

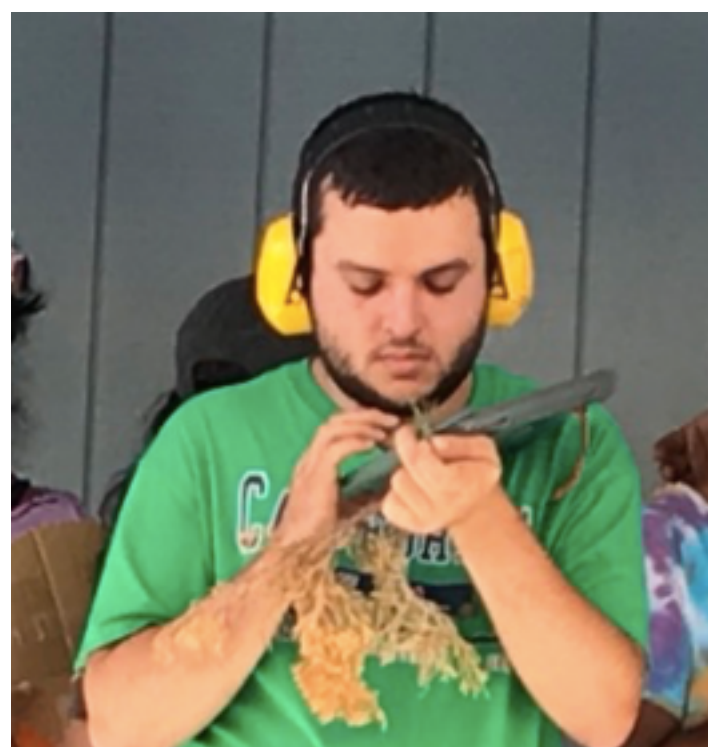
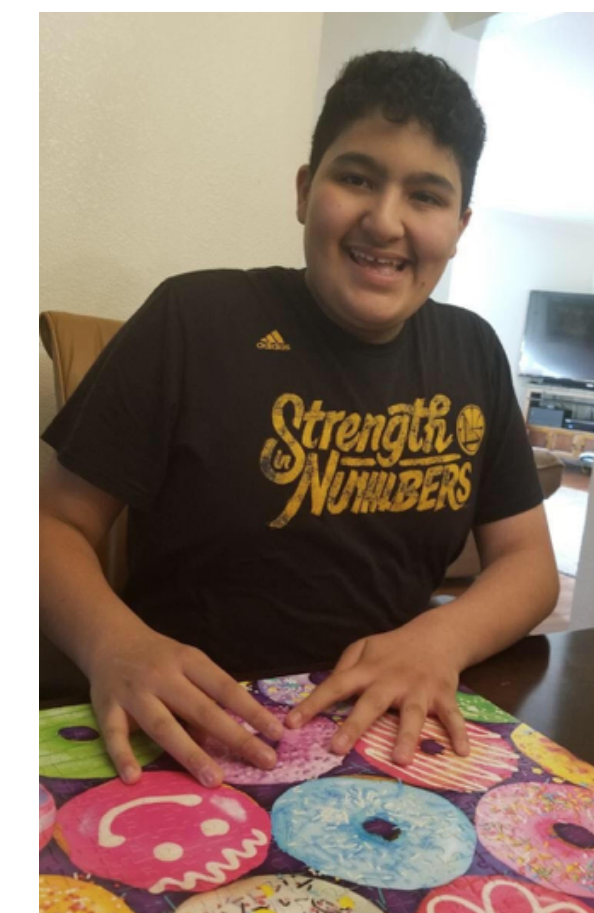


Supports for Autism in Adulthood: A Crisis of Quantity and Quality



Jill Escher
Immediate Past President
Autism Society San Francisco Bay Area

President
National Council on Severe Autism



Get to Know Us: sfautismsociety.org



Annual Conferences on Adult Autism/DD



2014 "A Place for Us" Adult Autism/DD Housing Conference



2015 "Let A Thousand Flowers Bloom" Adult Autism/DD Summit



2016 "Into the Future" Conference



2017 "Visionaries" Conference



Art: Rex Schmidt, Morgan Autism Center

2018 "Spectrum of Choice" Conference



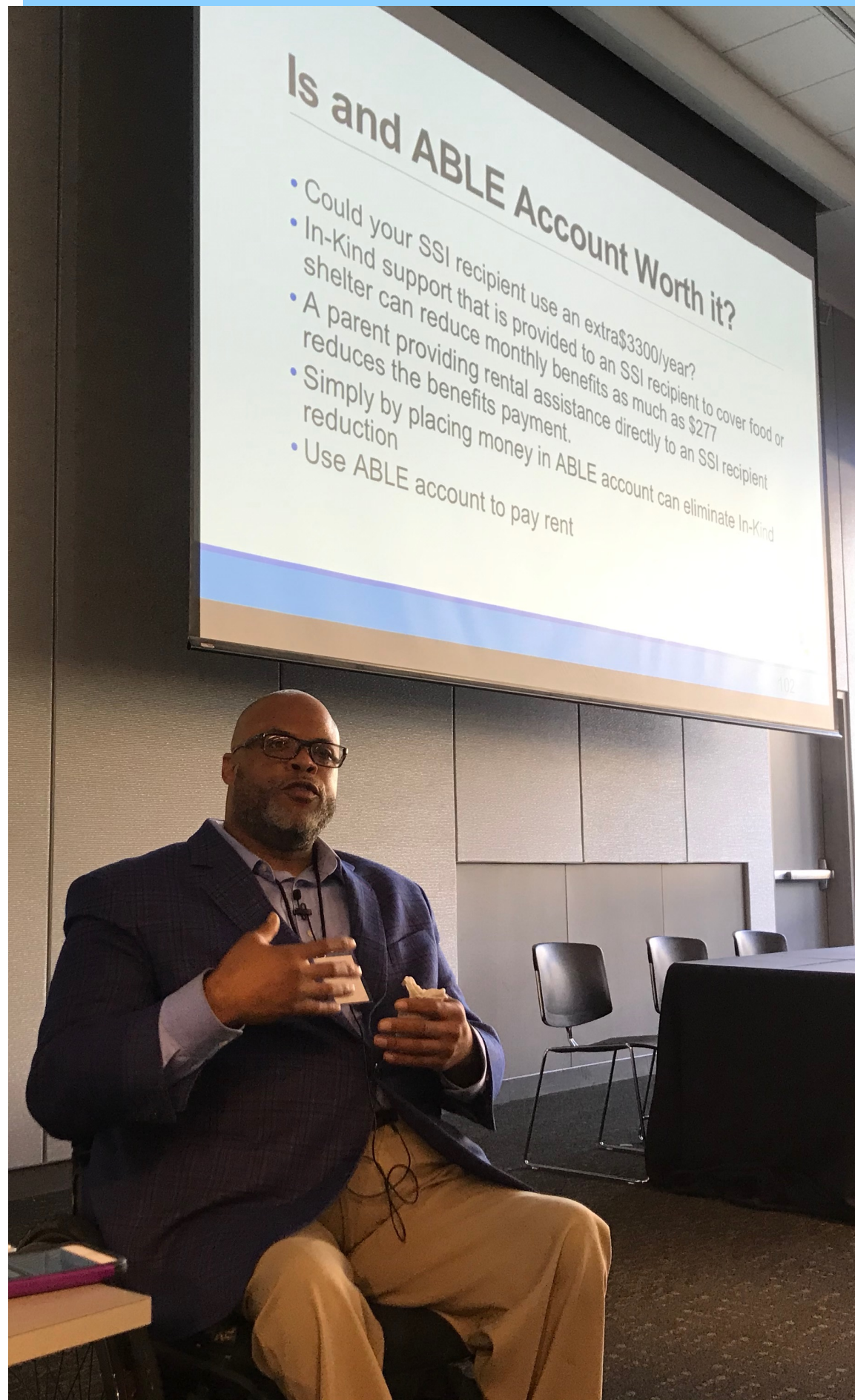
Artwork courtesy of Melissa Correa, College of Adaptive Arts

