Angeles 2014 Caseload: 27,915.



San Diego 2014 Caseload: 5,804.



Orange 2014 Caseload: 4,938.



Santa Clara 2014 Caseload: 3,151.

Figure 12: DDS autism cases, by birth year, in the ten most populous counties, with cumulative caseloads for those counties.

The striking surge in DDS autism rates, as reflected by birth year, is fairly consistent across counties, showing an increase in autism births in the early 1980s. DDS autism cases now tend to represent about .195 percent of overall county population, based on comparing 2014 DDS autism caseload with 2013 census figures. A notable exception is Los Angeles County, home to about one-third of the DDS autism cases, nearly 28,000 of 76,000 statewide cases, despite having about one-quarter of the state population. Its DDS autism cases represent .279 percent of its overall county population. This may be due to unknown demographic or biological factors, higher case ascertainment rates, and/or other factors.

9. DDS autism cases, children v adults, in ten most populous counties

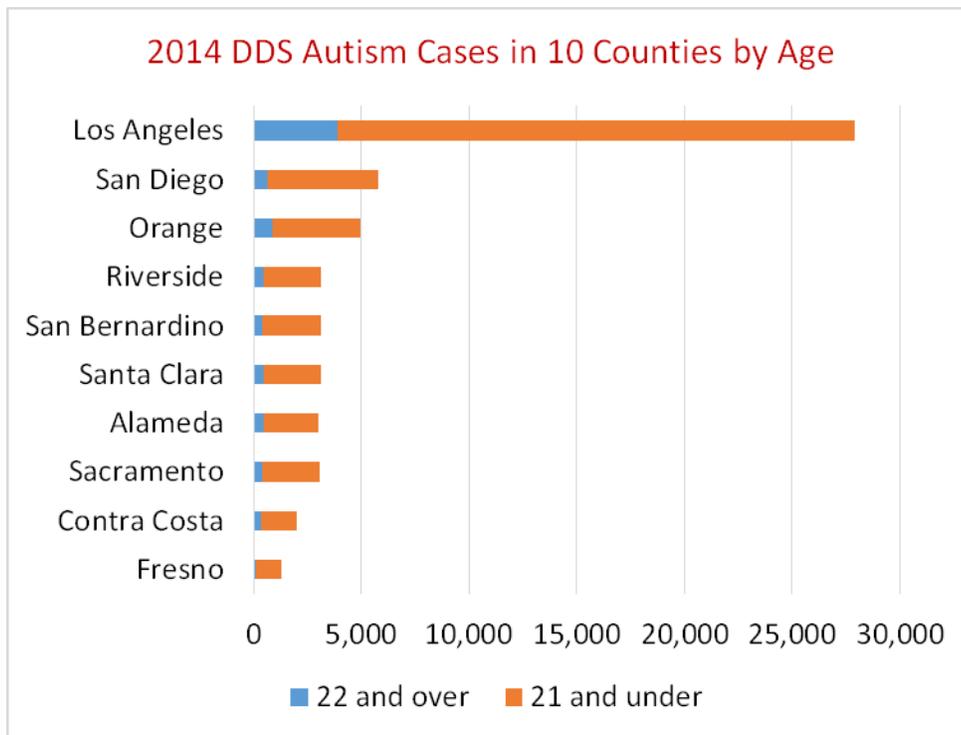


Figure 13: DDS autism cases, children (ages 3-21) v adults (ages 22+), in the ten most populous counties.

More than 80% of California's DDS autism population is aged 21 and under, a pattern that is fairly consistent across the counties.

10. Change in DDS autism cases, greater Bay Area, 1990 v 2015

DDS Autism Cases, Bay Area Counties, 1990 v 2015			
	1990	2015	% increase
Alameda	190	2,989	1573%
Contra Costa	117	2,027	1732%
Marin	58	163	281%
Napa	11	252	2291%
San Francisco	67	568	848%
San Mateo	71	748	1054%
Santa Clara	147	3,151	2144%
Santa Cruz	20	276	1380%
Solano	64	718	1122%
Sonoma	67	827	1234%
Greater Bay Area	754	11,719	1554%

Figure 14: Change in DDS autism cases, greater Bay Area, 1990 v 2015.

