

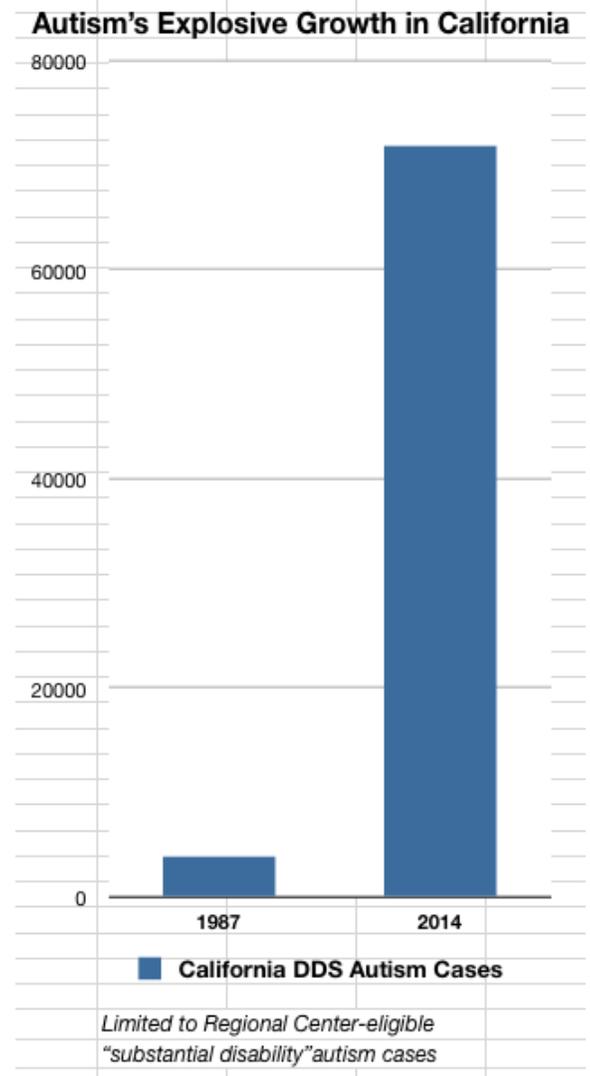
## 72,000-and-Growing: California’s Autism Epidemic

Escalating over more than two decades, California’s massive epidemic of disabling autism is now triggering the largest social services crisis in the state’s history. In this background, we discuss the well documented history of this ever-expanding epidemic and touch on the sweeping policy changes necessary to address the needs of an unprecedented dependent population aging out of school and now requiring lifespan care.

### What is the documented history of California’s autism epidemic?

At the end of 1987, the Department of Developmental Services (“DDS”) identified a total of **3,902** Californians with functionally and substantially disabling autism meeting the strict threshold of eligibility for DDS services. The entire DDS population at the time was 80,483. Now, more than two and half decades later, in mid-2014, DDS identifies **72,000** Californians with DDS-eligible autism meeting the same, or even more restrictive, criteria. The entire DDS population at this time is 282,000 and growing. While the strictly-defined DDS autism population soared 1,850%, the state’s population increased only 32%. Other developmental disability categories grew in numbers as well over this period, but at modest rates.

- In March 1999, alarmed by the unexpectedly sharp increase in the autism caseload since the 1980s, DDS issued a report summarizing the rise in DDS-eligible autism between end of the year for years 1987 and 1998 (“**1999 Report**”).
- The 1999 Report concluded that the number of persons entering the system with autism had increased dramatically between 1987 and 1998 relative to the other developmental disabilities.
- The 1999 Report showed that at end of 1987, there were 3,902 persons with DDS autism, or 4.85% of the



entire DDS caseload. By the end of 1998, there were 12,780 such individuals, representing 9.37% of the overall DDS caseload.