2019 Bay Area Adult Autism/DD Conference



Artwork by Cassie Searle, College of Adaptive Arts

2019 Conference with Stanford

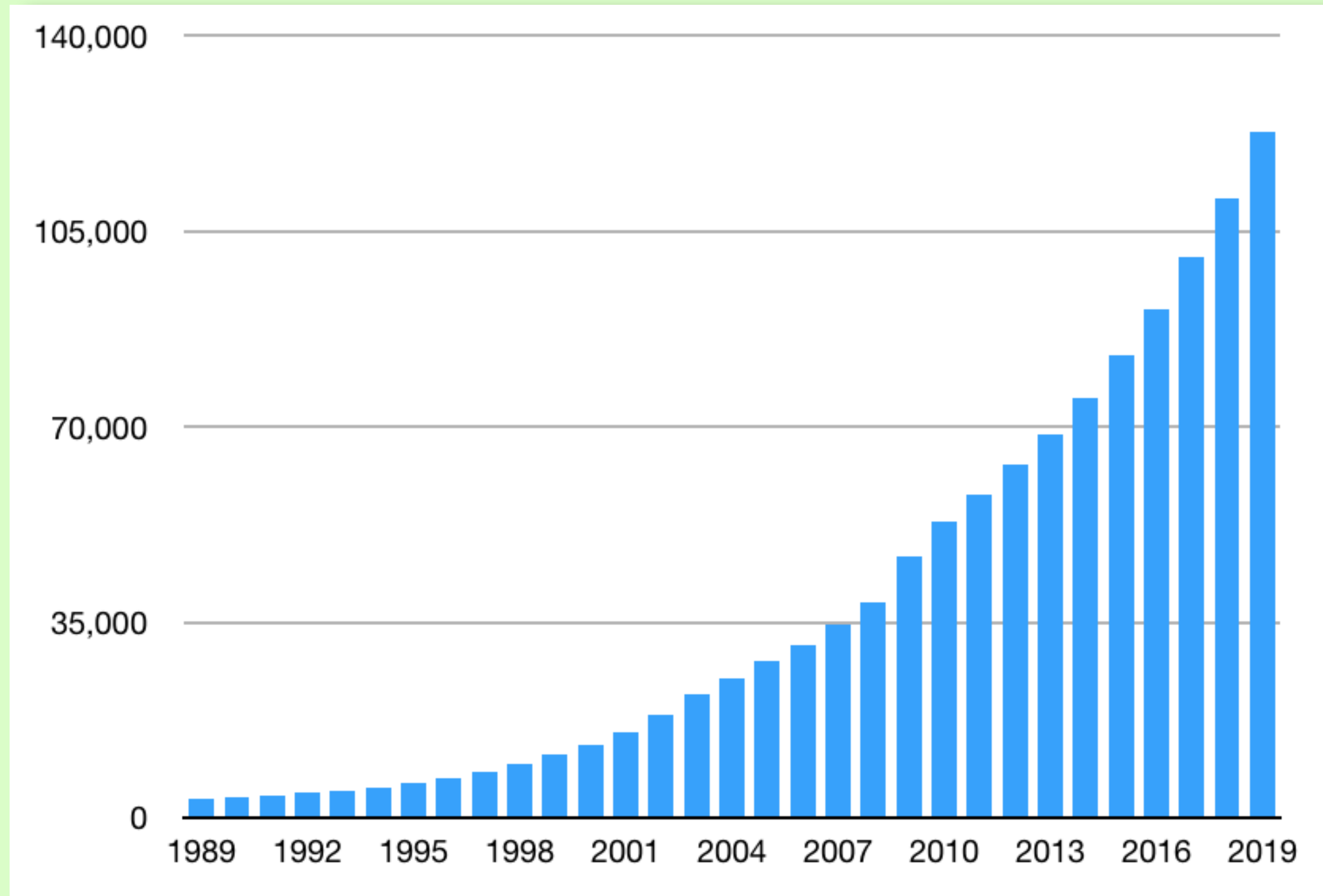


Adult Autism: The Crisis of Quantity



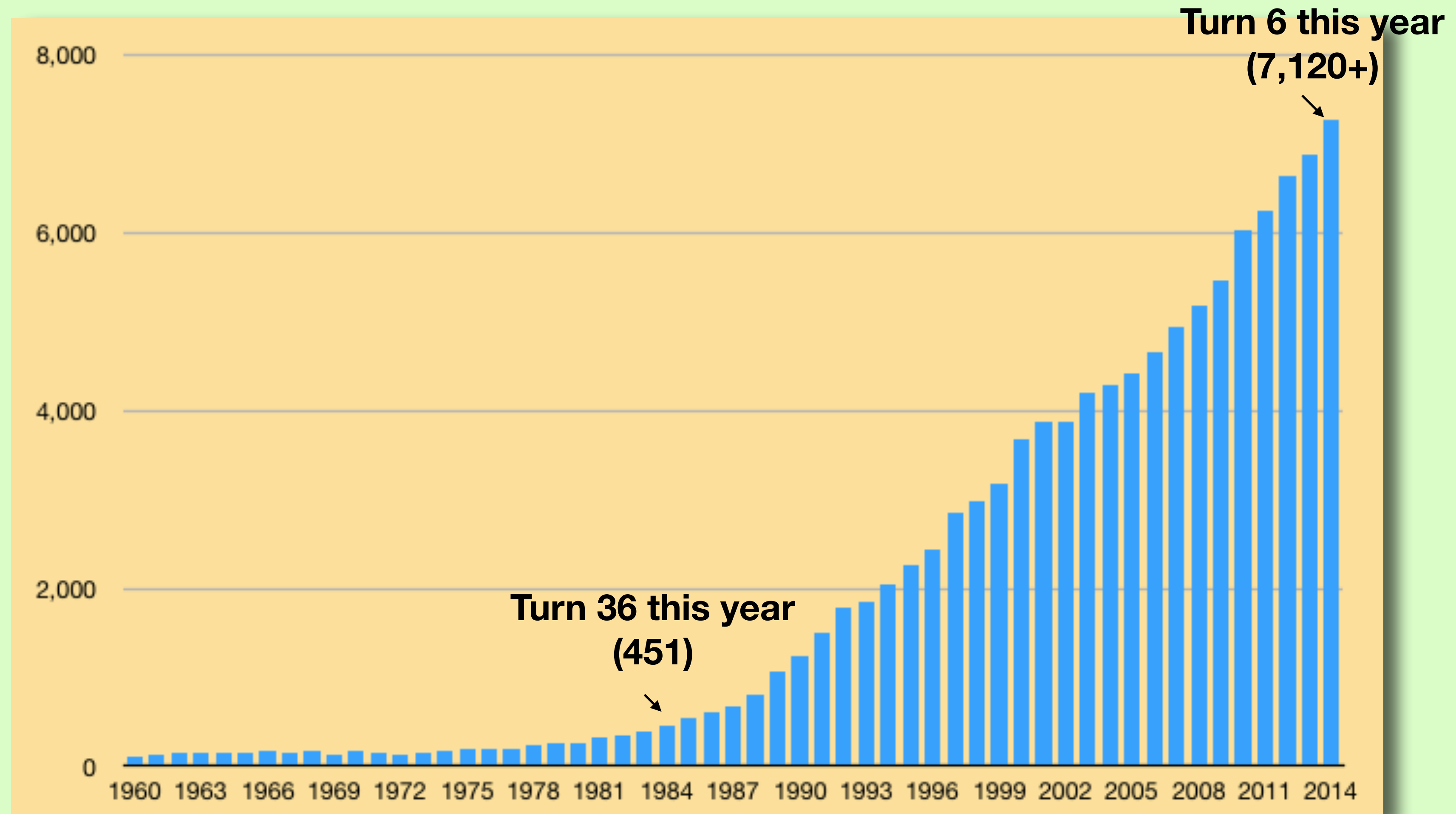
13 data slides ahead

DDS Consumers with Autism, 1989-2019



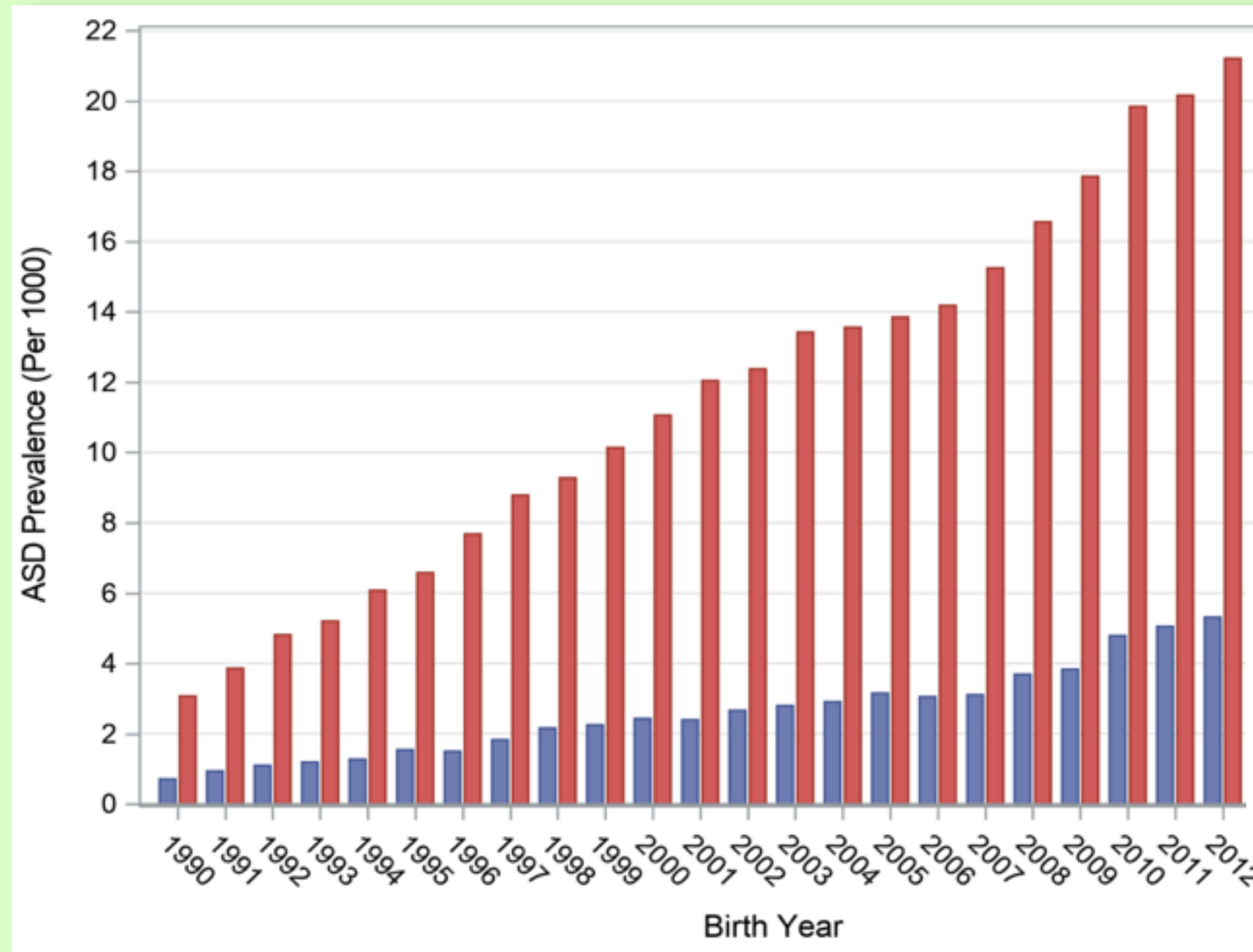
Source: DDS, based on DDS Fact Books, Quarterly Client Characteristics Reports, Public Records Act requests

DDS Autism Cases by Birth Year, 1960-2014



Source: DDS, per 2019 Public Records Act request

Prevalence of DDS Autism for Live Births in State, for Birth Years 1990-2012



More than 2% of all males born in state now end up as DDS autism cases.

Note: Cases decline in 2013-2018 birth years, consistent with usual delays in entering system.

