

Families in Crisis

**The Autism Society of California's
2018 Survey of Adults and Children with
Intellectual and Developmental Disabilities**

Autism Society of California
March 2019





Introduction

Since 2009, the Autism Society of California has been tracking the needs of children and adults with autism and other developmental disabilities in the diverse communities throughout California.

According to the California definition, a developmental disability is defined as occurring before the age of 18 and includes specific categories of eligible conditions: intellectual disability, epilepsy, cerebral palsy, autism, and “conditions requiring services similar to those required for persons with intellectual disabilities.” The Autism Society of California conservatively estimates 425,000 children and adults living with intellectual/developmental disabilities (I/DD), including autism, of which 80% are Regional Center clients. Additionally, there are an estimated 1.7 million California family members affected. The Autism Society affiliates throughout California are on the front lines, taking phone calls, talking with self-advocates and parents regarding the needs and barriers of this population.

The purpose of this report is to highlight the most recent findings regarding quality of life and unmet needs in the ID/DD community, and to empower those working in our communities—from government agencies to nonprofit community based organizations, to use this data to determine what barriers exist for our families. Agencies can then use the data as a call to action for public policies at the local, state, and federal levels to ensure that individuals with intellectual and developmental disorders and their families have access to appropriate services and resources.

All quotes in this report have been used verbatim and are italicized with quotation marks to help them stand out from the narrative.

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Methodology

The 2018 Autism Society of California (ASC) survey was conducted online from October 15th to October 31, 2018. The survey was widely disseminated through a variety of groups, including local chapters of the Autism Society, Regional Centers, State Council on Developmental Disability offices, and other community-based organizations.

California is a diverse state. As such, the family member survey was available in English, Spanish, and Chinese. The survey for self-advocates was available in English and Spanish. The Autism Society of California reached out to a number of community based organizations that serve both the Spanish speaking and Chinese communities.

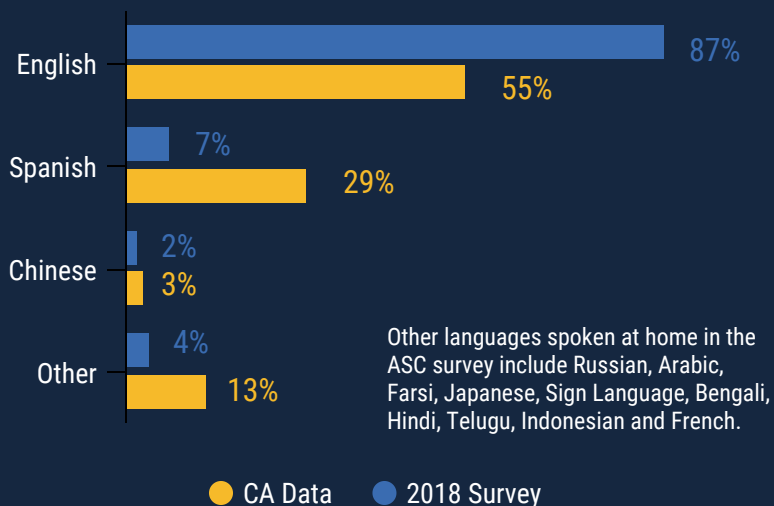
Overall 1,296 individuals participated in the 2018 ASC Survey. Participants were excluded if they were not a resident of California or, if they or their loved one did not have a developmental or intellectual disability. In the end 1,215 surveys were analyzed. We find this survey 95% accurate with a +/- 3%. The results are representative of the people who responded and may not be representative of all people with disabilities and their families.

- Respondents were from 37 of the 58 counties in California, with 64% of the respondents living in Southern California versus a census count of 57% living in Southern California. Of the 1,215 participants, 90% were parents, 9% were self-advocates and less than 1% were spouses, siblings or grandparents.
- Not surprisingly, because this was an Autism Society of California survey, most of the respondents' primary diagnosis was autism (83%). According to the California Department of Developmental Services (DDS) Dashboard, currently shows 20% of the entire DDS population has an autism diagnosis.
- The ASC Survey was made up of 12% of families who had children 0-5 years of age, 49% between 6-17 years of age, and 38% 18 years or older (1,207 survey respondents).
- 80% of survey participants are currently Regional Center clients (1,202 survey respondents).
- 46% of the children and 15% of the adults are currently receiving Behavioral Health Treatment (BHT or ABA) services (1,068 survey respondents).

Methodology

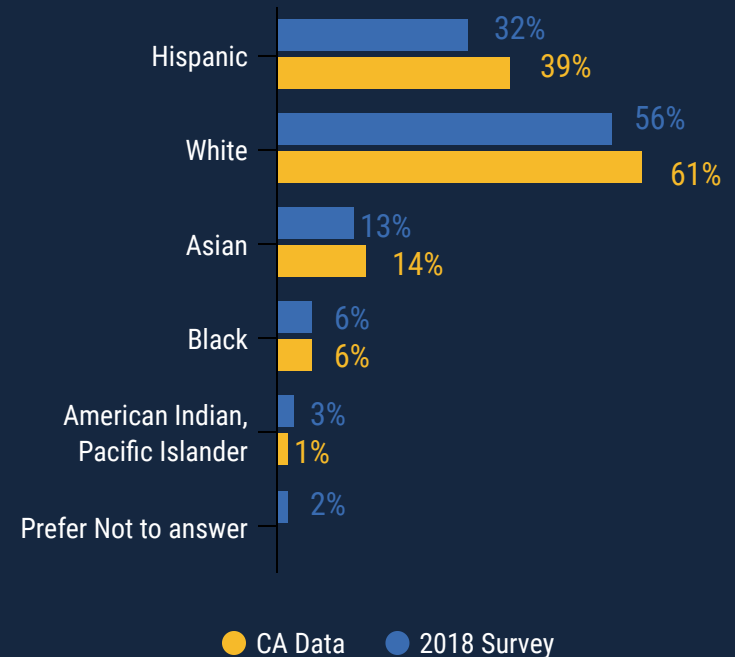
In 2018, the Autism Society improved on outreach efforts to diverse communities. This included in having the 2018 Survey translated in both Spanish and Chinese and having more success in having other community based organizations which primarily serve minority populations to distribute the survey. These efforts paid off and had a more representative ethnic population respond. According to the California 2017 American Community Survey, 39% of the 2017 California population was Hispanic and 13% were Asian. This survey had a 32% participation from Hispanic population and 14% from families who were of Asian decent.