- The 1999 Report found that the rate of the autism increase was more than four times as great as the other diagnostic categories.
- The 1999 Report found that in 1998, there were 1,685 persons with autism enrolled in the DDS system, a “number of persons far exceed[ing] the expected number determined by traditional incidence rates.”
- The 1999 Report cautioned, “If present rates of intake continue, there will be a need for: (1) greater emphasis on long range planning to develop suitable methods of delivering services, [and] (2) strategies for development of new and abundant resources.”
- The 1999 Report documented the birth dates of Regional Center eligible persons with autism, and reflected that the increase in autism births began slowly in about 1980, spiking sharply by 1990.
- The data shown in the 1999 Report also reflected that from about 1960 through about 1977 there were 200 or fewer autism births per year comprising the California DDS population.
- The State commissioned a study, published in 2002, to examine whether expanded diagnosis, immigration, or other factors could have caused the sharp spike in autism cases (“**2002 Study**”).
- The 2002 Study stated: “It is natural to discount that which we do not understand or force it to fit a paradigm with which we are comfortable. This study has been an attempt to determine whether or not the increased numbers are due to a real epidemic, or if the rise in autism cases can be explained by factors that have artificially created that increase.”
- The 2002 Study stated: “Has there been a loosening in the criteria used to diagnose autism, qualifying more children for Regional Center services and increasing the number of autism cases? We did not find this to be the case.”
- The 2002 Study stated: “Has the increase in cases of autism been created artificially by having ‘missed’ the diagnosis in the past, and instead reporting autistic children as ‘mentally retarded?’ This explanation was not supported by our data.”
- The 2002 Study stated: “Without evidence for an artificial increase in autism cases, we conclude that some, if not all, of the observed increase represents a true increase in cases of autism in California, and the number of cases presenting to the Regional Center system is not an overestimation of the number of children with autism in California.”
- The 2002 Study summarized as major findings the following:  
—”The observed increase in autism cases cannot be explained by a loosening in the criteria used to make the diagnosis.”

—”Some children reported by the Regional Centers with mental retardation and not autism did meet criteria for autism, but this misclassification does not appear to have changed over time.”  
—”Children served by the State's Regional Centers are largely native born and there has been no major migration of children into California that would explain the increase in autism.”

- In 2003, DDS issued another report, called “Autistic Spectrum Disorders, Changes In The California Caseload, An Update: 1999 Through 2002,” published April 2003 (“**2003 Report**”),

- The 2003 Report found that the number of persons with autism entering the system continues to increase dramatically, and that, “In fact, the rate first documented in the 1999 Report has accelerated in the last four years. Autism is and will most probably continue to be the fastest growing disability served by the regional center system.”

- The 2003 Report stated that the DDS autism population had grown to 20,377 as of December 2002.

- In 2007, DDS issued a report called, “Autistic Spectrum Disorders, Changes in the California Caseload An Update: June 1987 – June 2007” (“**2007 Report**”).

- The 2007 Report found that from June 1987 through June 2007, California experienced a 12-fold increase in individuals with autistic disorder being served by DDS, and that this number did not include those on the autism spectrum subject to a broader definition.

- The 2007 Report found that, “Currently there are more than 38,000 people in California receiving services for ASD, growth that has averaged 13.4 percent annually since 2002.”

- Regarding adults with autism, the 2007 Report found that “Currently, approximately 6,000 adults with a diagnosis of autism receive services from DDS,” and that by 2018, “the number of adults with autism being served by DDS will triple, to more than 19,000.”

- The 2007 Report found that between 1990 and 2000, “the number of persons with autism being served by regional centers rose 26 times faster than that of the general California population.”

- The 2007 Report found that “The ratio of males to females with autism in the DDS system is 4.6 to 1, consistent across all counties and with the scientific literature.”

- The 2007 Report concluded: “This document represents 20 years of longitudinal data about people with ASD who are served by the state’s DDS through care coordinated by 21 nonprofit regional centers. During this time in California, unprecedented growth occurred in the number of people with this neurodevelopmental disorder. Currently, nearly 39,000 people in California receive services from DDS for ASD. Many findings emerged during these two decades, including a decline in the average age of people with autism, a sizeable age wave of youth approaching adulthood, an increasing proportion of males who have ASD, and a diagnostic stability over time.”

- Outside of DDS, the California Department of Education counted 13,979 students aged 3-21 with autism in end of year 2000 and 84,526 such students at the end of 2013.

- Looking at the data from another perspective, whereas the DDS autism birth cohort before the 1980s was about 200 per year, or less, it is now at a minimum 4,000 per year. Including special education-defined autism, it is at least 6,000 additional autism cases per year.

### **“But haven’t people with autism always been around and we just didn’t notice?”**

Implicit in the argument that this staggering increase results from diagnostic shift or better awareness is the belief that “these people are okay, they’ve always been here, we just called them something different, like geeky, awkward, apraxic, learning disabled, or mentally retarded, or slow.” But this clearly cannot be true for at least four reasons. First, rates of related diagnoses such as intellectual disability, learning disabilities, speech and language impairments ADHD/ADD, and mental illness in California have all climbed, both within and without the DDS system, in many cases dramatically. Other related disabilities have not decreased over the past two decades.