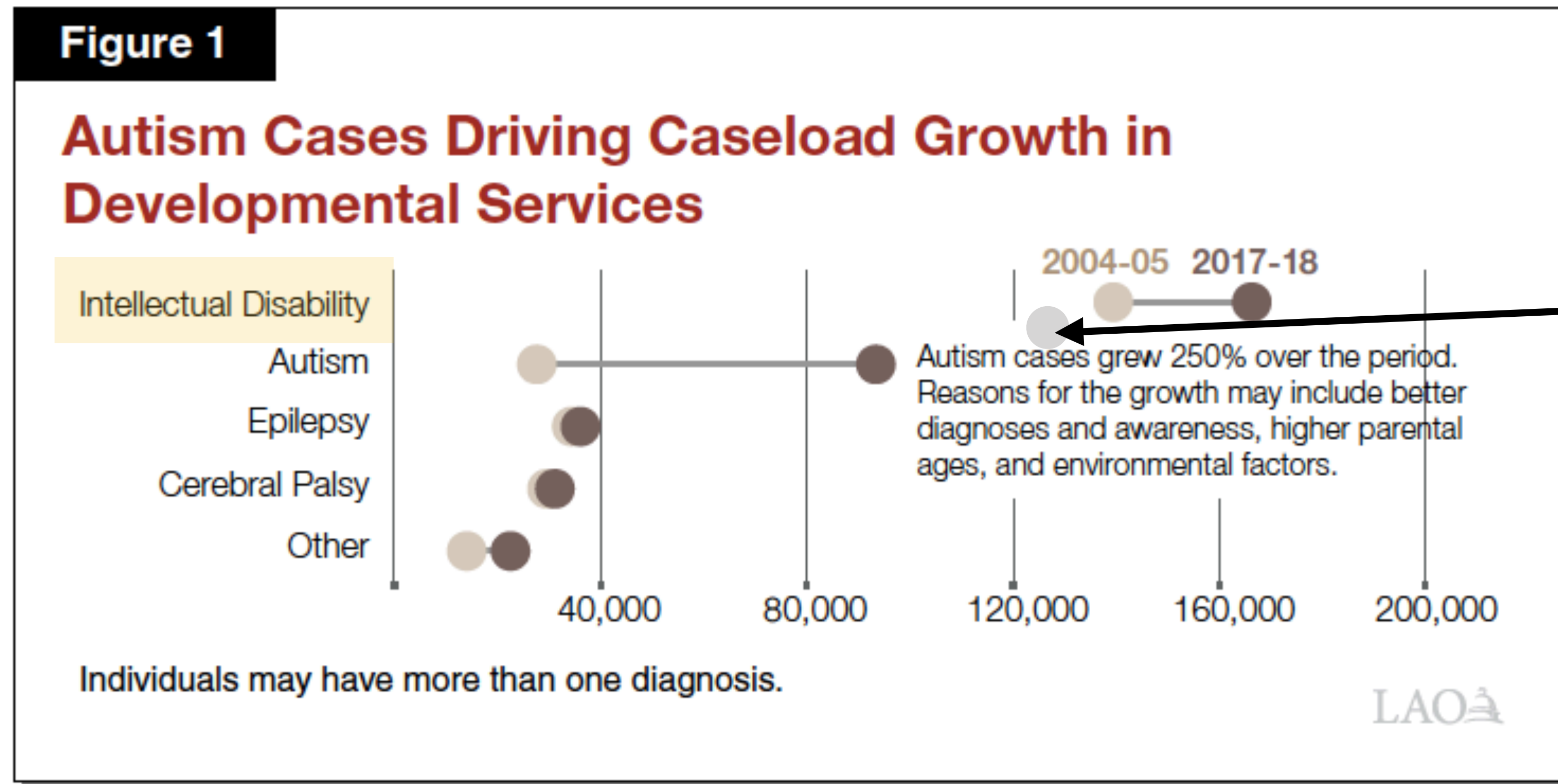
Source: California Department of Public Health, per SFASA data request. Data as of 2019 cases, based on California Department of Developmental Services data for live births in the state.

Calif Legislative Analysts Office

“Over the past five years, the number of consumers with **autism** has increased an average of 10.1 percent annually.” —LAO

13 year time horizon

What about ID?



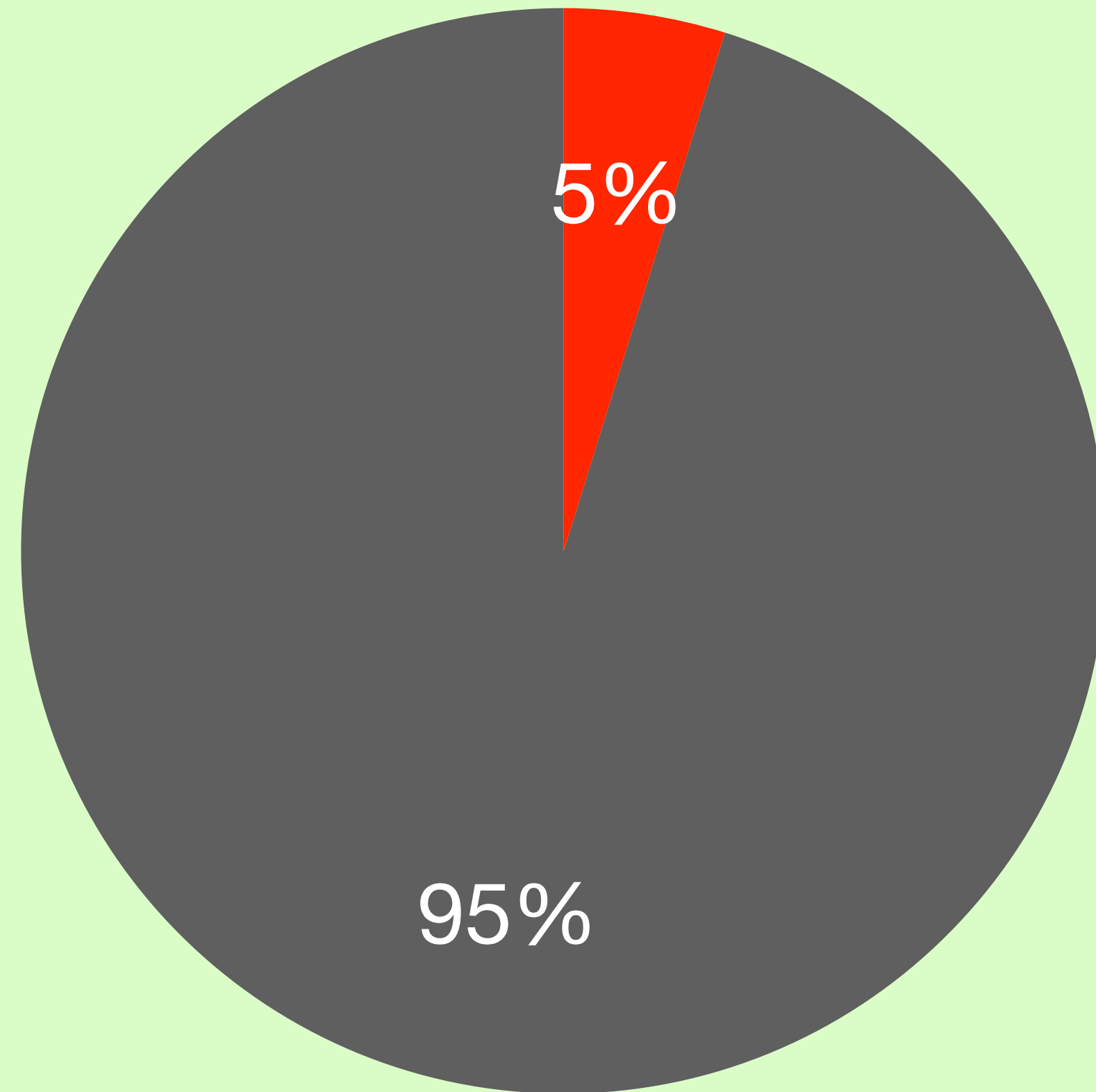
And now autism is here

Source: Legislative Analysts Office, 2019-20 Budget: Analysis of the Department of Developmental Services Budget