2018 ASC Survey Respondents Primary Language Spoken at Home



ASC Survey 1,202 survey respondents
CA State data <https://statisticalatlas.com/state/California/Languages>

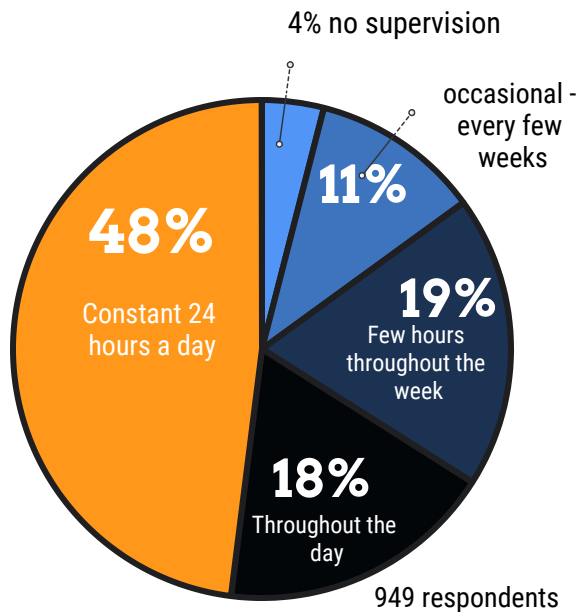
Ethnicity of Survey Participants vs CA Demographics (Multiple Answers Allowed)



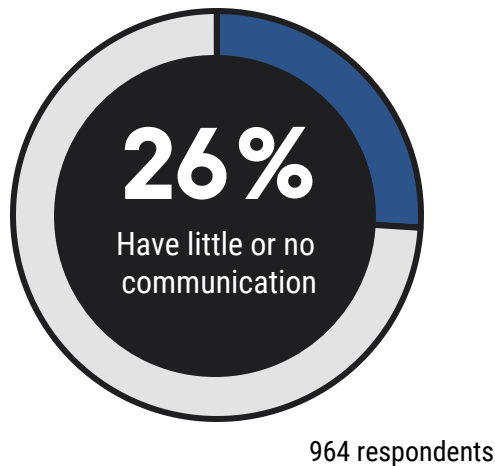
ASC Survey 1,202 survey respondents
CA State data from 2017 American Community Survey

Despite these gains in better representation of ethnically diverse families, the Autism Society of California is committed to improving our reach to families who primarily speak Spanish and other languages in the home. While the 2018 Survey did capture a representative 2% of families who spoke Chinese at home compared to the state average of 3%, the Statistical Atlas advises 29% of California homes speak Spanish while the 2018 Survey had a 7% response rate.

Supervision Needed to Go Out Into the Community



Able to Communicate Basic Needs and Wants



2018 Survey: Characteristics of the I/DD Population

We feel this is one of the most significant findings of this survey. While it is known there are a wide range of symptoms and level of impact of these symptoms in the I/DD population, the 2018 Autism Society of California Survey captured a snapshot of the needs to be safe in the community, be able to participate in social or recreational opportunities, make friends or have romantic relationships, be employed and find a supportive housing situation which works best for them.

- **66% of this population need 24 hour-a day or supervision throughout the day to be supported and safe; only 4% needed no supervision.** This finding is similar to what we found on our 2016 ASC Survey in which 64% of the population needed significant supervision throughout the day and 6% reportedly need no supervision.
- It is also important to point out that the **behaviors family members are concerned about most can have some significant consequences:** 42% of family members were concerned their loved one could run away or wander off; 40% were concerned with physical aggression towards others; 34% self-injurious behavior and 31% property destruction. If out in public, these behaviors could trigger a call to law enforcement highlighting the continued need for First Responder Training as well as qualified staff to accompany these individuals when they are out in public.
- **Approximately 1 in 4 children/adults cannot communicate their most basic needs or wants.** The Survey participants reported that 26% of the individuals cannot communicate their most basic needs or wants most of the time. This is a slight increase from the 2016 Survey which showed 21%. This is consistent with a 2018 Boston University study showing 30 % of children with autism never learn to speak more than a few words—those considered “nonverbal” or “minimally verbal.”

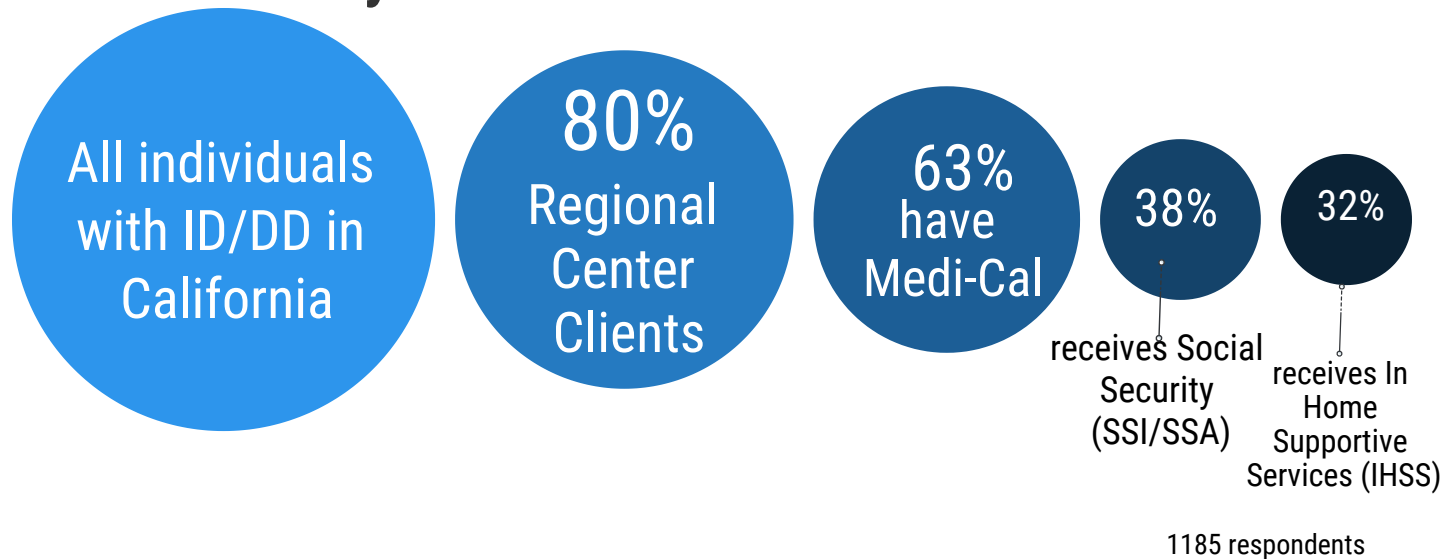
Behaviors Which Concern You Most (Multiple Answers)



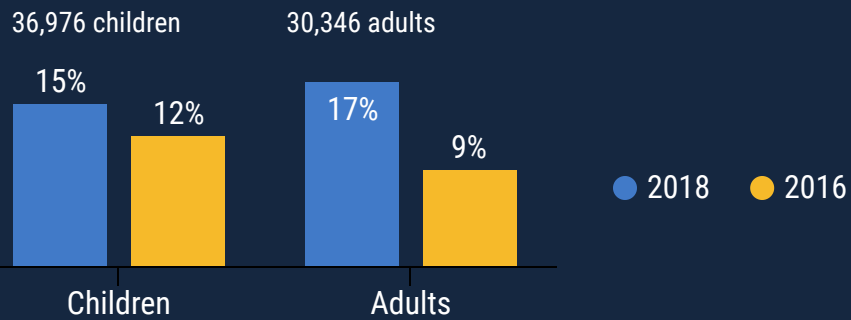
Complicating a families life is the multitude of agencies a family may need to access to obtain services. Each government agency has it's own assessment process and eligibility criteria. Therefore not all individuals will qualify for all services.

