




Autism in California 2020

A report to the public

Commissioned by the
Autism Society San Francisco Bay Area
Based on California Department of Developmental Disabilities data



More than 2 decades ago, autism cases began to increase

More than two decades ago, California began to recognize a surprising increase in autism cases in its Department of Developmental Services (DDS) system. In 1999, DDS issued a report that showed a startlingly rapid rise over the previous decade in the number of persons receiving services for autism. The DDS is the California agency that is responsible for coordinating services for persons of all ages with qualifying developmental disabilities. In 1999 it reported that its caseload of the most severe form of autism had increased from 3,864 to 11,995, a 210% increase, far greater than the increases in other developmental conditions. The agency concluded, referring to its autism caseload:

“...the number of young children coming into the system each year is significantly greater than in the past, and that the demand for services to meet the needs of this special population will continue to grow.”

—*California DDS 1999*

In 2003, the DDS issued an update, which demonstrated that the rise in the caseload had not only continued unabated, but was becoming steeper every year.

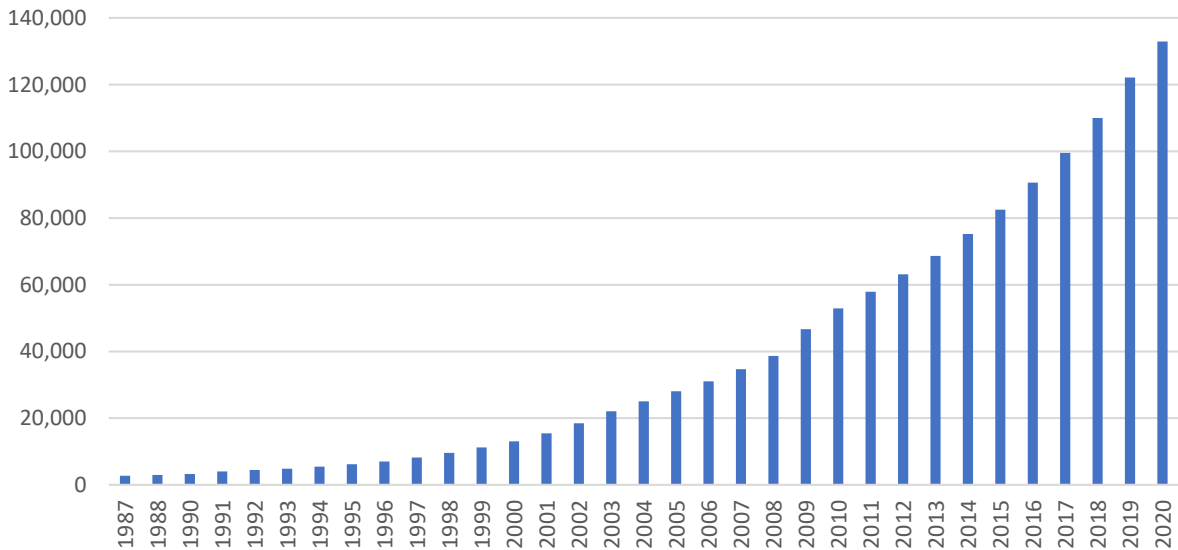
In 2007, another DDS report documented the continuing dramatic increase in the autism caseload, noting that “the number of persons with autism being served by the regional centers rose 26 times faster than that of the general California population.”

In 2009, scientists at the UC Davis MIND Institute analyzed the California autism prevalence and incidence (i.e., new diagnoses) rates based on the DDS data and all births in the state. Comparing children born from 1990 to 2002, they confirmed a continuing increase in rates of autism diagnoses that was substantial — a 600% rise — and determined that this growth could not be explained by changes in the underlying population or changes in the way autism was diagnosed.

Now, nearly 20 years after that period, DDS data reflects a continuing upward surge in autism in the state. The purpose of this report is to help bring the public—including individuals and families affected by autism, service providers, and local, state, and federal policymakers—up to date about this urgent public health issue that seldom receives the attention it warrants.

The increase continues

DDS Autism Caseload 1987 - 2020



Source: DDS

Increasing numbers of cases every year



1 in 54



U.S. children 8 years old
in 2016 have ASD

CDC report, 2020

This report extends the analysis of prevalence to the present day and broadly examines the impacts of autism, including for persons who are directly affected, for their families, and for the larger society.

California Department of Developmental Services: DDS

Provides services and support to California residents with:

- Cerebral Palsy
- Epilepsy
- **Autism**
- Intellectual Disability
- Other conditions closely related to intellectual/cognitive disability

Brief history of autism in the DDS:

1978
CA creates new Department of Developmental Services (DDS)
State moves administration of developmental services from the Dept. of Health to newly created DDS.

1990
Americans with Disabilities Act (ADA)
Federal civil rights law prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public.

1995
Autism increase
DDS begins documenting steady rise in individuals diagnosed with autism.

2001
ASD initiative
DDS launches Autism Spectrum Disorder (ASD) Initiative.

2002
Best practice guidelines
DDS publishes Best Practice Guidelines for screening, diagnosing and assessment of autism.

2007
California autism caseload continues to rise
DDS reports the caseload for autism is 38,000, rising at a rate of 13.4% per year for the previous 5 years. Projects caseload of 70,000 by mid- 2012.

1969
Lanterman act
California law establishes that people with developmental disabilities and their families have a right to the services and support they need in order to live like people who don't have disabilities.

1980
Regional centers
DDS transfers all responsibility for placement, case management and monitoring of clients in residential placement to regional centers throughout California

1993
Early intervention
DDS implements California Early Interventions Services Act requiring statewide services for eligible infants and toddlers from birth to 36 months.

1999
Alarming rise in autism
In a report to the CA State Legislature, DDS documents a large, unexpected increase in individuals seeking services for autism within the regional center system.

2001
Assembly bill 430
Establishes the need for the same diagnostic tools and same diagnostic methods to ensure consistency and accuracy of diagnosis of autism and other pervasive developmental disorders throughout CA.