The greater Bay Area experienced a more than 15-fold increase (1,554%) in its counties' DDS autism caseload between 1990 and 2015. The Bay Area is now home to about 12,000 DDS autism cases, up from 754 in 1990.

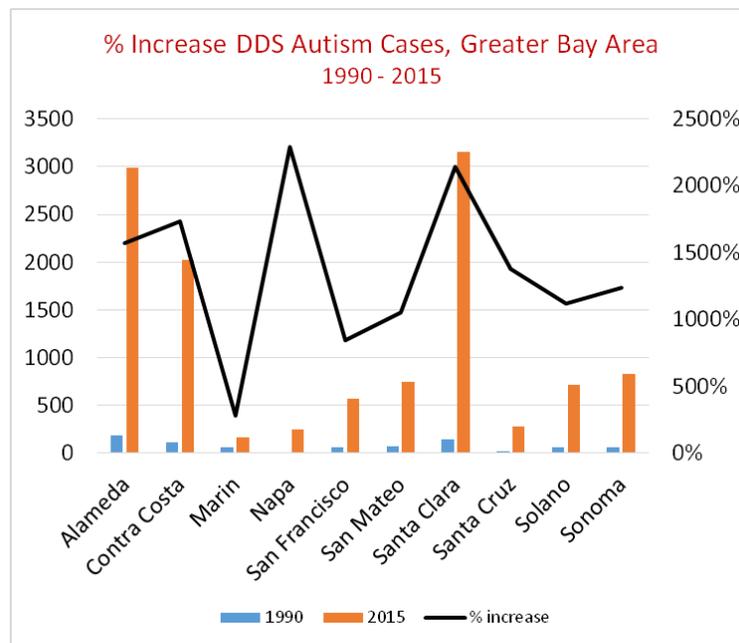


Figure 15: Increase in DDS autism cases in counties in the greater Bay Area, 1990-2015, with % increase.

11. Current Residence Type for DDS Autism Cases

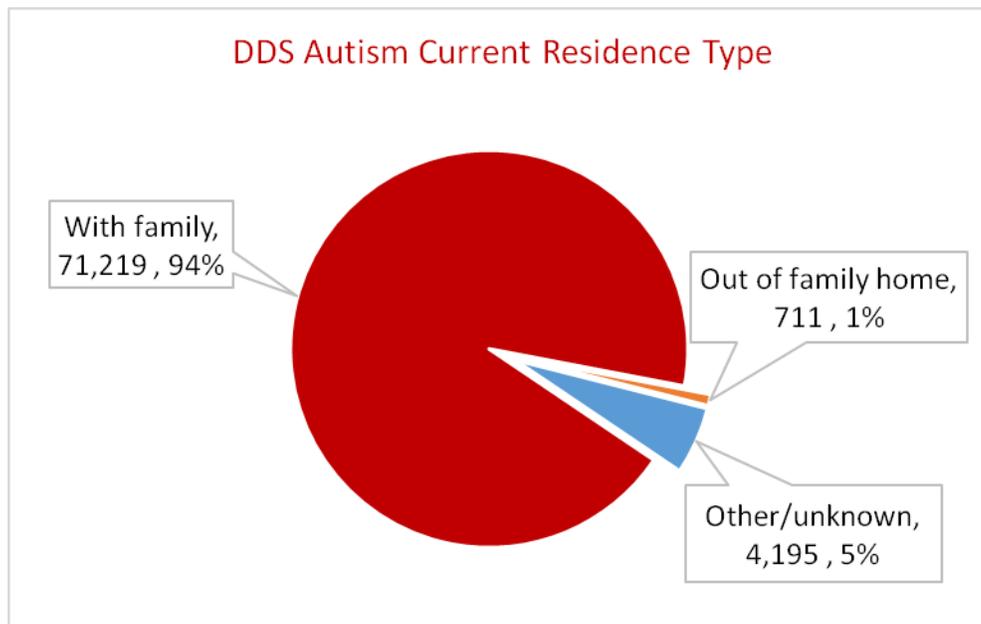


Figure 16: DDS autism by current residence type.