As children, individuals may or may not qualify for special education services in the K-12 education system, Regional Center Services, In Home Supportive Services, Social Security. In adulthood, self-advocates and families face re-assessments for Department of Rehabilitation services, Social Security benefits, and college support services. The chart below indicates the utilization rates of children and adults who participated in government services.

2018 Survey: Utilization of Government Services



Families in Crisis 2018 vs 2016 ASC Survey



67,000 Families in Crisis!

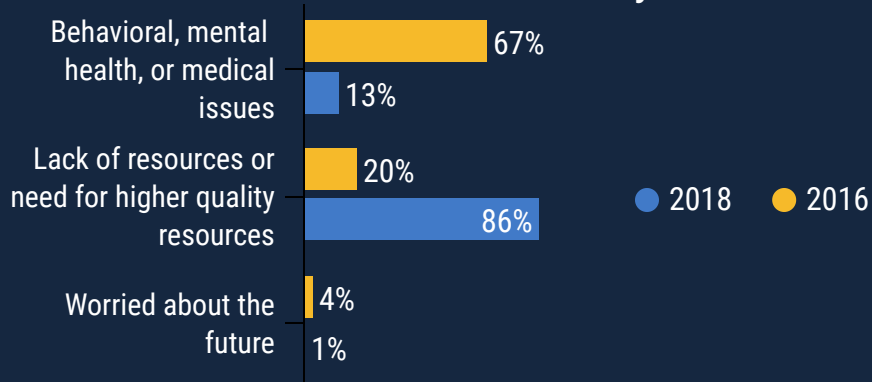
Various service systems may have their own definition of what constitutes "crisis." Individuals and families living with I/DD may not be able to quote the regulations, but to United States Supreme Court Justice Potter Stewart, these families "know it when they feel it." Unfortunately, the numbers of individuals and families who feel they are in crisis has increased since the 2016 ASC Survey. **Families with children who reported they were in crisis rose from 12% in 2016 to 15% in 2018 which represents 36,976 children.**

The news is worse for adults with I/DD. **The number of self-advocates and families who reported they were in crisis almost doubled from 2016 from 9% to 17% in 2018.**

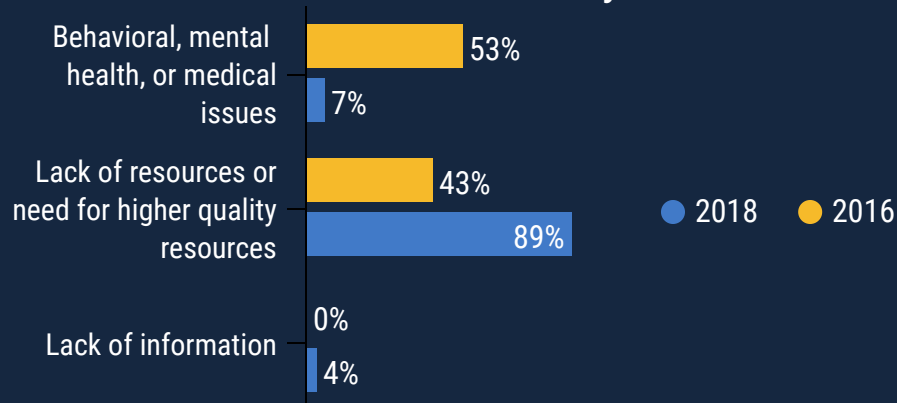
Additionally, **there was a large shift from 2016 to 2018 in the reasons why individuals and families were in crisis.**

- For children, in 2016, 67% of parents indicated the need for behavioral or medical support was the prominent reason for crisis compared to only 13% of families in 2018. We would hypothesize that this was due to Medi-Cal not covering Behavioral Health Treatment, speech and occupational therapy services at the time of the 2016 survey. Since then, the benefit has been offered not only to those with an autism diagnosis, but also those with ID/DD who have need.
- For self-advocates and families with adults there was also a large shift from what constituted a crisis. Likewise, access to behavioral, mental health or medical issues were the most common reasons an adult or family member was in crisis in 2016 (53%). This has decreased to 7% in 2018 while lack of resources or need for higher quality resources more than doubled from 43% to 89% in 2018. Also of note is that a lack of information about adult services appeared as an issue in the 2018 Survey.

Top Reasons for Children 0-17 yrs in Crisis 2018 vs 2016 ASC Survey



Top Reasons for Adults in Crisis 2018 vs 2016 ASC Survey



2018 Children: 616 survey participants and 362 self-advocates/family member of adults responded. Multiple answers allowed.

175,000 Families are in Desperate Need of Services!

Before an individual or family is in crisis, they usually have an unmet need. Because the Autism Society affiliates are on the front line answering calls and talking with individuals and families, we often hear about the needs. This is the first year we attempted to measure the unmet needs of individuals and families.

We were not prepared for the response to this question. Seventy-one (71%) of families of children and 91% of self-advocates/family members with adults indicated they currently have unmet needs.

Addressing these needs now is critical in order to prevent families from shifting into crisis. Some of these needs are due to restrictions and cuts made to necessary Regional Center services in 2008 which have not been restored. Further complicating this issue is the aging autism population, which requires innovative services with trained and well-paid staff.

This report will look at the top 5 resources needed as reported by self-advocates and families in the next part of the report.

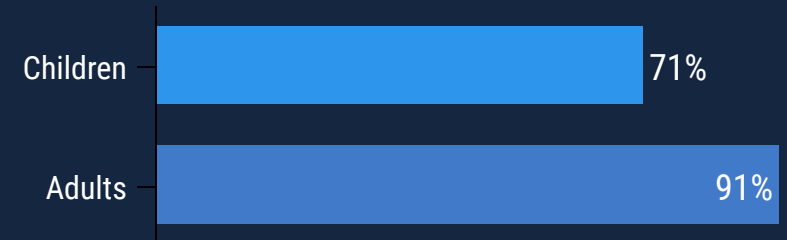
Top Unmet Needs for Children with I/DD as Reported:

- Social skills and community integration services
- Improve their child's ability to communicate
- Need for improved independence and safety skills so they can participate as a community member safely
- Various school issues
- Behavioral issues
- The need for a better trained, higher paid, more stable workforce to help with caretaking needs including IHSS and respite services.

Top Unmet Needs for Adults with I/DD as Reported:

- Social skills and community integration services
- Employment, job training and day services
- Need for improved independence and safety skills so they can participate as a community member safely
- The need for a better trained, higher paid, more stable workforce to help with caretaking needs including IHSS and respite services.
- Housing and supported living services

2018 ASC Survey Results - Unmet Needs



2018 Survey: 728 families of children responded; 362 self-advocates of families with adults responded

UNMET NEEDS FOR CHILDREN WITH I/DD

518 survey participants reported over needs in 18 different categories. Families were able to write narrative in order to express topics most important to them. Multiple answers were given. The top 5 unmet needs for children were:

- 30% - Social Skills and Community Integration
- 11% - Improve child's ability to communicate
- 10% - Improve Independence and Safety Skills
- 9% - School Issues
- 7% - Behavior Issues
- 7% - Issues with staff (respite, IHSS)



UNMET NEEDS FOR ADULTS WITH I/DD

There were 362 survey participants for adult issues who reported over needs in 12 different categories. Families were able to write in answers in narrative form to ensure the needs they expressed were the most important to them. Multiple answers were given. The top 5 unmet needs for adults were:

- 21% - Social Skills and Community Integration
- 20% - Employment, Job Training and Day Services
- 11% - Improve Independence and Safety Skills
- 11% - Issues with Staff
- 10% - Housing



"Community education, better programs that address individual needs and strengths, and SOCIAL GROUPS with special needs individuals AND neurotypical individuals in the same age range. Our kids are dying of loneliness, isolation, and lack of acceptance and opportunities. Where is the all-inclusive program???"