Percentage of DDS Consumers with Autism, 1993 v 2018

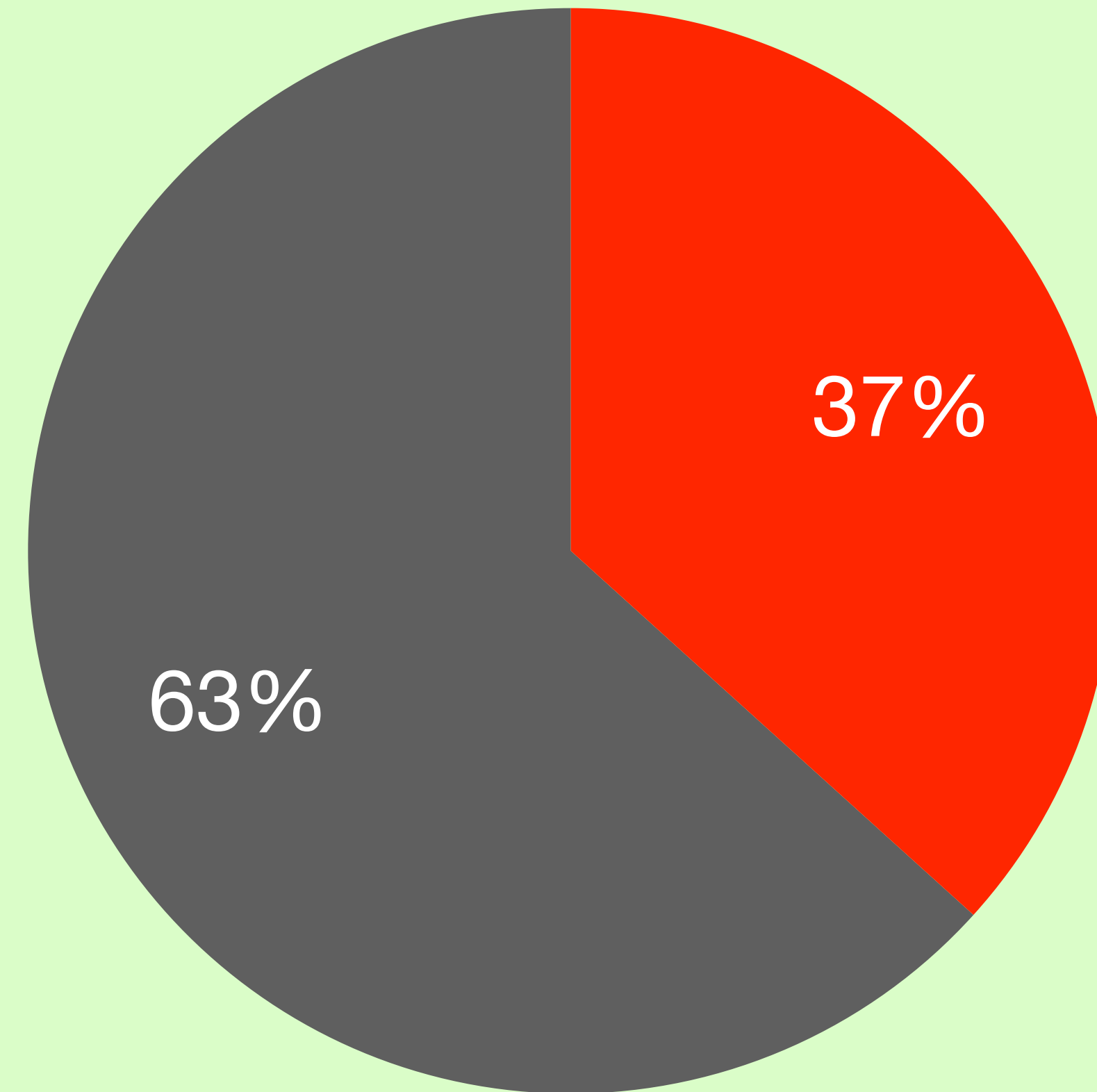
1993



Source: DDS Fact Book 1st ed. 1998

—25 years—

2018



Source: DDS Fact Book 16th ed. 2019

Bay Area DDS Autism Cases, 1990 v 2019



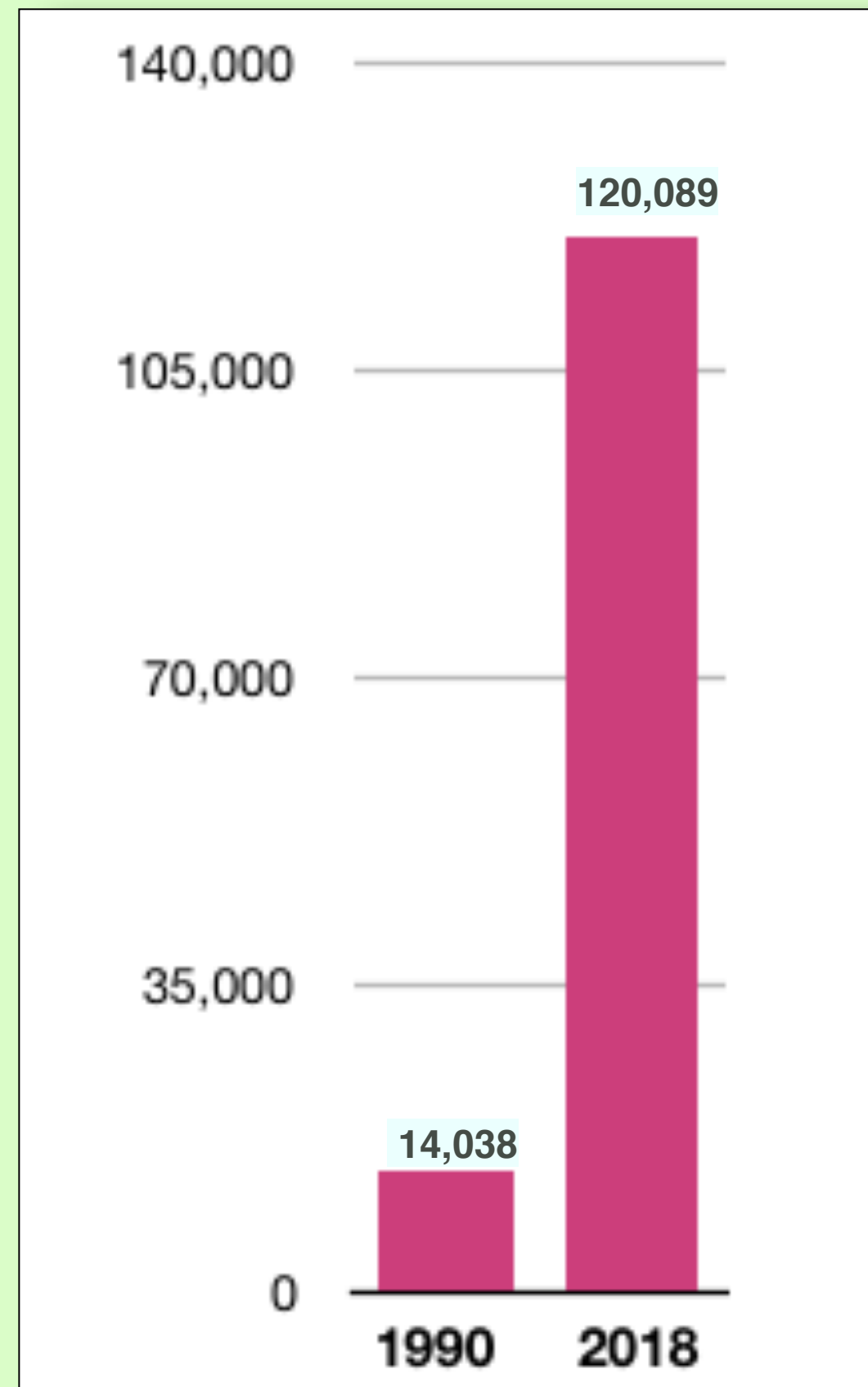
COUNTY	1990	2019	-FOLD INCREASE
ALAMEDA	190	4,677	25
CONTRA COSTA	117	3,390	29
SANTA CLARA	147	4,319	29
SAN MATEO	71	1,031	15

Source: DDS Quarterly Client Characteristics Reports, 2019 data as of June 2019



California Special Education Autism

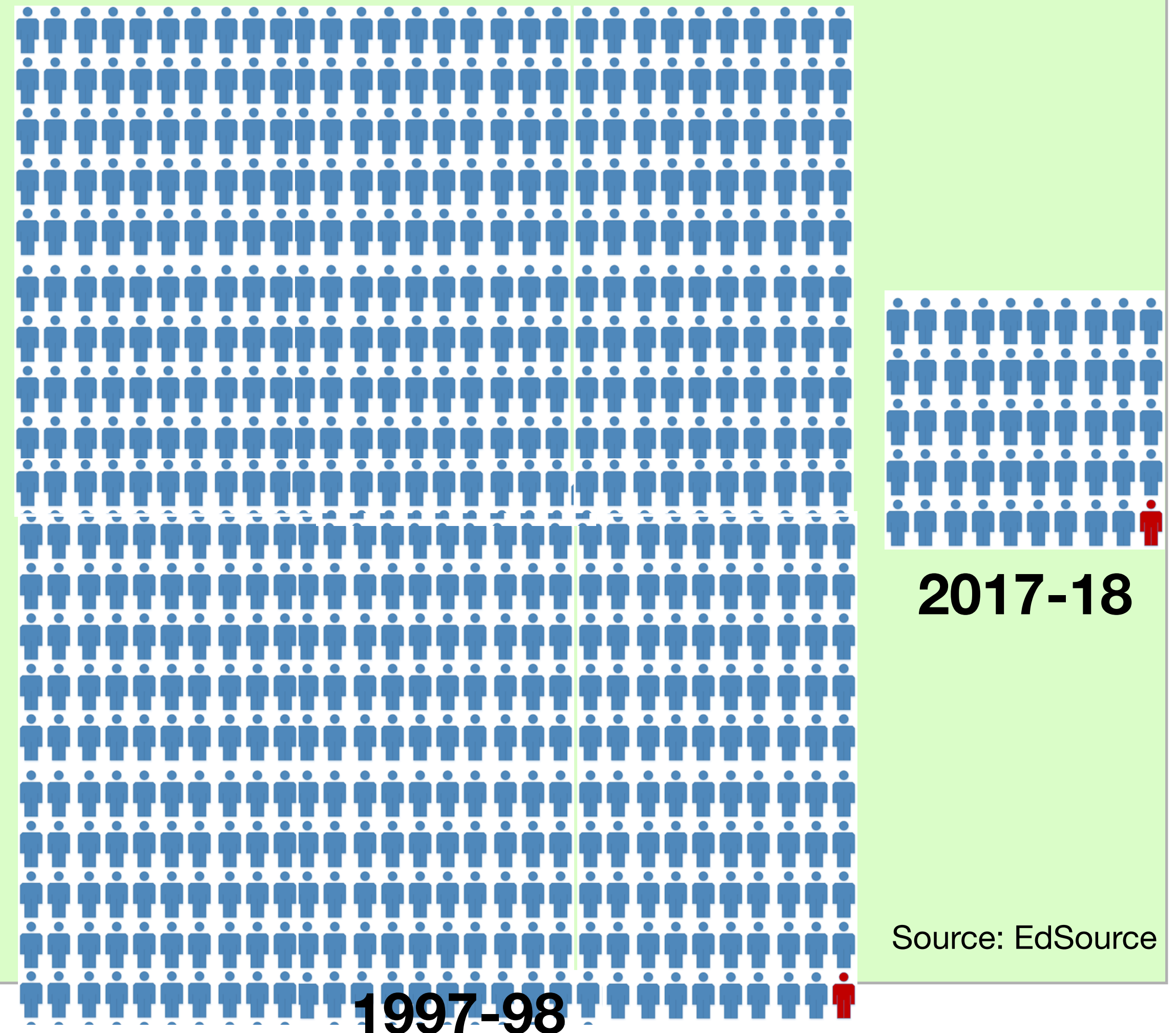
Cases, 1990 v 2018



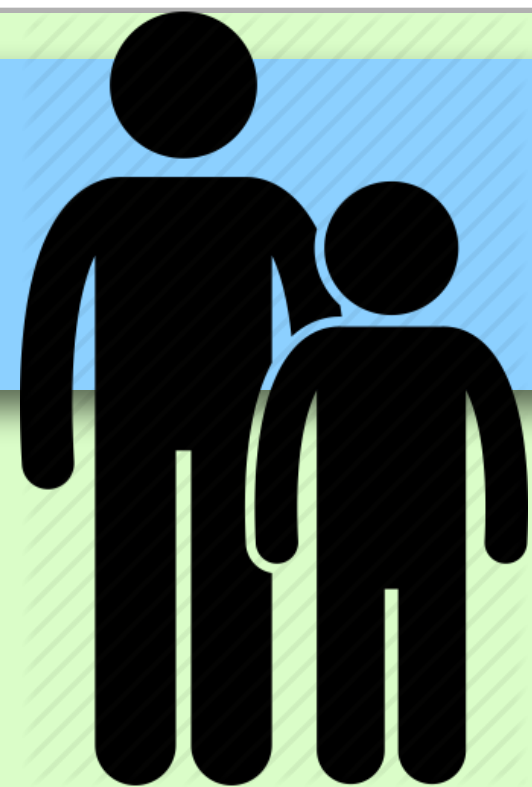
Source: California Department of Education, Dataquest