Second, the DDS autism cohort is composed of individuals with strikingly abnormal communication, social ability, and behaviors, possessing little to no potential for self-sufficiency, and no evidence whatsoever supports the idea that this obviously dependent population was overlooked by DDS in earlier generations. Third, as shown above, objective, carefully analyzed DDS reports firmly and consistently concluded that diagnostic shift could not account for the skyrocketing rates of autism. Fourth, DDS entry criteria have become more strict, not looser, over time.

### **“But we don’t understand what is causing all this autism.”**

It is certainly true that apart from findings of relatively minor autism risk factors—such as preterm birth, birth complications, early fetal antidepressant exposure, fetal anticonvulsant exposure, fetal exposure to infection, and certain fertility treatments—science has thus far failed to identify the vast majority of causes for the skyrocketing rates of the manifestly abnormal neurodevelopment we label as autism. It has been shown vaccination does not cause autism. However, comprehension of pathogenesis is not necessary to simply observe and declare an obvious aberration in the health of our latest generation of children. We hope research will soon uncover the roots of this widespread and unprecedented epidemic.

### **“Is epidemic the right word for this?”**

At the close of 1987, with 3,902 DDS-eligible autism cases, California was already in the midst of a baffling yet clearly perceptible epidemic of incapacitating autism compared to previous decades, when substantially and functionally incapacitating autism was an extremely rare condition occupying a tiny fraction of the DDS caseload. By 1999, with a tripling to 12,780 cases, California found itself deeper into an even more profound and alarming epidemic. By mid-2007, the 1987 number grew almost 10-fold, to 38,000 cases. Today, the 2014 number is

nearly double that of 2007, and nearly 20-fold greater than in 1987, with a 72,000 DDS-eligible autism population.

By definition, an epidemic occurs when new cases of a certain disease or condition in a given human population, and during a given period, substantially exceeds what is expected based on recent experience. Again, comprehension of pathogenesis is in no way a prerequisite to identifying an epidemic.

Based on the above DDS data, widely regarded as the most reliable autism case finding in the country, and founded on eligibility criteria that has unequivocally not loosened over time, California can say with an extremely high degree of confidence that the incidence of autism, to a shocking and obvious degree, exceeds what was expected based on historical experience, and is therefore epidemic.

If the shocking number of 72,000 with incapacitating autism is not epidemic, then one may reasonably ask, what is? A DDS autism population of 80,000? 90,000? 100,00? 200,000? Where would one draw the line?

While some may dislike the term “epidemic,” there is nothing derogatory or disrespectful in this conventional and meaningful word. To the contrary, to pussyfoot around the term of art, “epidemic,” and use a bland and vague term such as “increase” does a profound disserve to those who are affected and incapacitated by this ever-growing condition and in need of lifespan care. Furthermore, we believe that quibbling over semantics is a childish and preposterous waste of time in the midst of crisis affecting many tens of thousands of families rightfully panicked about their children’s futures.

### **“So, what should we do to meet the need?”**

The need is astonishingly vast. Based on existing statistics alone, and not including any new additions to the DDS caseload, within 18 years California’s autism adult population will easily occupy the *entire* current DDS budget of \$5 billion, grounded upon the conservative of financial estimate of \$70,000 in services, supports, supervision, and housing per dependent autistic adult.

This crisis is not about autism alone, the surge in the autism disabled population affects every person with a developmental disability in our state. In 2007 DDS served 6,000 adults with autism. By 2032, we will need to serve at least 72,000 such dependent adults, and most likely a much larger population of autistic children. Currently, nearly all people with autism live at home with parents or family, a temporary situation that will rapidly change as the autism population and caregivers both grow older.

Given the enormity of the need, we can no longer simply move chess pieces around a status quo adult services system that is broken and clearly unprepared to meet the tidal wave of demand. We believe the system will need an overhaul combined with dedicated streams of robust funding:

- Tremendous new resources for adult care, supervision, programming, and supported employment.

- New categories of subsidies and incentives to foster an abundance of supported housing solutions.
- A restructuring of licensing regulations to promote creative new supported housing solutions targeted at the intensive and complex needs of autistic adults.
- Policies that ensure that as autism parents age and pass away that high-quality ongoing case management and supervision is provided.
- Loosening of restrictive federal and state government regulations and local zoning codes that restrain options for housing and programs.

For details, please see our [July 14, 2014 Letter to the DDS Community Task Force](#) outlining the areas of major lifespan support need. For more information, please visit [sfautismsociety.org](http://sfautismsociety.org).