#1 Need: Social Recreation Services

The number one unmet need for adults and families is the lack of social and recreational services. Thirty percent (31%) of families with children and 21% of adults cited this as their biggest unmet need. This translates into an estimated 55,000 children and 36,000 adults.

Children and adults with and without complex needs should have safe places in the community to learn, be with friends, and participate in recreational opportunities. Time and time again, we hear from self advocates and their families of their dissatisfaction of their limited community access.

Parents and self-advocates reported having social and recreational services as their number one need. **Only 22% of parents of children and 23% of advocates and parents of adults reported they felt they had enough friends and/or social opportunities.**

In 2008, the California Legislature voted to suspend Regional Center Social Recreation services which stopped this vital service from being provided to Regional Center families. It is not enough to reinstate these services, they need to be configured to allow the entire population access. As a reminder, 25% of this population is minimally verbal and approximately 2/3 will require a high level of supervision. Families and self-advocates are looking for a place to learn recreational, social and relationship skills in a safe environment. This will require a trained and stable work force.



TOP BARRIERS THAT IMPEDE COMMUNITY PARTICIPATION

63%

Hard to find appropriate activities



31%

Child/adult not interested in going out



23%

Not enough authorized hours for staff to accompany person

21%

I'm too afraid what will happen if they have behaviors

19%

Staff not permitted to transport



18%

Can't find staff to work hours needed



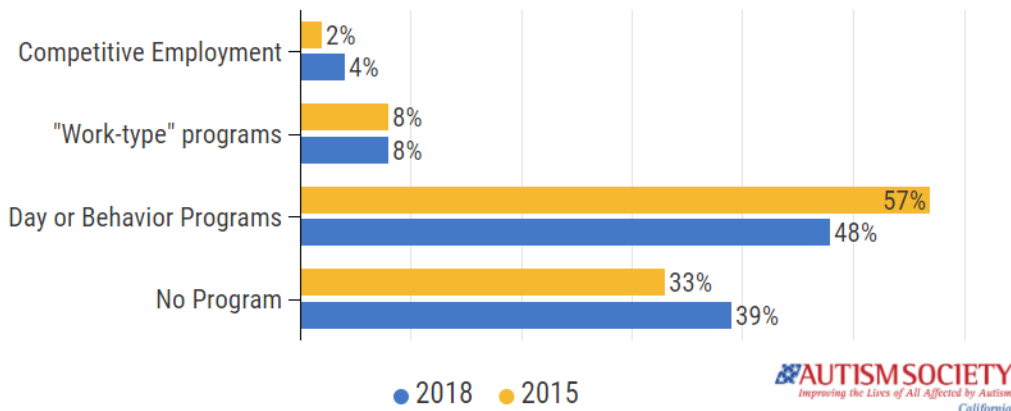
819 total survey participants

Call to Action

1. Restore Social Recreation and Camping funding to Regional Centers.
2. Restructure these services to allow for innovative services with trained, knowledgeable and consistent staff. Instead of monitoring an adult or child at a park, or walking the mall, or sitting in a coffee shop for hours, families want service providers to teach social and recreational skills while providing positive behavior intervention and support for those with different learning and communication needs.
3. Since 2008-09, Regional Centers require new vendors who provide certain services to accept either the state median rate or the Regional Centers' median rate —whichever is lower—rather than negotiate a rate. The Autism Society of California recommends Trailer Bill language to eliminate the use of median rates and allow Regional Centers to negotiate rates and develop flexible funding.

Current Employment for Adults in the Regional Center System

In the last 3 years, the number of adults in competitive employment doubled from 2% to 4%, however, the number of individuals with no type of program increased 6%.



Data from DDS Public Records Request May 2015 and Aug 2018 - does not include college

2018 ASC Survey - Who is Satisfied with Current Work Situation?

11% No Program

14% Self-employed or Family business

39% Day Program or Workshop

41% Supported Group

52% Part-time or Full-time employment

271 self-advocates/family member survey respondents

"More training employment options for adult clients. Day programs are too sheltered and repetitive."

"teach her work ready skills, find a vocation for her, train her in it."

"finding suitable & safe employment in the near future, such as internship w/mentor. Many employment programs have a long waiting list, or want to only offer custodial jobs."

#2 Need: Employment, Job Training, and Day Services

1 in 5 adults (20%) - 34,000 adults

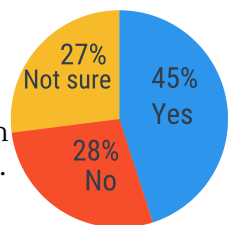
There are over 126,000 working-aged adults in the Regional Center system as of Aug 2018, up from 105,000 in 2015. Long-term underfunding of the current vocational service systems has left Regional Centers, the Department of Rehabilitation, and service providers struggling to serve more people with fewer resources. The development of innovative programs such as the Paid Internship Program (PIP) and the Competitive Employment Bonuses have made improvements to the Competitive Employment rate doubling it from 2% in 2015 to 4% in 2018.

According to the 2018 ASC Survey, while 81% of self-advocates and parents of adults feel it is important for the adult to work a minimum of 20 hours a week at an integrated job in the community receiving minimum wage or greater, according to Regional Center data, approximately 4% of this population has achieved this goal.

This a multi-faceted problem with many issues intertwined including:

1. Most families and self-advocates have the expectation of work in the community making minimum wage or more no matter how much supervision or behaviors may be an issue.
2. The ASC Survey showed 45% of the population which is not working and has no programs would like to work.
3. Most individuals in current adult day service programs report not being satisfied with current services.
4. This population has not had the opportunity to experience meaningful career exploration. This makes it difficult for them to access government programs such as Department of Rehabilitation (DOR), One Stops, or other programs when they do possess basic information.

ASC 2018 Survey
Adults with No Programs:
Do You Want to Work?