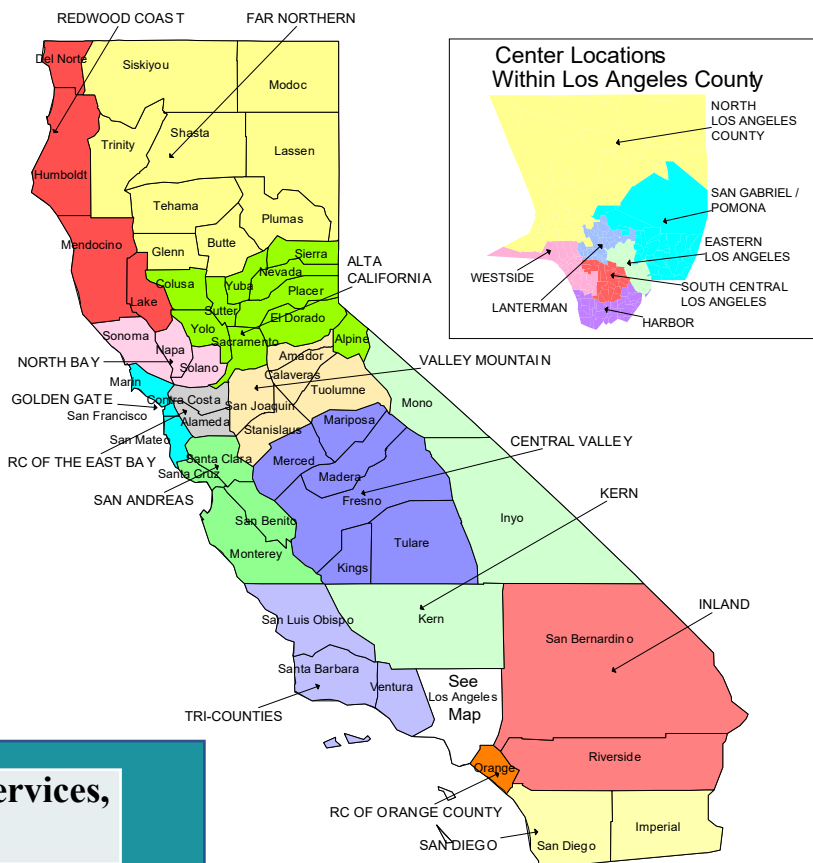
2003
Autism trends
DDS reports a continuing rapid rise in autism cases from 1990-2002. 3,800 new cases diagnosed in 2002.

2020 Alarming trend continues
DDS reports nearly 133,000 current autism cases, an increase of over 10,000 from 2019.

DDS autism cases

Department of Developmental Services Regional Centers

(Colors correspond to areas served by each Regional Center)



21

Regional Centers provide DDS services to eligible California residents

To be eligible for DDS services, autism cases must:

1. Meet diagnostic criteria for autism (ASD beginning 2013)
2. Exhibit significant functional limitations in at least 3 of 7 areas:
 - Self-care
 - Receptive and expressive language
 - Learning
 - Mobility
 - Self-direction
 - Capacity for independent living
 - Economic self-sufficiency
3. Have had the condition before the age of 18



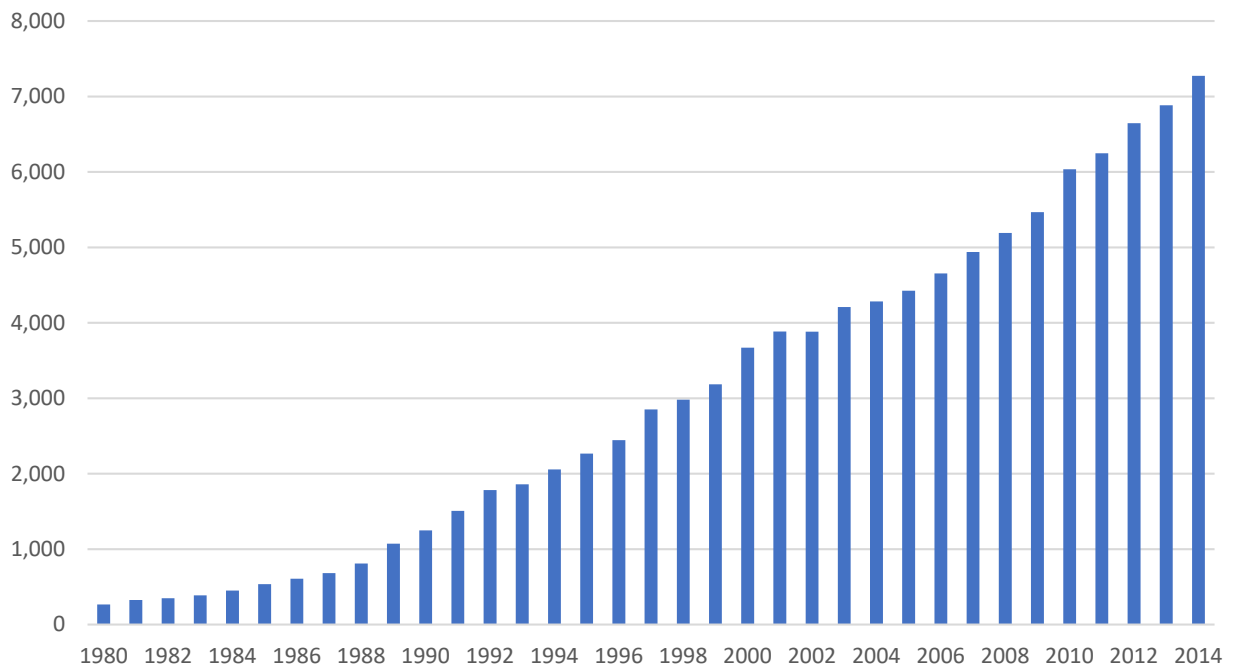
DDS autism cases:

Typically are the more substantially disabled among those on the autism spectrum. (Lake, 2014).

Eligibility was further restricted in 2003 when 3 areas of significant functional limitation were required. Prior to 2003 the requirement was not specific.