Only 1% of California's DDS autism population are documented to live apart from parents or family, and at least 94% remain at home with parents or family. As DDS autism school age-outs approach 2,000 cases per year, and as autism parents age and become less capable of providing daily care, it can be expected that pressure to increase housing options for DDS autism adults will increase each year.

12. Implications

California's developmental services system has experienced a staggering increase in cases of autism, a demographic phenomenon that carries profound implications for California's future, given the severe functional limitations presented by individuals with this level of disability. To address the unprecedented challenges before us:

We must actively plan for the intensive needs of this growing adult population. The influx of adult DDS autism cases, combined with the declining ability of parents to provide care, will require a structural overhaul and significant bolstering of our developmental services system. Current community resources are already documented as insufficient to address even the current population.

Of particular importance are: day programs and supported employment tailored to the often-intensive needs of adult autism; a wide array of community-based supported housing opportunities; and more robust case management as aging parents become increasingly incapable of providing oversight, abuse prevention, and care.

Public health resources should be deployed to provide ongoing surveillance, reporting, and research into the nature and extent of disabling autism in our state in order to guide reasonable and responsive planning and policy efforts.

California must take a leadership position on this national public health crisis. We should use our position as the nation's most populous state, and the one maintaining the most reliable and thorough autism population data, to strongly articulate the shape and scope of the crisis at the federal level.

13. Sources

- California Department of Developmental Services, birth cohort and caseload data, pursuant to Public Records Act requests, data received January 29, 2015 and March 27, 2015
- California Department of Developmental Services, CDER, <http://www.dds.ca.gov/FactsStats/Home.cfm>
- California Department of Developmental Services, Autistic Spectrum Disorders: Changes in the California Caseload, an Update: June 1987-June 2007, 2008
- California Department of Developmental Services, Autistic Spectrum Disorders: Changes in the California Caseload, an Update: 1999-2002, April 2003
- California Department of Developmental Services, Fact Book, 12th Edition, January 2015. http://www.dds.ca.gov/FactsStats/docs/factBook_12th.pdf
- California Department of Education, DataQuest, <http://dq.cde.ca.gov/dataquest/> (reporting cycle December 1, 2013)
- California Department of Public Health, prevalence data by gender, pursuant to Public Records Act request, data received April 14, 2015
- United States Census Bureau, 2013 population data. <http://www.census.gov/popest/data/state/totals/2013/index.html>

14. Acknowledgments

We wish to thank DDS staff, especially Nancy Lungren, for responding to our Public Records Act requests, the members of the Bay Area Adult Autism Collaborative for sharing their insights and information, and James Chung for his database work.

1. Lanterman Developmental Disabilities Services Act and related laws are found at Divisions 4.1, 4.5, and 4.7 of the Welfare and Institutions Code and Title 14 of the Government Code.
2. We note that DDS has somewhat disputed our characterization that it encompasses only a subset of the clinically defined California autism population, emphasizing that the 21 DDS-commissioned nonprofit regional centers, which perform the eligibility assessments pursuant to the Lanterman Act, do a tremendous amount of outreach in their communities to educate families and assess potential cases of autism. The internal data system, called CDER, has been overhauled, the DDS system population was reassessed over a three-year span, and new changes to the DSM were incorporated. (For further information about intake and eligibility, please see the DDS website at www.dds.ca.gov.) That said, it is common knowledge that clinically diagnosed autism cases are routinely turned away from regional centers as not exhibiting sufficiently incapacitating disability. In addition, based on a comparison of DDS autism cases by birth year to same birth year California Special Education autism cases, it appears that DDS autism represents approximately 59% of the special education-defined autism population.
3. We noted minor discrepancies between some of the DDS data obtained we obtained via Public Records Act requests and data published in various DDS and other state materials. Most likely these small differences (for example, in autism cases in any given year) are due to variations in time the data was collected. None of these discrepancies were significant and they should not distract from the broader picture presented. Unless otherwise noted, the source of all data represented in this report is DDS.
4. See "On the Brink of Collapse," Association of Regional Center Agencies, March 2015
5. Department of Developmental Services, Changes in the Population of Persons with Autism and Pervasive Developmental Disorders, in California's Developmental Services System: 1987 through 1998, March 1999.