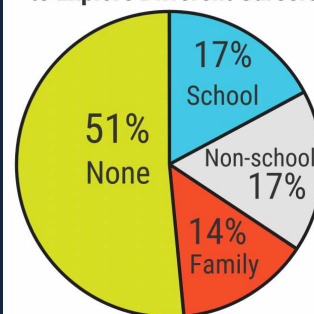
86 adult survey respondents

Call to Action

1. We urge the Department of Developmental Services (DDS), Department of Rehabilitation (DOR) and the California Department of Education to set aggressive employment goals specifically for the ID/DD population. These goals should include competitive integrated employment, hours worked, hourly wages, and the number of individuals who have their own business. We encourage the formation of a statewide stakeholder group to assist these agencies in developing the goals.
2. This system change will require a continued investment into building capacity and collaboration among service agencies. Education and training on best practices and ongoing technical assistance is needed in a variety of areas such as behavior management, employment, ACRE certification, sensory and communication needs. This needs to be done for management, line staff and educators.
3. Encourage teaching early vocational skills to improve workforce readiness. Employment opportunities should be meaningful to the student and the family, and the time spent should be significant in preparing the student for a 20-40 hour work week.
4. Abolish median rates and allow for start-up funding for programs and services within the Regional Center's discretion. Allow Regional Centers to negotiate and develop flexible funding and innovative service models for job developing, job exploration, employment training, and work skills development programs – all with accountability.
5. Invest in customized employment. Because 60-70% of this population has severe behavioral issues and they may be a danger to themselves or others, funding streams must be developed for quality vocational assessments (like the Discovery model) as well as customized employment supports.
6. Allow for funding for job development programs that provide training for technical as well as social/work skills. We have a generation of adults who have not had work experience and need to be taught the skills and given opportunities to practice them in order to be successful in the community.
7. Continue to reward results through the Paid Internship Program (PIP) and the Competitive Integrated Employment (CIE) Incentive Payments.
8. Clarify expectations. All services should be focused around person centered practices. Families are frustrated when a vendor's definition of community integration is walking around the mall versus true skill building and training. There should be a range of options for all individuals.

Autism Society of California 2018 Survey Barriers to Employment for Adults with Intellectual and Developmental Disabilities

Has the Adult Had Opportunities to Explore Different Careers?



324 survey respondents

Little Job Exploration Leads to Multitude of Barriers

There are many consequences to having little or no job exploration: not only do individuals not know what kind of job they would like, they do not know the accommodations they may need at a job site. Many also lack the unwritten social rules of having a job - group skills, working with the opposite sex, etc. This lack of social skills was in fact identified as the biggest barrier by more than half of the adult survey participants.

34%

Know What Kind of Job or Career They Want to Have

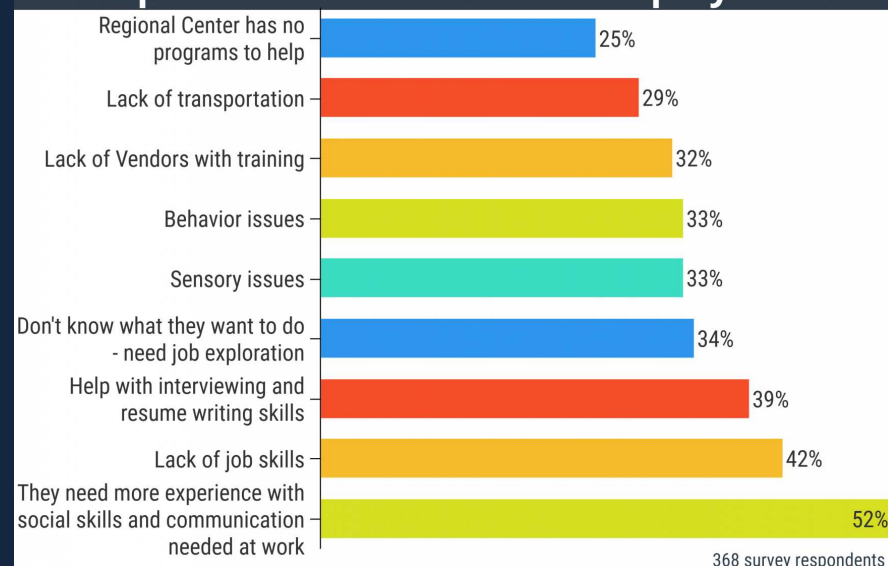
380 survey respondents

32%

Can Identify Accommodations Needed for Work

380 survey respondents

Top Identified Barriers for Employment



368 survey respondents

#3 Need: Independence and Safety Skills

10% children - 17,600 children
11% adults - 18,000 adults

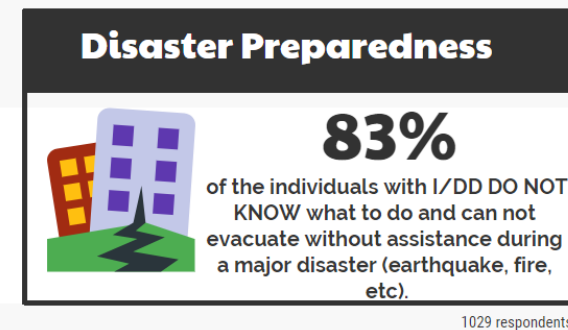
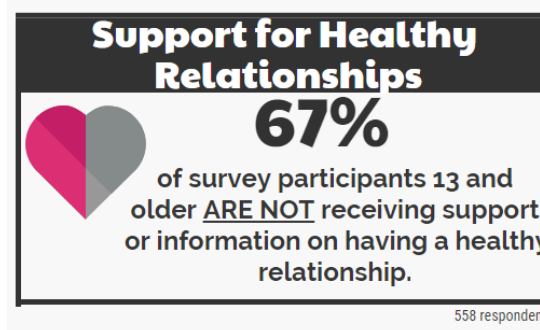
Self-advocates and parents stated their frustration with the lack of resources and services to help their loved one be more independent in the community. These skills may be on the top of the list for most parents, but parents with loved ones with intellectual and developmental disabilities may have a slightly different list of priorities and concerns and their worries may extend into adulthood.

This category included the lack of functional living skills, safety skills including emergency and disaster preparedness training, relationship skills and self-advocacy skills.

Learning differences, limited situational awareness, behavioral, sensory and communication issues are often areas of need and concern. Skills should be taught repetitively, with visual supports, and in a variety of settings. Because someone knows how to cross a street by their school does not mean they know how to cross a street by their house.

Call to Action

Children and adults should have training in these skills through many agencies - schools, behavioral agencies, and vendored programs. They should be delivered in a culturally sensitive way with parent education so that the parents can reinforce the skills learned.



#4 Need: Staffing

1 in 14 children (7%) - 11,800 children

1 in 10 adults (11%) - 18,000 adults

Considering over half of the families with children and 40% of the families with adults have loved ones which require 24 hour a day supervision, the need for a trained and stable work force to assist parents is not surprising.

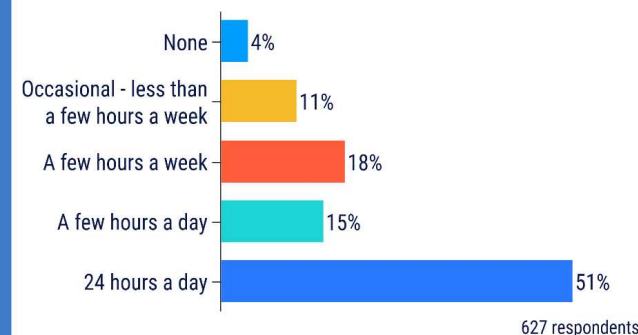
We frequently hear stories about these caregivers having to work two or three jobs just to make ends meet.