Large, steady rise in autism cases every birth year

Numbers of DDS autism cases in 2019 by birth year



Source: DDS

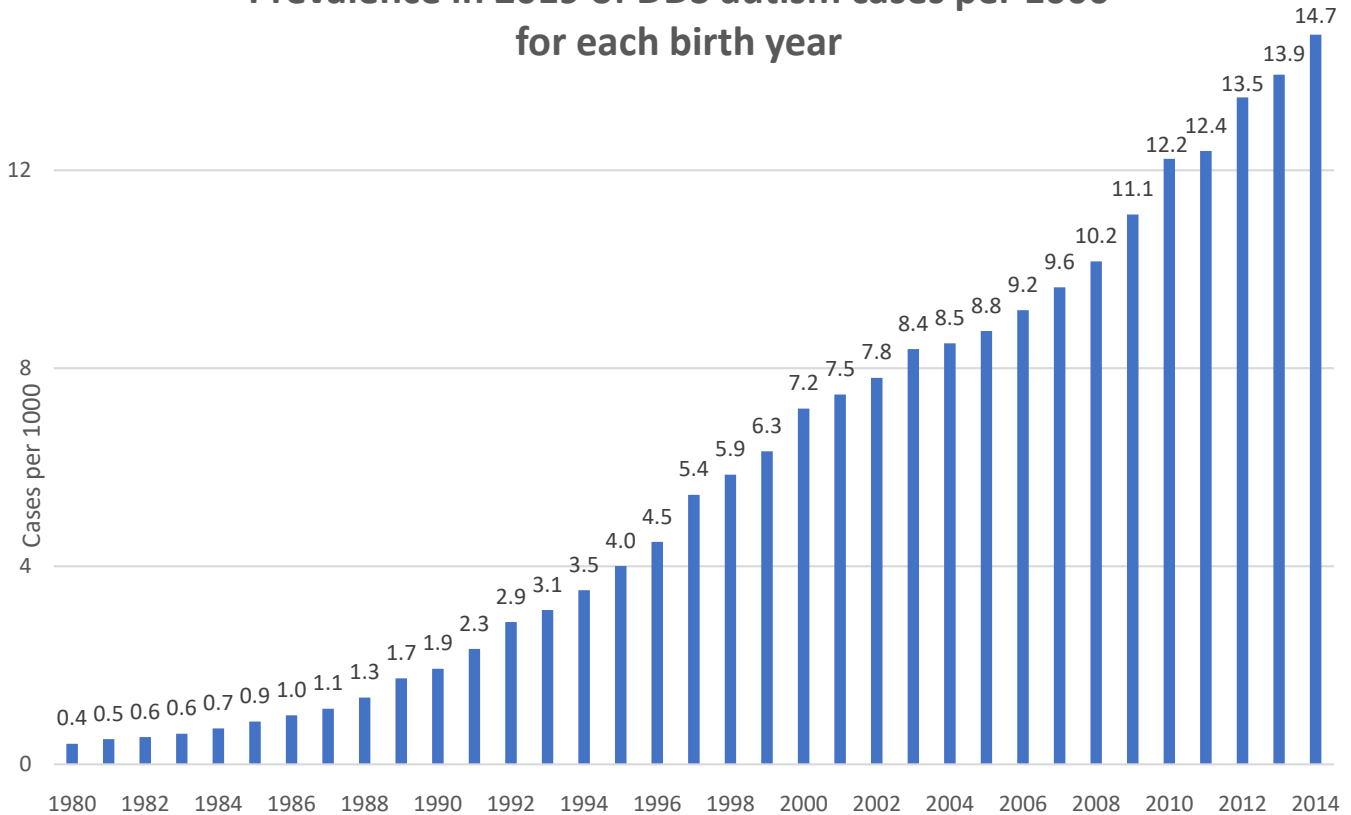
- All cases of autism met DDS criteria (see p.5), which:
 - are more restrictive than general ASD diagnoses
 - became even more restrictive in 2003
- Each birth year brings substantially more new cases than the ones before it
- Far more young people now have autism than ever before
- Those young people will soon mature and we can expect *vastly* more adults with autism than there are today

For example, for every 40-year-old with DDS autism in 2020, we can expect to see at least **27** 40-year-olds with DDS autism in 2054.

- Diagnoses occur over all ages; most cases are diagnosed by age 10.
- Children with autism born after 2009 are undercounted since some won't be diagnosed until after 2019
- Children with autism born after 2014 are omitted from the figure because of even greater undercounting. Many of them won't be diagnosed until after 2019.

Steep rise in autism prevalence by birth year

Prevalence in 2019 of DDS autism cases per 1000 for each birth year



Source: DDS & US Census

Prevalence in 2019 for each birth year (1980-2014) is the number of DDS autism cases in 2019 born that year divided by the 2019 California population having that same birth year.

The prevalence (so far) for birth year 2014 is over **36 times** that of 1980.

This alarming birth year prevalence trend has urgent implications for both policy and science.

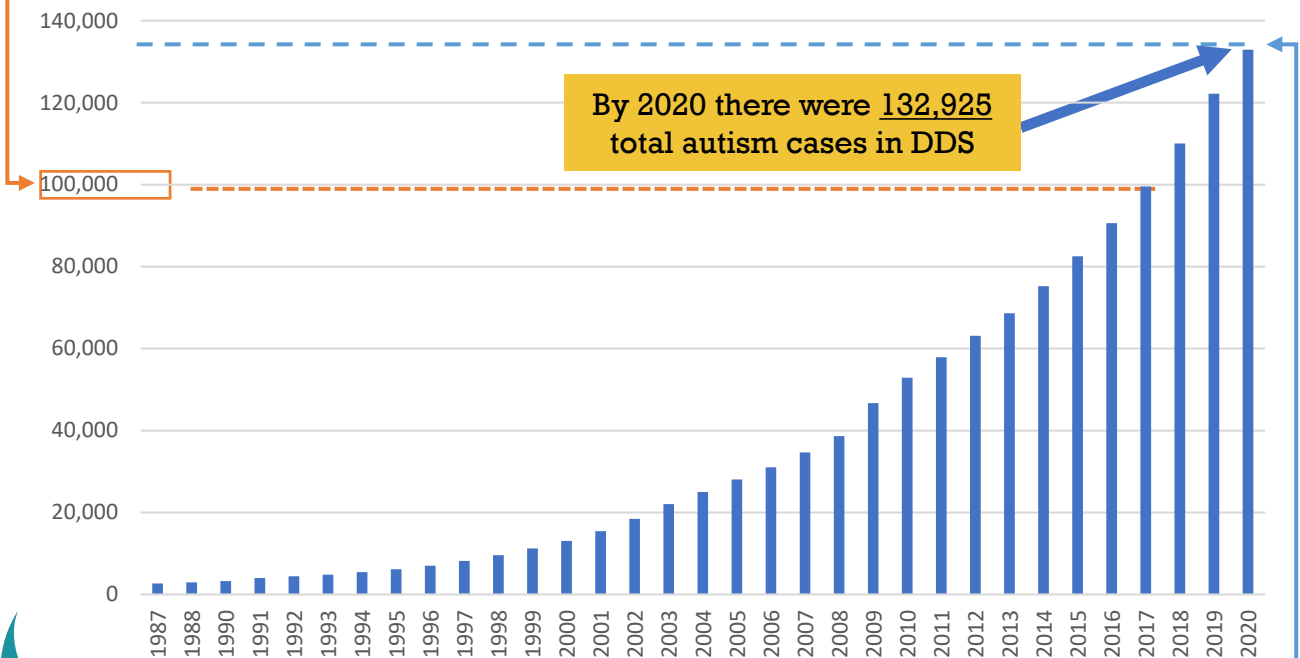
- Increasing prevalence by birth year implies a substantial effect from increases in causal factors, raising important questions for research
- A popular hypothesis that the increase is largely due to greater awareness, changing criteria, and other diagnostic factors has not been substantiated
- The hypothesis that vaccines are responsible for the increase has been ruled out by numerous scientific studies

How many total autism cases are there currently in the CA DDS system?

