January 22, 2020

Re: Request for California Autism Reporting Program at CDPH

Dear Director Angell,

We are writing on behalf of the approximately 200,000 California families now affected by autism spectrum disorders. Over the past three decades, autism has exploded to become our state’s most pressing and costly public health crisis—from about 3,000 cases in the Department of Developmental Services (DDS) system in the mid-1980s to more than 122,000 such cases today. This number reflects only more severe forms of autism and does not include higher functioning forms ineligible for developmental services. Whereas the state saw just a few hundred DDS autism cases per birth year through the early 1980s, we now see more than 7,200 DDS autism births per year, a truly alarming rate of serious, lifelong neurodevelopmental impairment for which our state has no precedent.

Despite the relentless surge of disabling autism in our state, little has been done to provide surveillance, analysis, forecasting, or reporting to the public or policymakers. Accordingly, to facilitate better understanding about the scope and nature of this public health crisis we ask that California DPH consider the launch of a California Autism Reporting Program (CARP) including the following:

1. An Annual California Autism Report tracking important data such as DDS incidence by birth year, prevalence. Analysis could also include functional (degree of impairment), demographic, regional, and other characteristics, as may be available through DDS, birth records, Department of Education or other sources. The report should also include forecasts for growth in adult autism based on current data.
3. Staff person or persons devoted to managing this program.

We have met with CDPH staff from time to time over the past several years, and we know that some efforts have been made to further reporting (such as occasionally reporting DDS autism prevalence numbers) and etiology-related research. We are very grateful for these efforts. But a thorough program is now needed. California DDS autism data, known as the most robust data
on developmental disability-type autism in the country, has profound implications not just for California, but for the nation and internationally. The Appendix provides background data that reflects the dramatic increase in autism in our state, as well as the projected surge in cases having elderly or deceased parents, portending an overwhelming social services crisis.

Studies have noted that both public and private expenditures are likely to surge as ever-growing populations age out of the school system and into the adult system,\(^1\) and that national costs of autism are projected to reach $461 billion for 2025. The study authors noted that “If the prevalence of ASD continues to grow as it has in recent years, ASD costs will likely far exceed those of diabetes and ADHD by 2025.”\(^2\) And prevalence has indeed continued to grow in recent years. The costs to our families, educational system, social services, and taxpayers are simply astronomical, a dire situation that will only intensify as ever-larger cohorts of parents and family caregivers age, become infirm, and pass away.

While it is clear vaccines have not contributed to the autism increase, nevertheless this surge in serious neurodevelopmental pathology is alarmingly real and warrants the strongest public concern. Further, even without the dire projections we have provided, the current prevalence of disabling autism is sufficient cause for CDPH to initiate the CARP. CDPH has, for example, a program for Alzheimers, yet autism is and will continue to be a larger and more costly challenge for the state and its families, now and decades from now.

To the extent that any CARP items would fall outside the scope of CDPH abilities or budgets we ask the department to consider “low-hanging fruit,” such as annual prevalence reporting while advocates seek budget authority for other aspects of the program, such as active surveillance.

The people and policymakers of California deserve a robust autism reporting, analysis and surveillance system from the Department of Public Health. We hope that you agree with our assessment and will have some time to meet or discuss this pressing matter by phone or videoconference at your convenience.

We thank you very much for your consideration of our proposal.

Very truly yours,

Denise Haas
President

Jill Escher
Immediate Past President

Cristina Moretto
Advocacy Chair

\(^1\) Leigh et al. Spending by California’s Department of Developmental Services for Persons with Autism across Demographic and Expenditure Categories. PLoS One 2016;25;11(3) e0151970.

Total number of DDS consumers with autism per year, for years 1989 to 2019. A baffled DDS grew alarmed when autism, once a rare disorder seldom seen in the Developmental Centers or elsewhere in the system, reached 16,000 cases in the late 1990s. DDS then published its own reports investigating the nature of the surge but found no evidence for diagnostic shifts or immigration explaining the population increase. In 2003 the legislature heightened eligibility requirements to enter the DDS system; there has been no broadening of criteria as is sometimes reported.

DDS data indicates that the autism caseload has grown from about 3,000 cases in the DDS system in the mid-1980s to **more than 122,000 such cases today**

Source: Compiled from California Department of Developmental Services data from CDER and PRA requests in 2015, 2016, and 2017.
By birth year, one can see that the numbers of DDS autism consumers continue to increase in a near exponential fashion. For 2014, 7,273 autism births are recorded in the DDS system. For birth years after 2014, the numbers of cases drop off because many of them have not been diagnosed or deemed eligible; it takes until approximately 10 years of age for many cases to enter the system.

Source: California Department of Developmental Services, 2020 data, per PRA request.
CDPH analysis of prevalence of DDS autism cases live-born in the state reflects a sharp increase, with a steady 4:1 M;F ratio. More than 2% of all males now end up as DDS autism cases.

While the graph above has not been published, a CDPH prevalence report based on earlier data found a 10-fold increase from 1.1 cases per 1,000 births in 1987 to 11.0 cases per 1,000 births in 2013. (https://www.cdph.ca.gov/Programs/CCDPHP/DEODC/EHIB/EES/CDPH%20Document%20Library/ADA1-%20CA%20Autism%20Prevalence%201987-2013%2007132018%20-%20MR.pdf)

Source: California Department of Public Health, 2019 data (internal document)
The following two graphs show projections for future DDS autism cases, based on current DDS cases by birth year. They are both based on conservative assumptions, explained below. In reality, the situation is likely far more dire.

Under these projections, the overall autism caseload will grow by more than 50% in ten years and will double in 20 years. Conservatively, California will see nearly 300,000 developmental disability-type autism cases in 2050.

Alarmingly, the number of cases with parents age 65 or older (or deceased) is projected to grow by 250% in ten years, 855% in 20 years, and 17-fold in 30 years. Almost all of these cases will require public supports, to varying degrees, for housing, day programs, and medical care.
The conservative assumptions used in these two projections are as follows:

- 2020 data and projections for 2030, 2040, and 2050 are based on DDS data for **start** of year 2020. The numbers will be substantially higher by end of year.

- For 1990, 2000, and 2010 data is simple based on DDS autism caseload data.

- For birth years 1920-2014, projections assume no further caseload additions.

- Projections for 2030, 2040, 2050 assumes cases in 0-6 years of age are diagnosed over several years of age, similar to actual experience in DDS in birth years before 2020.

- Even though DDS autism cases are now climbing more than 300 cases by birth year over the previous year, these projections conservatively assume that cases in 2015-2040 birth years decline from peak in 2014 (7,273 births) by 100 cases per year.

- The bottom graph assumes all parents are 28 years older than child (based on research showing U.S. average age for mother is 26 and father is 30).

- Projections assume .88 case retention rate each year after case reaches age 50, or a death rate of 12% per year, which is likely a higher death rate than will be seen in reality.
California Special Education Autism Cases, 1990 v 2018

In the California schools, which adhere to a broader definition of autism, autism cases in Special Education have also skyrocketed, from 14,038 cases in 1990 to 120,089 in 2018, an 855% increase. The proportion of children diagnosed with autism has risen from 1 in 600 students in 1997-98 to 1 in 50 students in 2017-18, a 12-fold increase.