Prevalence, 1997-98 v 2017-18

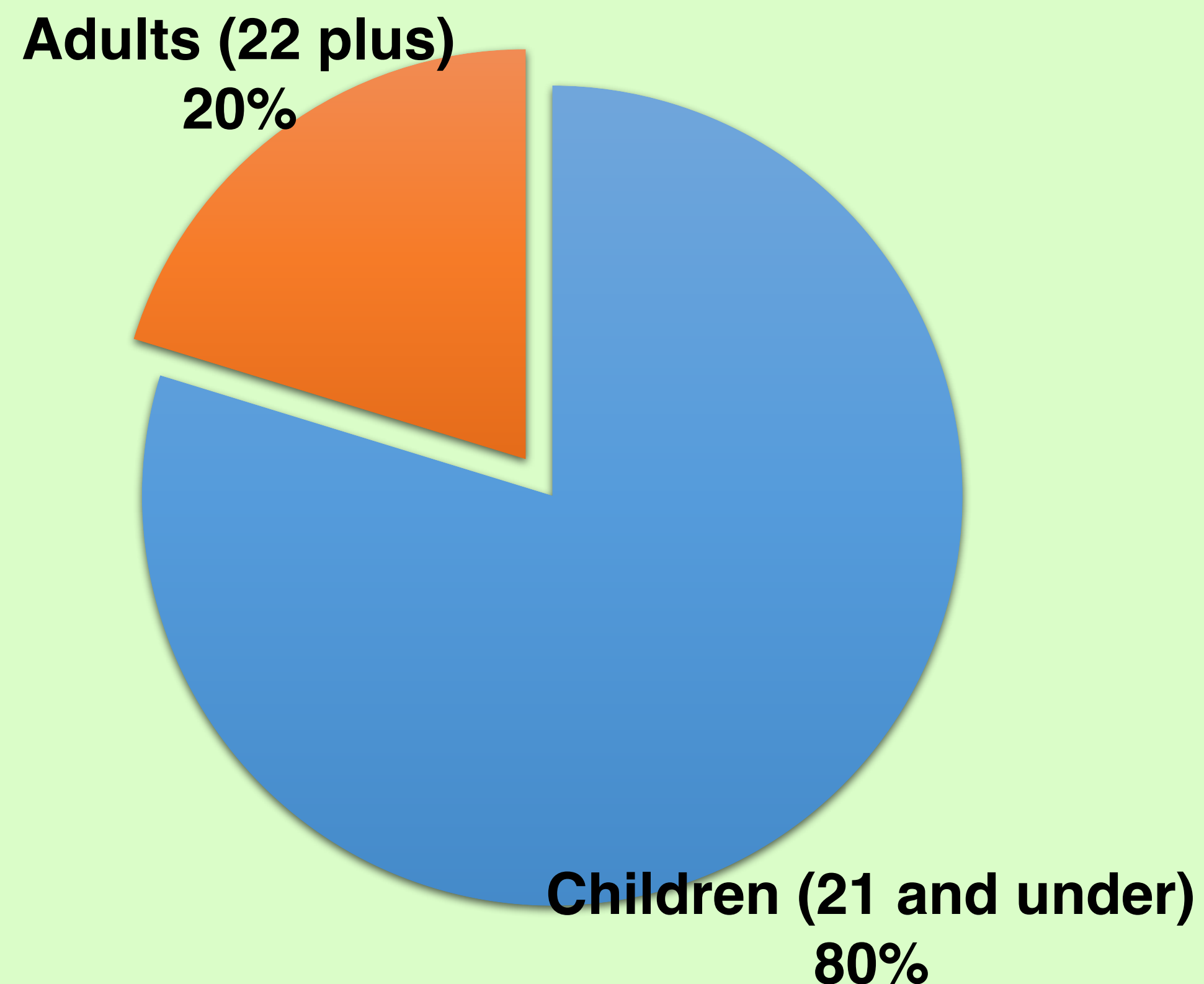
1 in 600 v 1 in 50: a 12-fold increase in 20 years



Source: EdSource



Children v Adults with DDS Autism



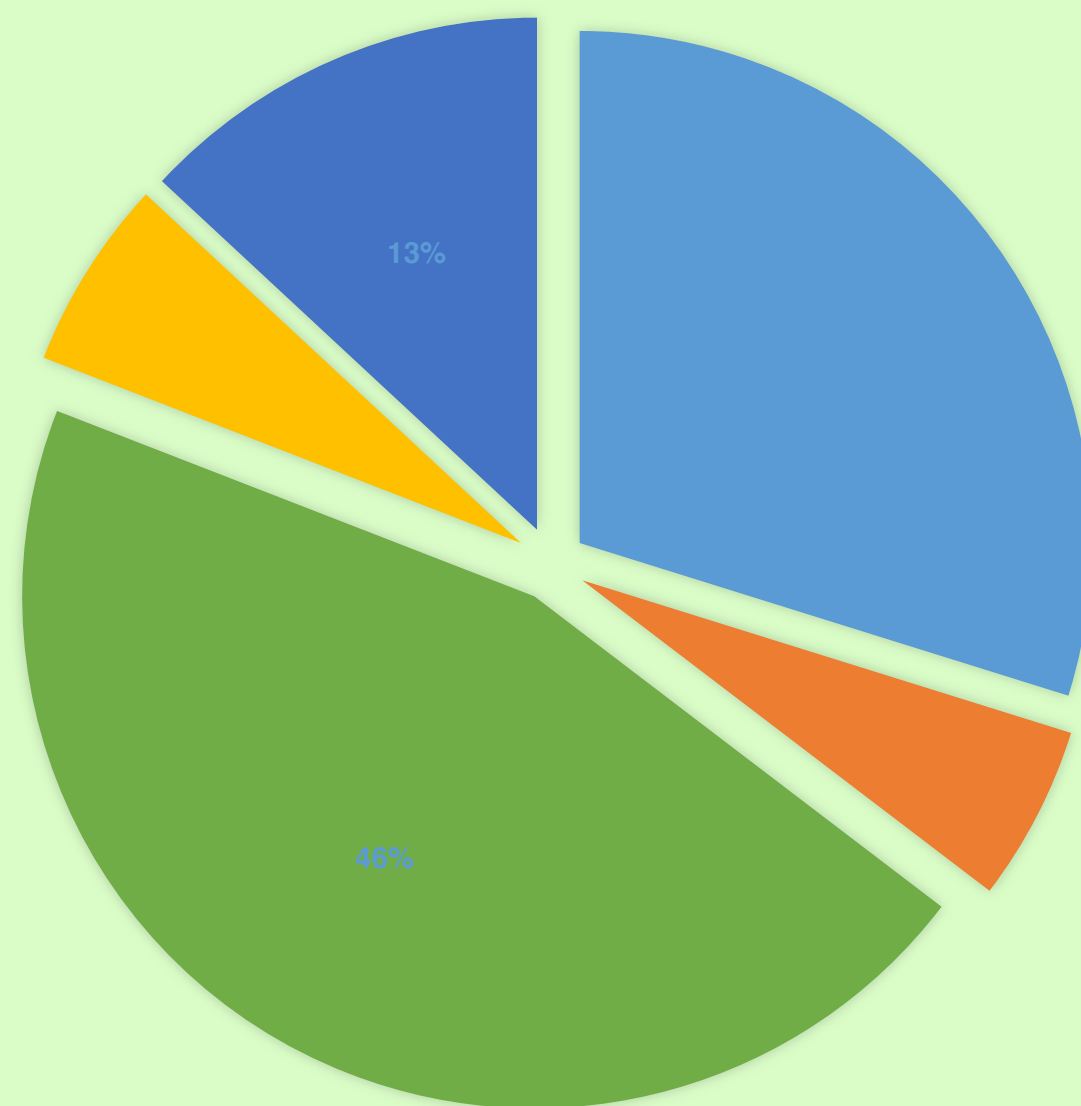
- Children make up 80% of the DDS autism population
- Individuals with autism will make up the majority of DDS adult population in 10 to 15 years
- The DDS adult autism population will grow 5x over the next 20 years

Source: Lauren Libero, DDS. Based on CDER data for Status 2 consumers as of July 2018