Call to Action

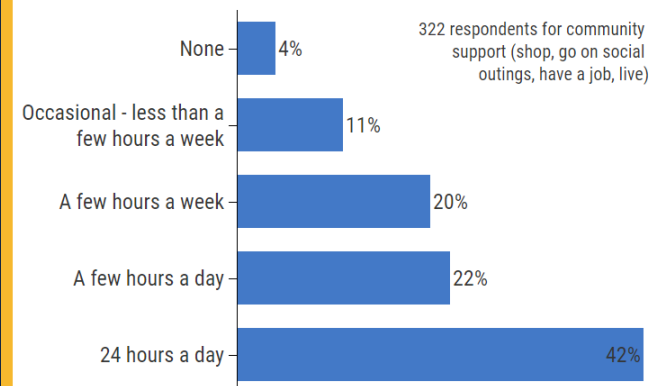
1. Community providers add significant value to the lives, health and well-being of individuals with I/DD and their families. These direct care providers need to be compensated for their worth with a competitive wage with benefits including paid vacations and sick time.
2. Paid training should include specific training to meet the individual's needs including medical, behavioral strategies including, prompting, positive behavior reinforcement, sensory and communication strategies.
3. High schools and colleges should develop Career Technical Education (CTE) with supports for the ID/DD population to expose students to this field.

"Would love to take my daughter on a vacation/sightseeing but respite workers not allowed to flush John's cecostomy (the Regional Center says it is a medical procedure) and I have no family/friends willing to watch my son overnight. The last two times we have been on vacation, my son has wandered off and we have had to involve police, so I am afraid of taking him on vacation."

How much support is needed for a child with ID/DD ?



How much support is needed for an adult with ID/DD ?



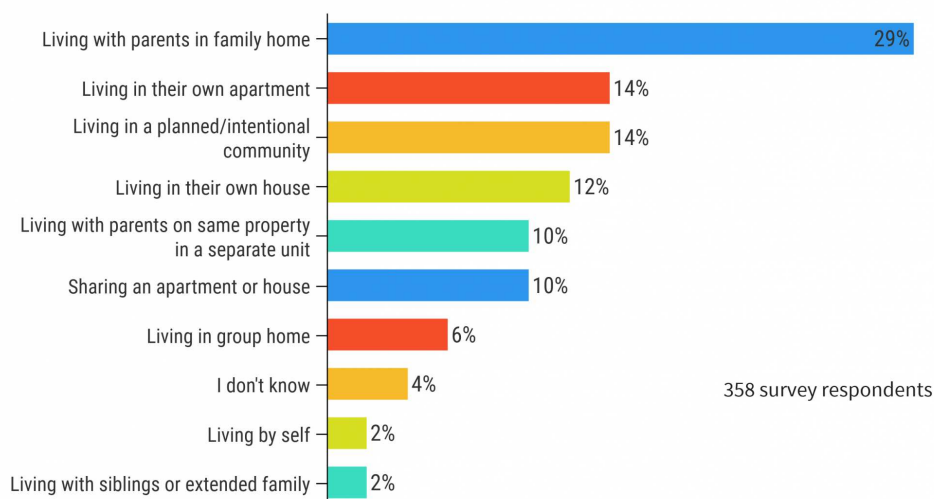
Housing

for individuals with I/DD

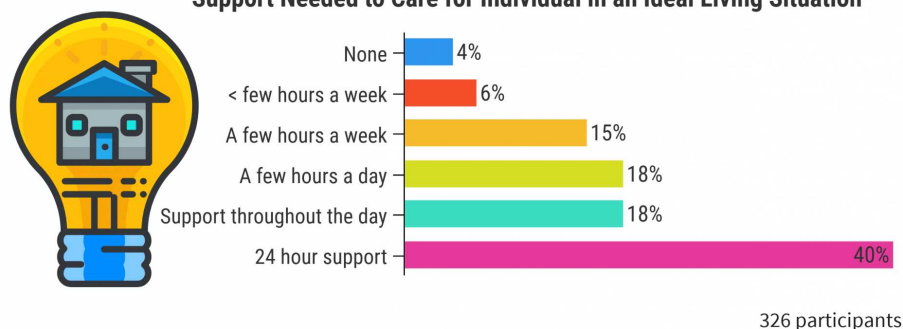
29%

of parents believe living with them is the most appropriate place for their loved one to live. This is a decrease from 2016 when 37% of parents believed it was the most appropriate place.

Preferred Living Arrangement



Support Needed to Care for Individual in an Ideal Living Situation



#5 Need: Housing and Supported Living Services

1 in 10 adults (10%) - 17,000 adults

All parents may wonder what life will be like for their children when they are gone, but for parents with children and adults with ID/DD, the issue of a safe place with supportive, loving staff to assist them becomes particularly poignant. Making matters more complicated are the emotions surrounding congregate care living i.e. group homes, intentional communities, campus living, etc. Families want to be able to choose the living situation which would keep their loved one safe, provide the appropriate level of support with trained staff and opportunities for social and vocational services. This includes being able to be with whom you want to spend time with. The Autism Society of California believes there should be a range of options and supports for these person-centered choices.

The Lanterman Act provides opportunities for adults with developmental disabilities, regardless of the degree of disability, to receive supports necessary to live in homes that they own or lease. The California housing crisis impacts any decisions to live independently. Unfortunately, an individual reliant upon SSI cannot bear the hefty weight of housing costs and as a result, living independently may not be a realistic option. Because of the lack of staff to cover all the hours necessary, many parents have no choice and either do not work or reduce the number of hours they do work. Many of these families do not have additional income to assist with rent and related expenses. Self-advocates and families indicated in the 2018 Survey that cost of rent was the top concern related to housing (66%).

Almost equally important in the 2018 Survey was staffing to help support the living arrangement. While Regional Centers offer supported living services (SLS) to help individuals exercise meaningful choices and control their daily lives, current regulations require that to be eligible for SLS, the individual is required to live in his or her own home - not in the family home.

The Autism Society of California agrees with the ARCA's 2018 Report, "Building a System for Tomorrow," that the housing crisis impacts all low-income families. However, for individuals with disabilities who depends solely on Supplemental Security Income (SSI), which typically is less than \$12,000 a year, the lack of affordable housing is a tremendous barrier for independence and a meaningful quality of life.

Top Concerns Related to Securing Housing for the Individual - Multiple Answers

1. Paying for the rent/mortgage and related expenses - 66%
2. Finding quality support staff - 62%
3. Safety Issues - 54%
4. Paying for the support needed - 49%
5. Finding staff who will stay long-term - 47%
6. I don't know how or where to find housing information - 27%



384 participants

Call to Action:

1. Expand rental assistance programs. Rental assistance may include: Housing Choice Vouchers, Public Housing, Project-Based Section 8, Section 811, Section 202, DDS Rental Unit, Housing Choice Vouchers, and DDS Affordable Housing projects.
2. Change the regulations to allow for Supported Living Services (SLS) services to be provided in the family home.
3. Clarify current DDS regulations which allow adults to live and receive support services in accessory dwelling housing units (ADUs). ADU's and Jr. ADU's can be a successful approach to creating new housing. These include attachments to family homes, converted garages, tiny homes in the back yard, etc which are allowed through local zoning ordinances. The 21 Regional Centers should all adhere to the California state definition of a ADU or Jr ADU and be standardized in their interpretation to incentivize and remove barriers for families in creating an ADU.
4. All the various types of housing models should be considered and not discouraged by regional centers. The wide variety of models currently being utilized and available throughout the USA should be utilized including farm communities, congregate type of housing, integrated housing etc. The Medicaid HCBS policy does not prohibit these type of communities as long as certain criteria are met.
5. Support staff for housing must be adequately compensated and be given a livable wage.