At the start of 2018, the total number of persons — all ages — with a diagnosis of autistic disorder or autism spectrum disorder in the California DDS system, **surpassed 100,000**.

The graph below depicts the accelerating rise in autism cases over nearly 3 decades. By contrast, the rate of California's population growth in the last four years was less than 3%

DDS Autism Caseload 1987 - 2020



By 2020 there were 132,925 total autism cases in DDS

Note: thousands more cases entered the system and left before 2020. Source: DDS

This is an increase of about 13.6% per year

➤ **In the 7 years from 2013 to 2020 we added as many cases as in the 33 years from 1980 to 2013**

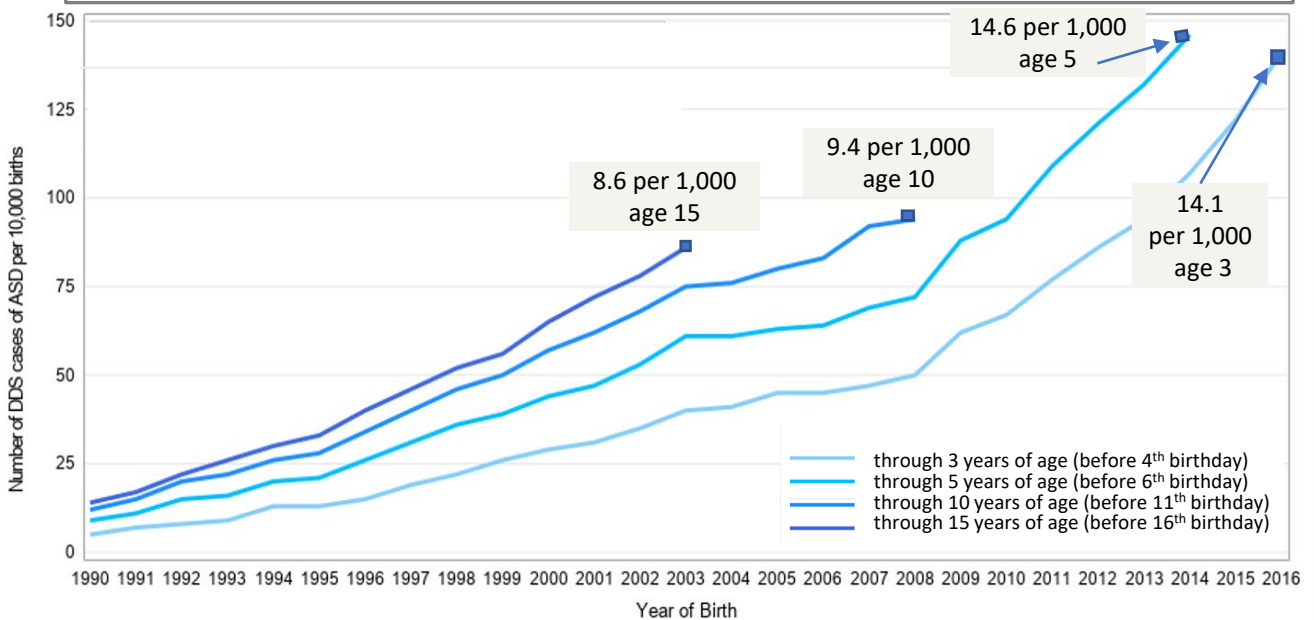
The growth is primarily in children

Most cases of autism in California are diagnosed between 3 and 4 years of age.

However, many children are diagnosed after age 5 and even after age 10.



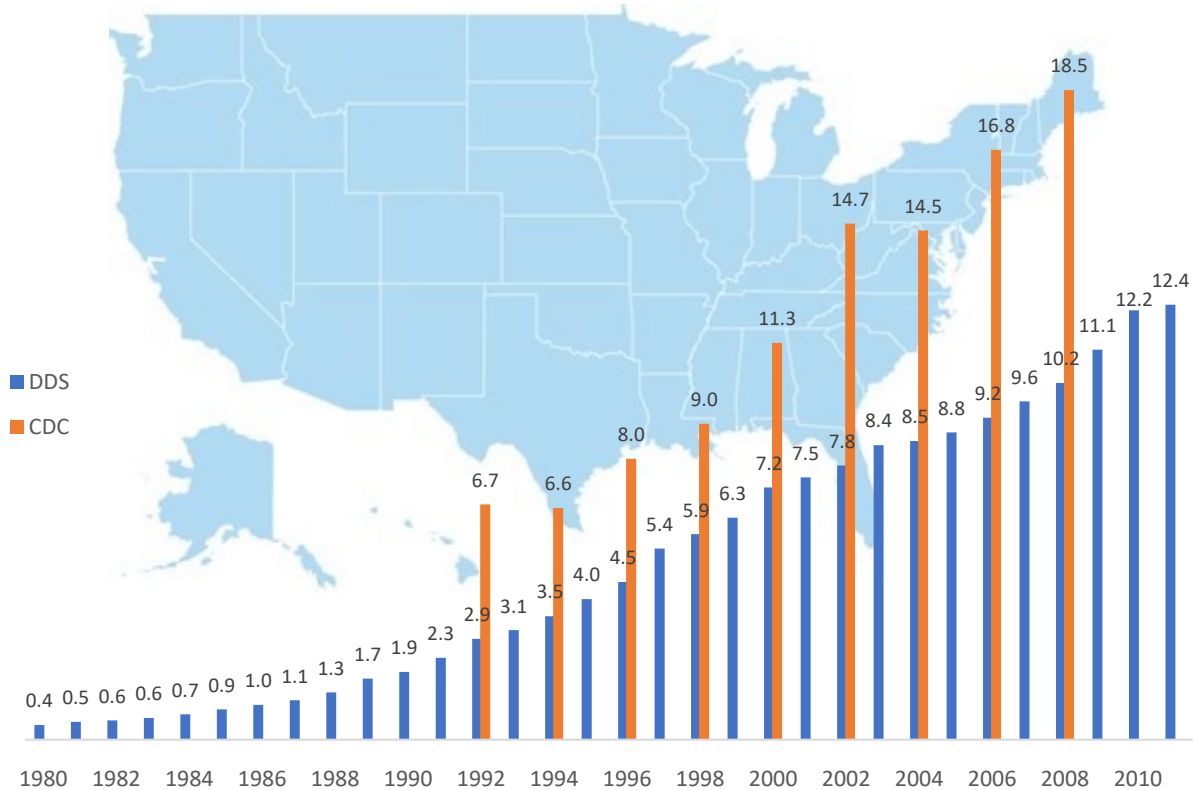
Cumulative diagnoses of autism through ages 3, 5, 10, and 15, for birth years 1990-2016