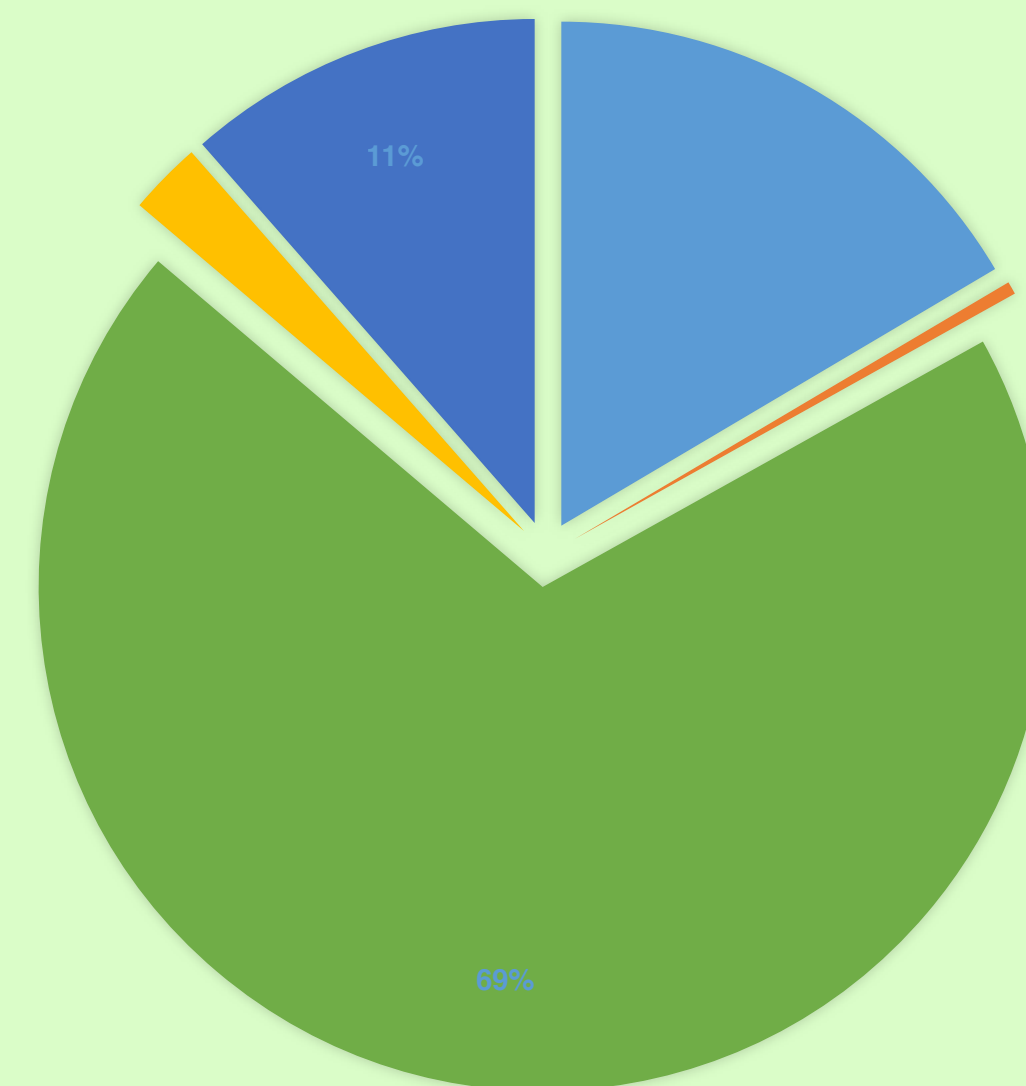
Housing: More Adults with Autism Living with Parents



- Community Care
- Parent/Guardian Home
- Independent Living
- Developmental Center
- ICF/SNF



2008



2018

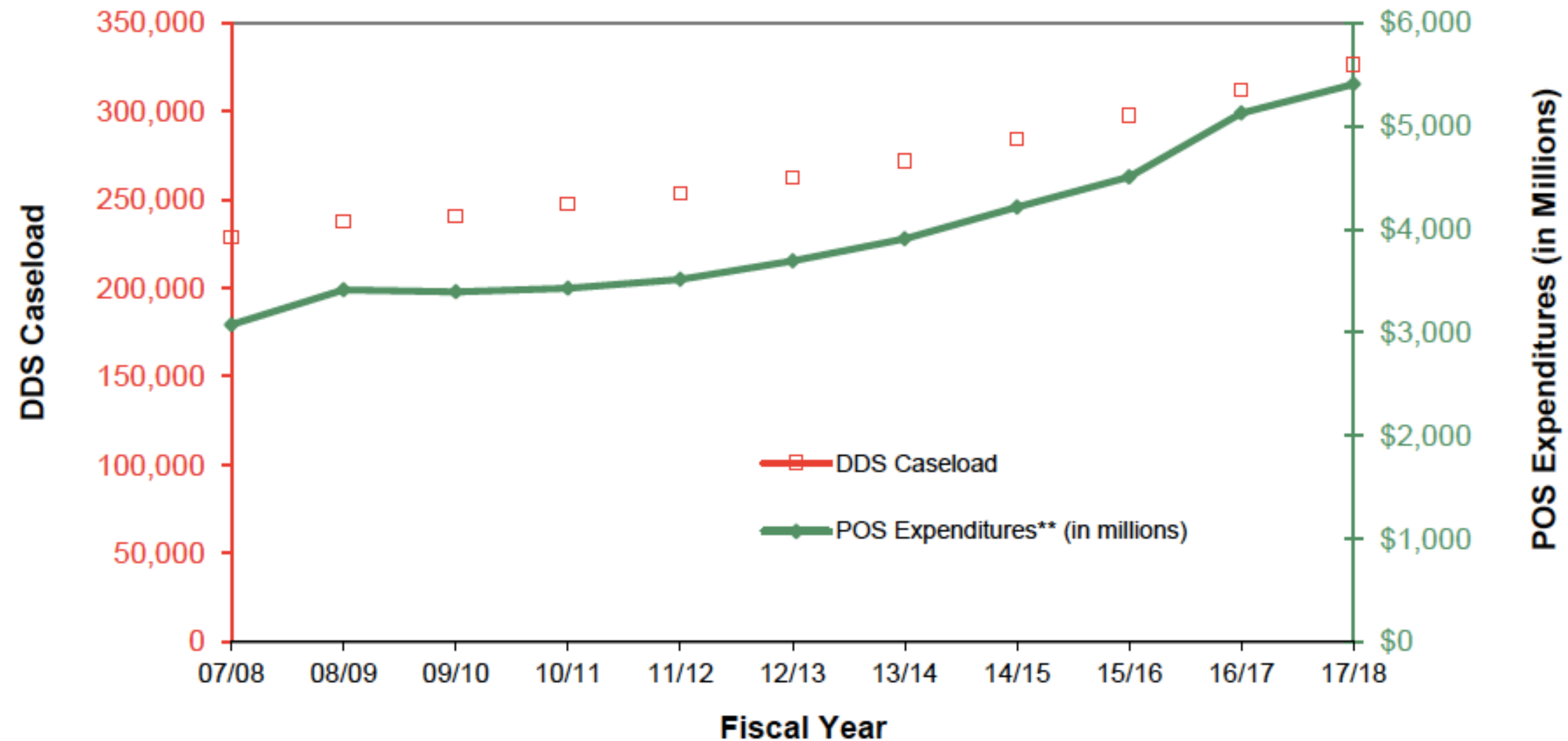
- DCs now negligible; ICFs declining
- Community Care (group homes) has decreased, from 30% to 16%
- Independent living remained stable
- **Parent/guardian home has increased** from 45% (2,979) to **69%** (14,762)

Source: Lauren Libero, DDS, based on CDER data for Status 2 consumers as of July of each year.



DDS Caseload and Purchase of Service Expenditures, 2008-2018

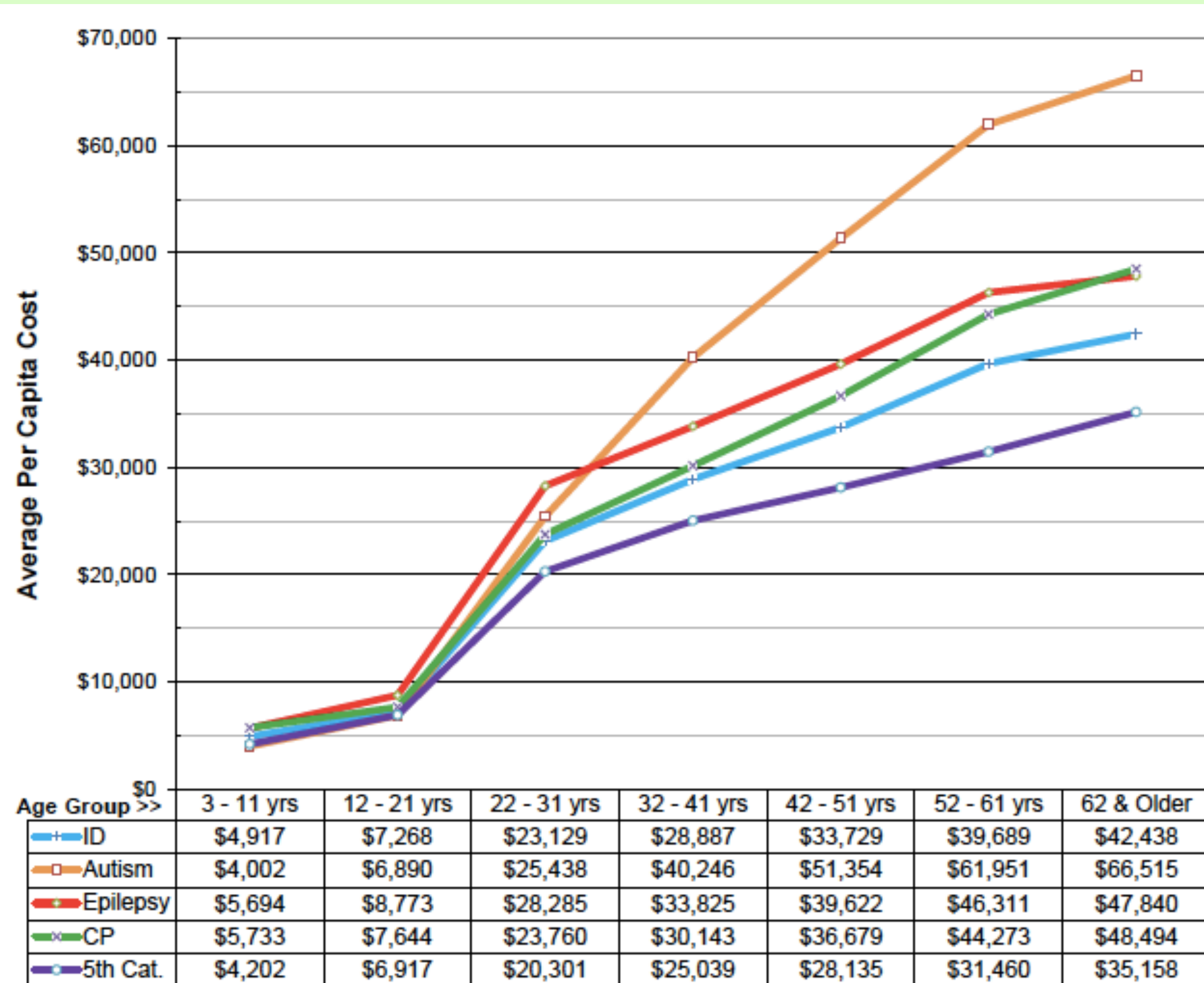
Figure 17: DDS Caseload Number and POS Expenditure Amount (in Millions) for FY 2007-08 to FY 2017-18