" Supportive living situation before my husband and I die. He would love to be in a community where he could have his own apartment but would be safe and have someone checking in on him. "

"A supportive community, a high quality agency, and a decent home. I would like to see him live in an intentional but integrated community. Homes and apartments can be very isolating for the non-verbal and severely impacted. "

"A long term housing and behavioral support plan that we can feel confident about. The main obstacle is finding and keeping qualified care providers. They don't get paid nearly enough for what they do."



Quality of Life Indicators

Communication

According to a 2018 Boston University study, about 30 percent of people diagnosed with autism spectrum disorder "never learn to speak more than a few words." This is consistent with our 2018 Survey showing 26% of our survey population can not communicate what they need or want most of the time.

An individual who is unable to communicate effectively is unable to participate meaningfully in many activities, and is at great risk for delays in cognitive, social and emotional development. It is critical all individuals have the ability to communicate and be able to get their needs and wants met.

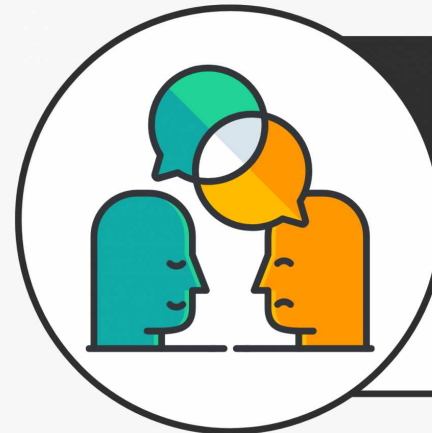
Communication can take many forms such as speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech-generating devices, etc. This can be referred to as Augmentative and Alternative Communication (AAC). AAC refers to "a set of tools and strategies that an individual uses to solve every day communicative challenges."

Many adult users become extremely proficient with their AAC, and are able to communicate anything they want to, in any circumstance they find themselves in. Additionally, numerous studies have found that the introduction of AAC frequently has a positive affect on speech; children who are given AAC often develop speech faster than they would have otherwise (Bodine & Beukelman, 1991; Van Tatenhove, 1987).

Interestingly only 57% of those families who have a loved one who can not communicate have explored using technology to help increase communication.

Autism Society of California 2018 Survey Results Communication

for individuals with Intellectual/Developmental Disabilities



Communicating Basic Wants and Needs

26%

of individuals with I/DD can not communicate what they want or need most of the time. This compares with 21% from the 2016 ASC Survey.

964 respondents



Technology

57%

of these families have explored using technology such as iPads, phones, and other special devices using special software or apps like Proloquo2go, (AAC) – to help their child or adult with I/DD.

231 respondent

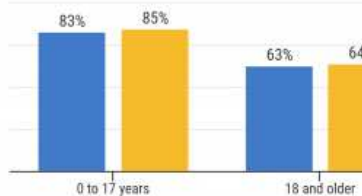
"My child needs more assistance in finding ways to communicate. They need support to help them not just with getting a job later in life but, communicate with others. This is prime with this disability and not focus enough with these young people. The average child has difficulty in making friends being included, excepted by others. 100 times worse for our children."

Autism Society of California's 2018 Survey Results

Dental Care Indicators for the I/DD Population

Last Dental Visit

How Long Since Last Dental Visit



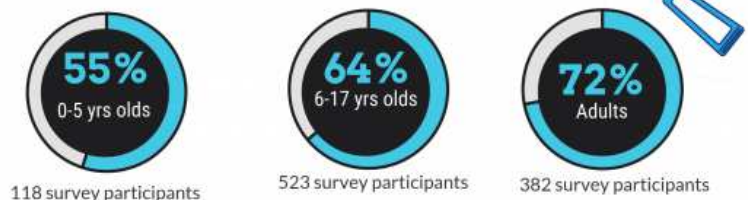
● 2018 Survey ● Average American
Average American Statistics come from the National Center for Health Statistics: CDC Oral and Dental Health - <https://www.cdc.gov/nchs/fastats/dental.htm>

204 survey participants

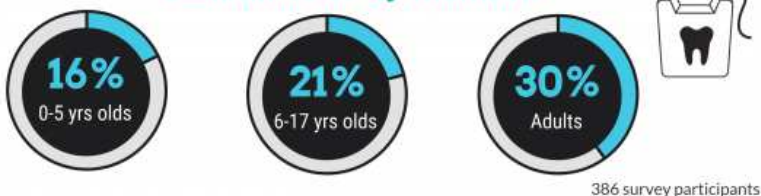
Reasons Why You Haven't Visited Dentist in Last 12 Months

1. Don't have or cannot find a dentist who knows how to work with special needs (34%).
2. Fear of the dentist and/ or past bad experience (30%).
3. Do not have pain or other dental problems that needed care (20%).
4. The behaviors to get them out of the house and to the dentist chair too severe (17%).
5. High cost and/ or no insurance (13%).

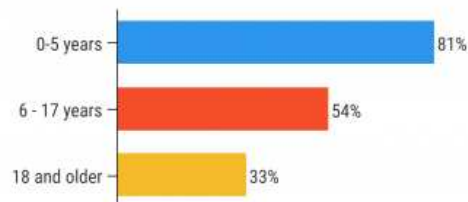
The individual usually brushes their teeth twice a day either with assistance or by themselves



The individual usually flosses once a day with assistance or by themselves



Usually Needs Assistance with Teeth Cleaning/Flossing



Dental Care and Oral Health

Recognizing oral health as a population health management imperative. The Healthy People 2020 Project, a federal initiative to chart the nation's public health issues and develop action plans to overcome them, identifies oral health as one of the key indicators of a healthy population. Good dental care is linked to reduced risk of diabetes, heart disease, stroke, premature or low birth weight, and chronic oral pain. Poor oral health often goes hand-in-hand with lower levels of education, restricted access to care, and lower rates of health insurance coverage.¹

According to the Center for Disease Control, for the average American:²

- 84.6% of children aged 2-17 years visited the dentist in the past year (2016) compared to 83% of the 2018 Survey respondents.
- 64% of adults aged 18-64 visited the dentist in the past year (2016) compared to 63% of the 2018 ASC Survey respondents.

The survey reflects that individuals with I/DD are visiting the dentist at the same rate as most Americans.

According to the American Academy of Pediatrics, parents should be brushing a child's teeth until age 6 years, and floss until 8-10 years.³ From the data we gathered, 33% of adults with Intellectual/Developmental Disabilities need assistance from care takers to brush their teeth/floss. This is another example of additional care for 1/3 of our adult population and half of school-aged children that must be provided by caretakers in order to maintain their health.

¹ Dental Care is the Missing Piece of Population Health Management - <https://healthitanalytics.com/news/dental-care-is-the-missing-piece-of-population-health-management>

² Center for Disease Control Oral and Dental Health - <https://www.cdc.gov/nchs/fastats/dental.htm>

³ American Academy of Pediatrics - A Pediatrics Guide to Children's Oral Health Flip Chart - https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Oral-Health/Documents/OralHealthFCpagesF2_2_1.pdf

Health Indicators

Most health indicators showed similarities between individuals with Intellectual/Developmental Disabilities and the average American - except when it came to healthy eating habits.