Complete data not available through age 15 for births after 2003; through age 10 for births after 2008; through age 5 for births 2014-2016

Comparing California DDS to U.S. CDC autism rates

DDS and US CDC autism prevalence per 1,000 by birth year

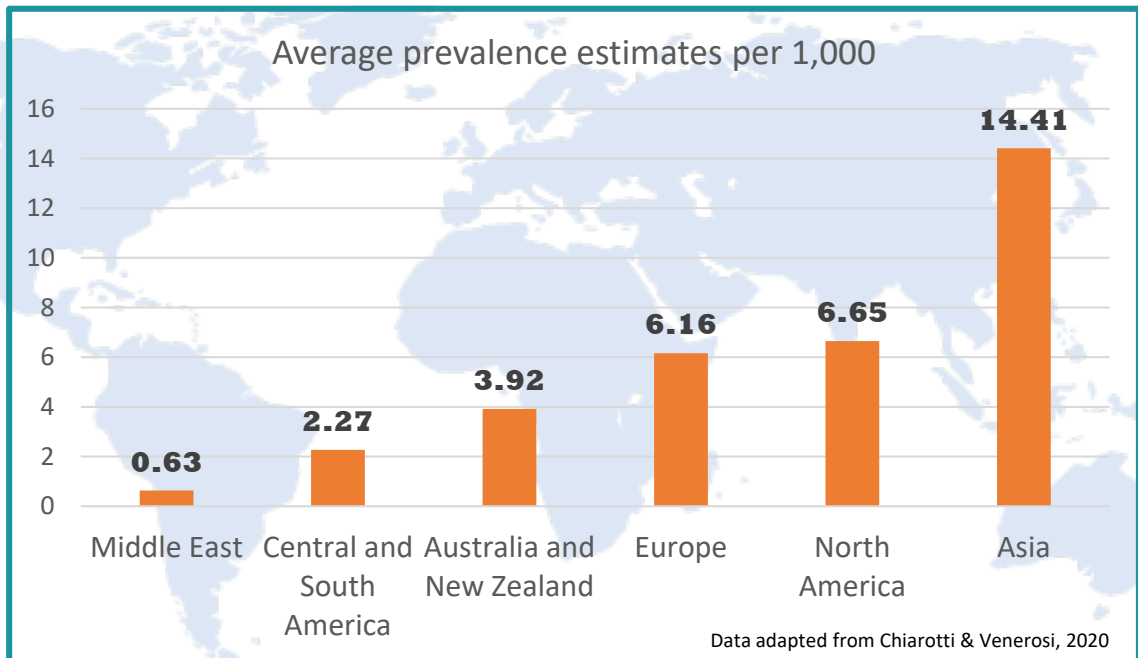


Source: DDS, CDC ADDM, & US Census

California DDS and US CDC have similar trends

- CDC Autism and Development Disability Monitoring Network (ADDM) reports show higher estimated prevalence than the California DDS finds
- This is expected, as the California DDS has more stringent criteria and excludes milder cases

In context: autism rates around the world



Worldwide autism rates were reviewed in 2020. (Chiarotti & Venerosi, 2020)

- The study analyzed data from 42 different studies, with a special focus on publications in 2014 or later.

Researchers found:

- Overall, the worldwide prevalence rates ranged from 0.63 in the Middle East to 14.41 in Asia (per 1,000 individuals).
- Prevalence rates had increased over the last 20 years.

Some challenges:

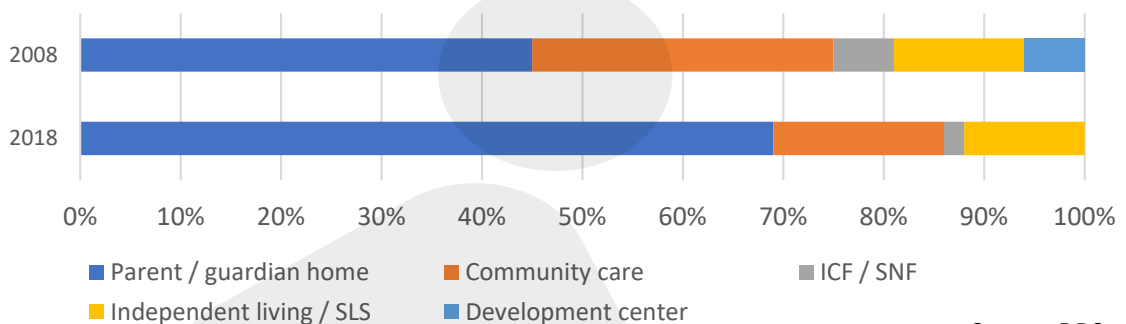
- Variation in methodologies used for diagnosis and data collection makes comparisons difficult.
- The report relied on average estimates, while prevalence estimates can still vary widely between and within countries.

Adults with autism

The main driver of growth in autism prevalence has been increasing rates of diagnoses of people born in recent years. Most are diagnosed before age 4.

Only 21.5% of autism cases in the DDS system are 21 years or older. Half of these (10%) are in the range of 28 to 98 years old.

Living situation adults with autism



Source: DDS

Adults with autism increasingly live with their parents or guardians. When their parents become too old, most of them will have to move to some other facility.

Many of those more seriously affected are not suited for independent living.

The vast majority of DDS adults with autism have neither volunteer nor paid employment.