Source: DDS Fact Book 16th ed., 2019



Per Capita DDS Expenditures, By Disability and Age (does not include SSI, IHSS, housing support, out of pocket, etc)



**DDS Autism cases
markedly more costly
after age 22, after
school age-out**

Source: DDS Fact Book 16th ed., 2019



Astronomical Costs of Autism



Autism costs estimated to reach nearly \$500 billion, **potentially \$1 trillion**, by 2025

(Leigh P, 2015)

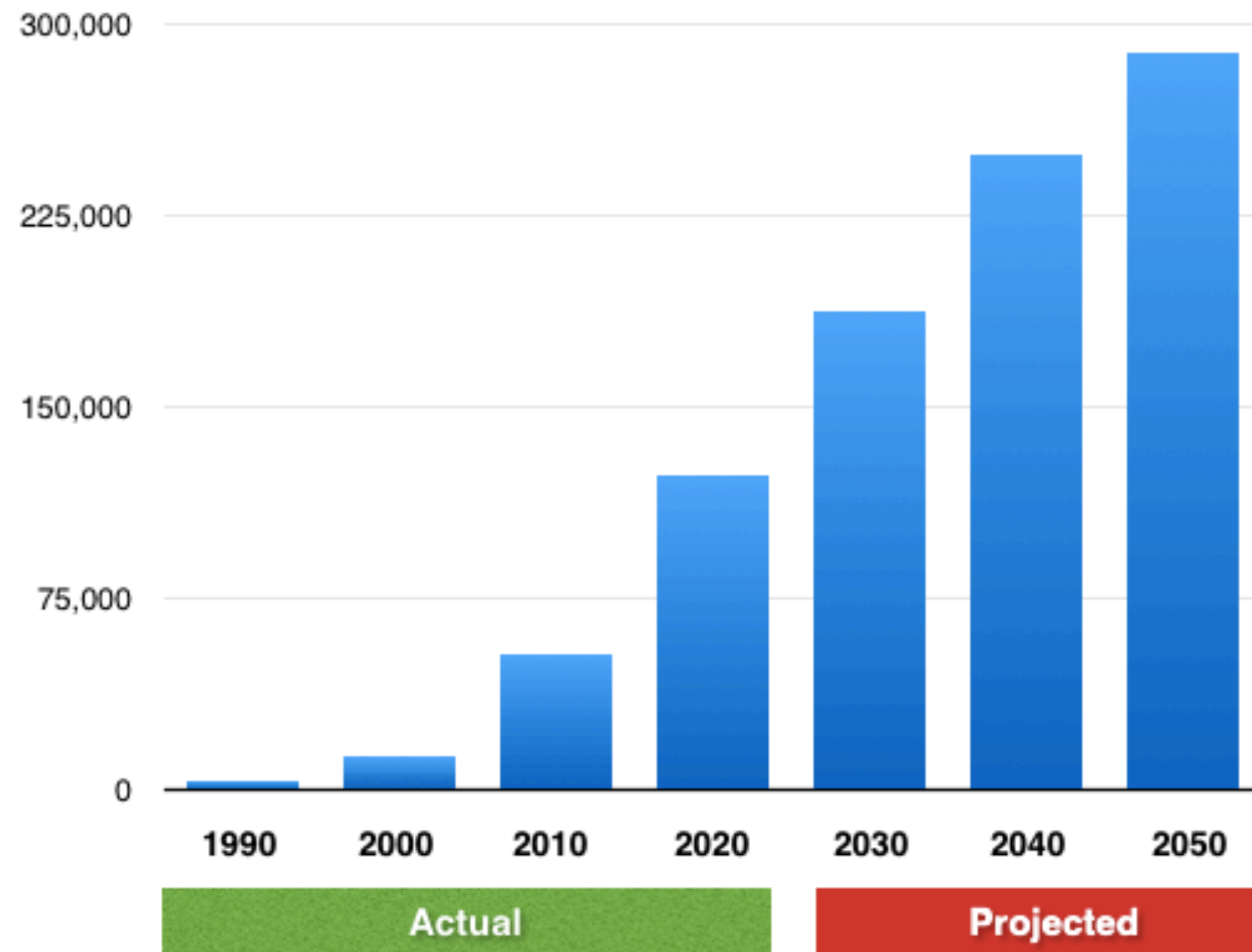
“The current costs of ASD are more than double the combined costs of stroke and hypertension and on a par with the costs of diabetes.”

And this is likely an underestimate.

The Future Looks (Frankly) Catastrophic

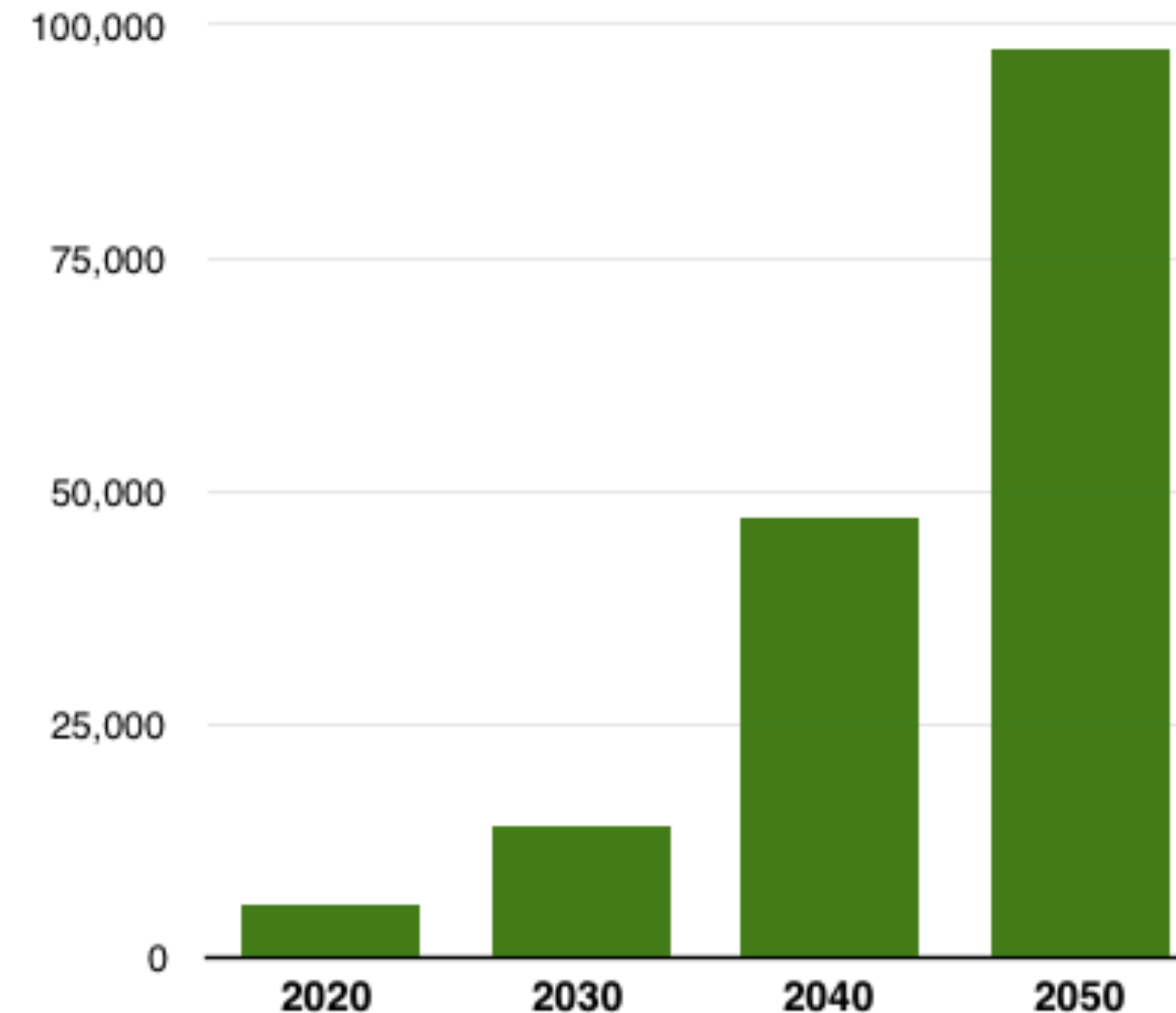


Total DDS Autism Cases, Actual and Projected 1990-2050, Assuming Negative Annual Growth After 2014



175k DDS-qualifying autism cases in 10 years; 300k in 30 years

DDS Autism Cases with Parents 65+, Projected, 2020-2050, Assuming Negative Annual Growth After 2014



2.5-fold increase in autistic adults with aged parents in 10 years; 17-fold in 30 years

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.

But What Does the Field Say?



PRIMER

NATURE REVIEWS | DISEASE PrIMERs | Article citation ID: (2020) 6:5

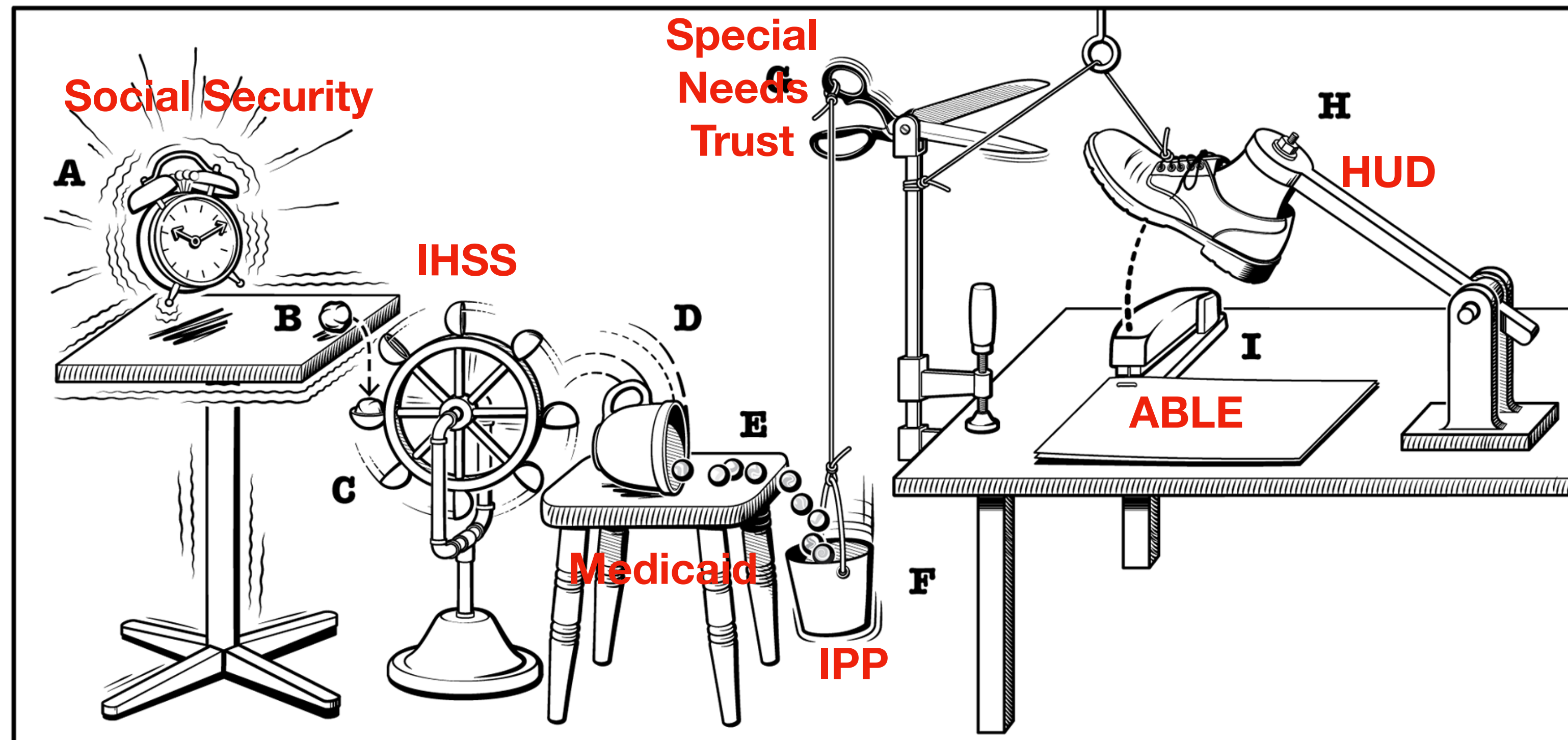
Autism spectrum disorder

Catherine Lord^{1}, Traolach S. Brugha², Tony Charman³, James Cusack⁴, Guillaume Dumas⁵, Thomas Frazier⁶, Emily J. H. Jones⁷, Rebecca M. Jones^{8,9}, Andrew Pickles³, Matthew W. State¹⁰, Julie Lounds Taylor¹¹ and Jeremy Veenstra-VanderWeele¹²*

Many individuals and groups presume that rates of autism are increasing over time, but this supposition is based on data from administrative records rather than community-based studies. Indeed, after accounting for methodological variations between studies, there was no clear evidence of a change in the prevalence of autism in the community between 1990 and 2010 (ref.13 [Global Burden of Disease Study 2017](#)).

Next: The Crisis of Quality

Our fragmented system was not designed for so large and complex an adult autism population



Autism: Not just a label, but qualitatively different characteristics



- Lower self-help and adaptive skills
- Lower executive functioning
- Sensory processing dysfunction
- Anxiety
- Need for sameness
- Lower abstract thinking
- Difficulties with complex learning
- Poor social communication; social relatedness
- Comorbidities
- Challenging behaviors/tantrums/meltdowns/
aggression/violence/property destruction

Bottom Line

- Higher staff **ratios**: day programs are mostly 8:1, up to 3:1
- Specialized **training** (and staff retention is low, burnout high)
- **Specialized programming** and settings in some cases
- Significantly higher **costs**
- Plus, non-regional center clients lack access to adult programs, though private-pay options are increasing



Pragmatic Advice for Today



AUTISM/DD ADULTHOOD CHECKLIST

Parents of children with autism/DDs are often overwhelmed by the complexities of transitioning out of the school system into the fragmented system of adult care. This checklist is intended to provide an overview of many of the elements to consider during this transition period and beyond.

IEP TRANSITION PLAN

BEFORE
AGE 18

Special Education services end after high school graduation or age 22, whichever comes first. By age 16, or earlier if deemed necessary, the IEP must include post-secondary education goals towards the functional life skills, higher ed, employment and other goals for adulthood, based on assessment. Seek referrals to maximize appropriate support and service options as individuals age out of school. The IEP team may include Dept. of Rehabilitation staff for input on services and supports such as job training or other services, including counseling on post-secondary options, community living services, independent living skills and assistive technology.

POST-SECONDARY ACCOMMODATIONS

BEFORE
AGE 18

For the young adults who can take advantage of post-secondary programs such as community colleges or 4-year colleges, Section 504 accommodations can be sought through the disability centers of those schools.

Accommodations may also be requested for employment. <https://askjan.org/> Specialized programs specifically for young adults with ASD are also available, for example College Living Experience and College Internship Program.

REGIONAL CENTER IPP

HIGH
SCHOOL

Most adults with significantly disabling autism are clients of the regional centers where each client's services are governed by an IPP, or Individualized Program Plan. Regional center is the "payer of last resort" — it funds services after generic resources are exhausted (e.g., Social Security, IHSS). The RC taps into the federal Medicaid Waiver/Home and Community-Based Waiver Services to help pay for community-based services. This allows individuals otherwise requiring an institutional level of care to be served at home or in the community. An IPP can include, for example:

- In-home respite / Out-of-home respite
- Transportation services
- Adult day programs / Supported employment
- Behavioral services (must exhaust private health insurance first)
- Residential/living options: Board and Care (group homes); Intermediate Care Facilities; Supported Living Services / Independent Living Services / Family Home Agency / Assistance with finding affordable housing

CONSERVATORSHIP

AROUND
17 1/2

Once an individual turns 18, he or she is considered a legal adult, no matter how dependent or disabled. Conservatorship is a legal means to protect vulnerable adults by transferring some authority to parents or others who the court finds will act in the best interests of the disabled individual. It is prudent to have a conservatorship hearing before the 18th birthday. After the birthday, your child is

An Overview of Transition To-Do's: Free at sfautismsociety.org

- English
- Spanish
- Vietnamese
- Tagalog
- Soon: Mandarin

The next three slides summarize these checklist items.

Public Benefits



Service	Approx value, annual
Special Ed Transition IEP	\$10,000- \$250,000
RC IPP Day Program/Supported Employment	\$5,000- \$50,000
RC IPP Crisis Services	\$5,000- \$500,000
RC IPP Licensed Residential Homes	\$80,000- \$300,000
RC IPP SLS or ILS	\$15,000- \$300,000
RC IPP Self-Determination	
RC IPP Tailored Day Program	
Department of Rehabilitation	
County In-Home Support Services (Protective Supervision)	\$5,000- \$50,000
Social Security (SSI/SSDI)	\$8,000- \$15,000
Medi-Cal	
Subsidized Housing	\$5,000- \$30,000
Transportation	
CalFresh	\$1,000-\$2,400

Housing Options



One of our properties in Santa Cruz which serves 6 higher functioning adults with autism/I/DD.

Brick and Mortar	Support
Live with parents/family in home	ILS; IHSS; Self-Determination
<p>“Own home”</p> <ul style="list-style-type: none"> • Accessory Dwelling Unit • Rental home or apartment (market rate of low-income set-aside unit) • Owned home/townhome/condo • Clustered; Family LLC (eg Peralta Apartments, Fremont) 	SLS; ILS; IHSS; Self-Determination
Licensed residential home/ Enhanced Behavior Home	Part of package
ICF	Part of package

Legal and Financial Planning



Legal protections	
Conservatorship	<ul style="list-style-type: none">• Contracts, housing, health care, sexual relationships
Power of Attorney	<ul style="list-style-type: none">• Requires cognitive capacity to delegate authority
Special Needs Trusts	<ul style="list-style-type: none">• Accumulate assets while retaining eligibility for means-tested public benefits
Letters of Instruction	<ul style="list-style-type: none">• No legal weight but important guiding document



Financial Planning	
ABLE Accounts	<ul style="list-style-type: none">• \$15k/year up to \$100k, without losing public benefits
Life Insurance for SNTs	<ul style="list-style-type: none">• Funded upon death of parent(s)
Property/assets in SNTs	<ul style="list-style-type: none">• Property, gifts

But... Autism's \$500k/year Problem

Miami Herald



- Florida paid a care home about **\$514,000 per year** to ensure Arnaldo Rios-Soto and neighbors were safe.
- Three care workers around the clock close enough to intervene if his behavior jeopardized his safety, or that of others. Arnaldo had bit off the tip of a caregiver's finger, and bit or assaulted more than two dozen staff members or residents at a previous facility, requiring emergency medical care.
- APD reduced funding to **\$440,000 per year**, meaning three workers would supervise Arnaldo during the day, two overnight, and one during some training activities.
- The agency plans to cap services to developmentally disabled people who reside in the community, and outside institutions, at **\$205,000 annually**.

Autism Is a National Emergency; The Future Depends on 20x More Programs, and Lower Costs

Can research help expand programs? **YES**

Can research help lower costs? **YES**

Treatments for adults are desperately needed!

Especially to reduce severe behaviors



Example: Both my kids are nonverbal “Level 3 autism,” but...



\$\$

- Mild behaviors
- Adaptable



\$\$\$\$\$\$

- Dangerous, destructive behaviors
- Highly restricted activities

Contact



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