Over 35% of all autism cases in DDS were born in the decade 2001-2010, and are on the verge of adulthood.

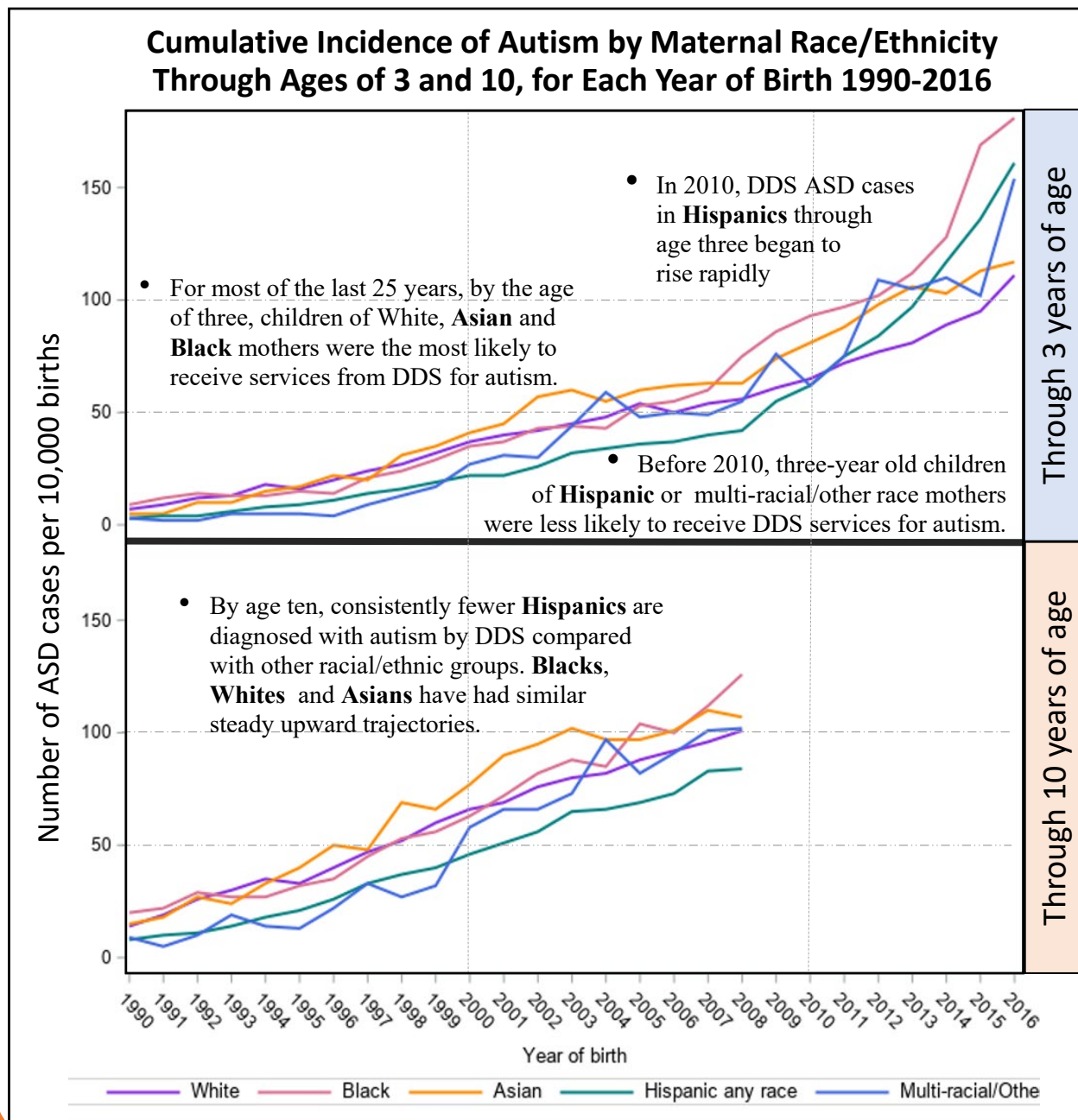
Caring for adults with autism is a growing concern.

As time passes, larger numbers will need not just housing, but also 24-hour care.

What happens when their parents die?

It is critical that policy at all levels, federal, state and local, adequately considers the future needs of the burgeoning population disabled by autism.

DDS Autism by Race & Ethnicity



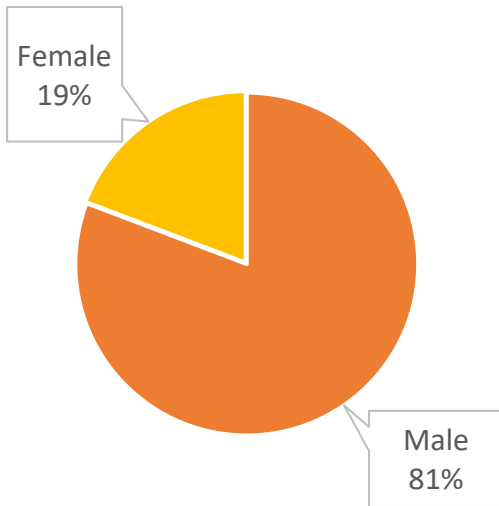
The steady rise in children receiving DDS services is evident in all racial/ethnic groups. Far from plateauing, the trajectories in early childhood appear steeper in recent years. Children of Hispanic (vs. non-Hispanic) mothers were less frequently diagnosed with ASD, but this is changing.



Autism rates have been rising among all racial and ethnic groups

Sex of DDS autism cases

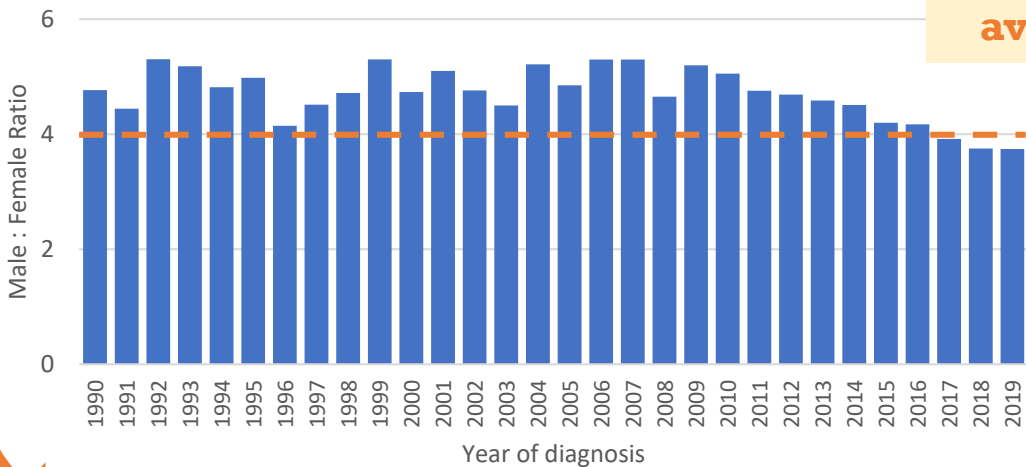
Based on current caseload in DDS, **81%** of autism cases are males, while only **19%** are females.



Numerous theories have been proposed to explain the sharp sex differences. It may stem from a combination of factors.

Boys with autism outnumber girls 4:1, on average.

Male: Female Ratio of autism Cases in California DDS by Year, 1990-2019



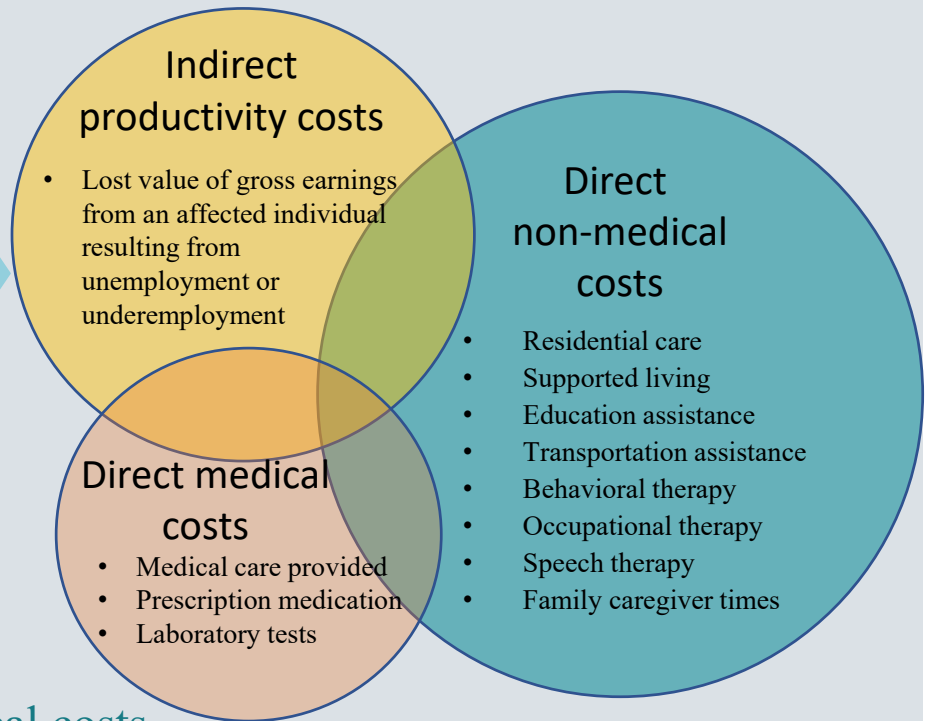
This figure shows that for most of the last few decades the male:female ratio in the DDS caseload has fluctuated between 4 and 5. Since 2009 this ratio has been slowly declining.

California's spending on autism

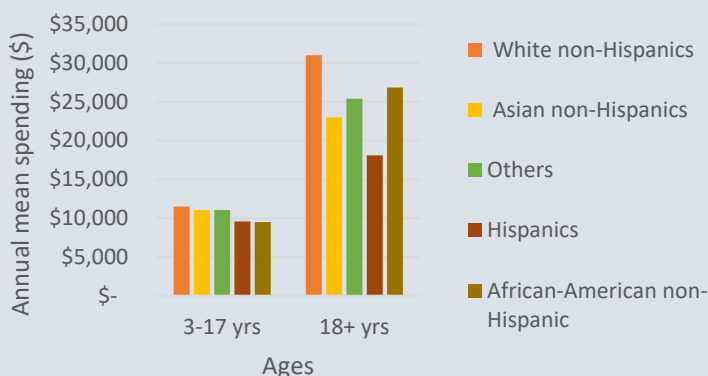
California's spending on autism falls into three categories.

All 3 are substantial, but what sets autism apart from many other diseases and conditions is the large share of –

Direct non-medical costs.



California's annual expenditures per person for autism by race/ethnicity



State spending on autism differs little by race/ethnicity in childhood. However, in adulthood: spending on Hispanics with autism is considerably lower than for White non-Hispanics with autism

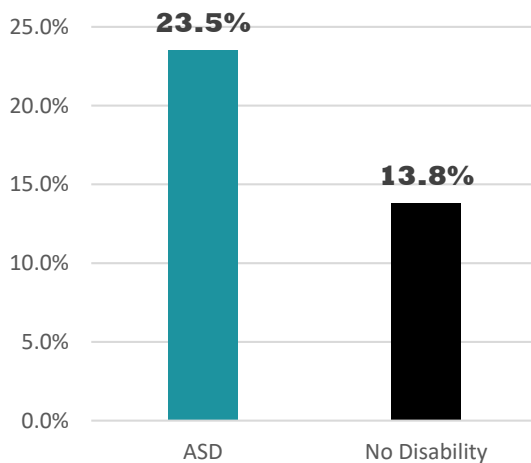
No difference by sex in state spending on persons with autism (data not shown)

Adapted from Leigh & Hertz-Picciotto, 2015

California's spending on autism typically rises after ages 18-21 when Department of Education-funded services are no longer available, and out-of-home placement, day services, and other direct non-medical expenditures are needed. (DDS Factbooks, 2019)

Cost of autism to families and affected individuals

Divorce Rate among families



The rate of divorce among families of children with autism is **nearly twice the rate** in families where children have no disabilities (Hartley, Barker et. al 2010)

A national study found that for youth with autism (broad spectrum, not the more severely impacted DDS population):

- Two years after high school, more than **50% had no paid job experience**, technical education, or college
- **34% had attended college**
- **Just over ½ had held paid employment** during the first 6 years after high school.

(Shattuck, Narendorf et. al 2012)

- *The numbers may be worse for DDS autism consumers, who tend to be more seriously disabled.*

Prospects after high school?



The profile of autism: accompanying impairments

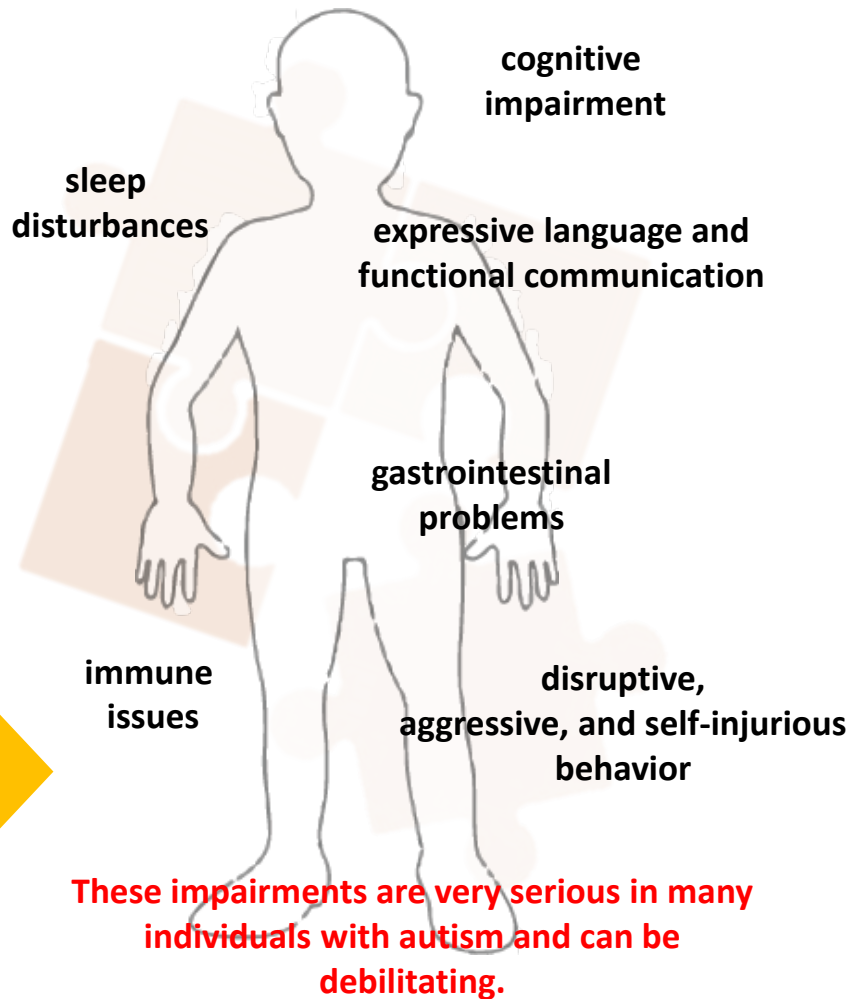
Hollywood's portrayal of autism vs reality

The popular media often portrays autistic characters who display remarkable talent and genius-like skill.

These characters are generally high-functioning, verbal, and quirky, with intense focus on certain subjects.

In contrast, the reality is that significant and permanent functional impairments are common among individuals with autism.

Common functional impairments in autism



Autistic or autistic-like characters in movies and TV shows:

- Raymond Babbit (Dustin Hoffman) in the 1988 movie Rain man
- Dr. Murphy (Freddie Highmore) on ABC's The Good Doctor
- Sheldon Cooper (Jim Parsons) on CBS' The Big Bang Theory

Conclusions

This report reviews the latest data on the time trends of DDS autism in California, provides an overview of the demographic characteristics of autism, and highlights some aspects of autism that impact independence and quality of life.

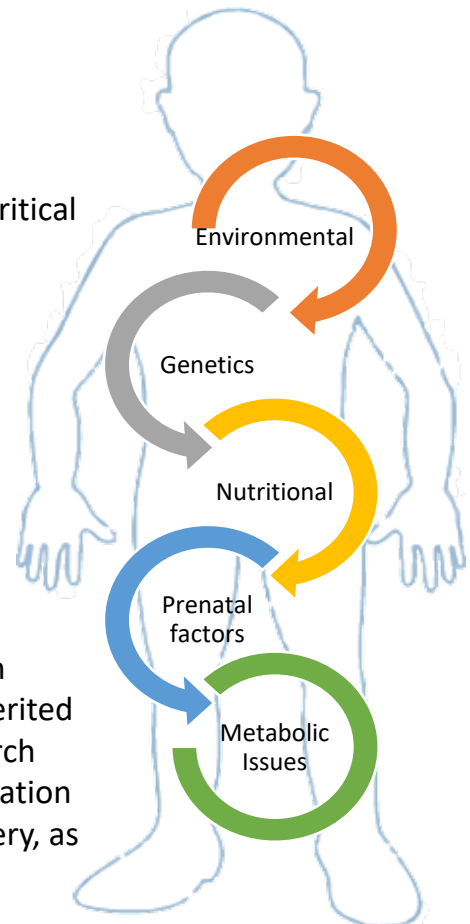
The extraordinarily rapid and long-lasting rise in birth year prevalence has far-reaching implications.

The challenge of caring for adults with autism

- Major issue for families and social service agencies
- Many are not able to live independently nor work and require substantial supports over their lifespans.
- The costs to the DDS system for adults with autism far outstrips spending for children, even though over 2/3 of these adults live with their parents now.
- The growing wave of disabled children will cause a large upswell in the numbers of disabled adults, greatly increasing the costs to California for support, especially as their parents age and become unable to care for them.
- California will need policy changes to increase capacity for supporting the rapid growth in the numbers of disabled adults with autism.

What is causing the increase?

- The enormous increase in the birth year prevalence of DDS autism—approximately 11% per year—raises the critical question: what factors are fueling the increase?
- The increase is unlikely to result from diagnostic factors such as broadening criteria or greater awareness.
- Abundant research finds no evidence that vaccines cause autism.
- Scientific publications show significantly elevated risk of autism from numerous environmental factors. These include pesticides, air pollution, adverse maternal and birth conditions, parental age, and infection.
- Research strongly supports that autism is heritable with hundreds of genes altering susceptibility. However, inherited genes cannot explain a rapid increase over time. Research into interactions of environmental exposures in combination with genetics and epigenetics may help solve this mystery, as published and ongoing studies are demonstrating.



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Partial funding provided by:

Autism Society San Francisco Bay Area

Autism Society of California

Escher Family Fund at Silicon Valley Community Foundation

This report can be found as a PDF file at sfautismsociety.org.