- The Department of Health and Human Services recommends adults get at least 150 minutes of moderate aerobic activity. The Autism Society of California Survey showed 50% of the family members or self-advocates reported meeting this goal. The CDC/National Center for Health Statistics in Jan 2017 showed that 53% of Americans met this goal.¹
- 61% of the 2018 adult survey respondents reported eating healthy compared to 75% of American adults (2016 poll conducted by NPR conducted with Truven Health Analytics).
- Survey results show that 83% of adults with Intellectual/Developmental Disabilities had visited a doctor in the last year compared to 85% of American adults.

1. CDC - Ambulatory Care Use and Physician Office Visits - <https://www.cdc.gov/nchs/fastats/physician-visits.htm>

Autism Society of California's 2018 Survey Results Health Indicators for the Adult I/DD Population

Exercise - 50% survey participants

The Department of Health and Human Services recommends adults get at least 150 minutes per week of moderate aerobic activity. The Autism Society of California Survey showed 50% of the family members or self-advocates reported meeting this goal. The CDC/National Center for Health Statistics in Jan 2017 showed that 53% of Americans met this goal.

389 survey participants



Eating Healthy

61% of the self advocates and family members with an adult reported this is compared to a 2016 poll conducted by NPR conducted with Truven Health Analytics which reported 75% of Americans believe they eat a healthy diet.

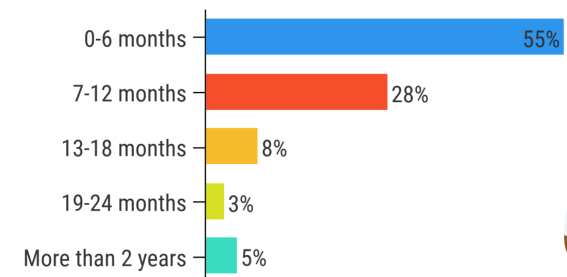
331 survey participants



Visiting the Doctor

Survey results that 83% of adults with I/DD had visited a doctor for a check up with in the last year compared to 85% for the average American.

Last Time an Adult with I/DD Visited Doctor for Medical Check Up



2018 ASC Survey - 386 survey participants

Average American: CDC - Ambulatory Care Use and Physician Office Visits - <https://www.cdc.gov/nchs/fastats/physician-visits.htm>



Safety Indicators

for Individuals with Intellectual/Developmental Disabilities



Disaster Preparedness

83%

of the individuals with I/DD DO NOT KNOW what to do and can not evacuate without assistance during a major disaster (earthquake, fire, etc).

1029 respondents



Safety in the Community

92%

of survey participants are concerned about safety issues in the community.

994 respondents

Safety Issues for Families and Self-Advocates with Intellectual/Developmental Disabilities

Typical Families

Bullying/cyberbullying (61%)
Not enough exercise (60%)
Unhealthy eating (57%)
Drug abuse (56%)
Internet safety (55%)
Child abuse and neglect (53%)
Suicide (45%)
Depression (44%)
Teen pregnancy (43%)
Stress (43%)

92% of parents and self-advocates are concerned about safety issues in the community.

Families of Children and Adults with I/DD

Being made fun of or disrespected (71%)
Bullying (63%)
Being abused (60%)
Having a major meltdown or tantrum (55%)
Will wander or be lured away (55%)
How to have a healthy relationship (29%)
May hurt someone (25%)
Will get arrested or 5150'd (22%)

Source: CS Mott Children's Hospital
National Poll on Children's Health 2017
2,051 survey participants

Source: Autism Society of California
2018 Survey of Individuals with ID/DD
994 survey respondents

Safety

Individuals and families in our community agreed that not having safety training and tools was a large unmet need for this population. It ranked third on the list of needed resources.

In a YouGov 2018 Survey, 41% of Americans say they're not prepared for a natural disaster, while 83% of the 2018 Autism Society of California respondents indicated the person with I/DD is not prepared.¹

Ninety-two percent (92%) of 2018 Autism Society of California Survey participants are concerned about safety issues in the community. Top issues for our community differ from typical parents. Top issues include:

- Being made fun of or disrespected (71%)
- Bullying (63%) This is comparable to the average parent in which 61% advised this was their top concern.
- Being abused (60%)
- Having a major meltdown or tantrum (55%)

While unintentional injuries are the leading cause of death for everyone from age 1 to 44, people with intellectual and developmental disabilities are at even higher risk. People with such disabilities are 4 times more likely to die in a fire, 6 times more likely to die from a fall, and 6 times more likely to die from drowning. As regulations and services push for individuals to be out in the community more and more, individuals and families want to feel that they are equipped with the right training and tools to ensure their safety in the community. Further, individuals and families worry if the community will embrace them.

1 YouGov - <https://today.yougov.com/topics/lifestyle/articles-reports/2018/07/17/americans-disaster-preparedness-2018>

2 Prevention 1st - <https://prevention1st.org/how-can-people-with-disabilities-be-safe-while-living-independently/>

Sexuality

Sexuality is part of the human experience. Human sexuality plays a role in everyone's life. Sexual feelings are normal, and there are many ways of expressing them. If a person has a disability, it does not change any of this.

For decades, people with Intellectual/Developmental Disabilities have been thought to be asexual, having no need for loving and fulfilling relationships with others. Individuals with intellectual or developmental disabilities frequently lack access to appropriate sex education in schools and other settings.

Equally important is relationships. While many adults with Intellectual/Developmental Disabilities can figure out the mechanics of sex, additional support may be needed around relationships. How to meet someone, how to court someone, how to break up with someone can all be difficult.

For the 2/3 of this population who are more impacted, families struggle with how to support their sexuality. There are little if no resources available for them.

The Autism Society of California 2018 Survey Sexual Orientation

Sexual Orientation at This Time of Teen or Adult with I/DD

Heterosexual 60%

Asexual 20%

Bisexual 2%

Gay or Lesbian 1%

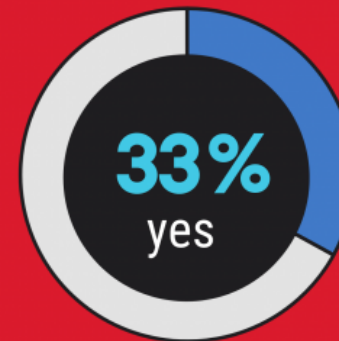
Pansexual 1%

Prefer Not to Answer 16%



590 Survey Participants

Receiving Support for Healthy Relationships Based on Sexual Preference - Ages 13 years and older



558 Survey Participants

Relationship and sexuality training was an area that came up frequently in the unmet need section of the survey.

Autism Society of California 2018 Survey

Service Systems



Applied Behavior Analysis (ABA) Services

Applied Behavior Analysis (ABA) is an evidence-based treatment that has been demonstrated to remediate the core symptoms of autism and related developmental disabilities to a greater extent than any other intervention. While the Autism Society of California promotes many different evidence-based treatments and believes not one treatment meets the needs of everyone.

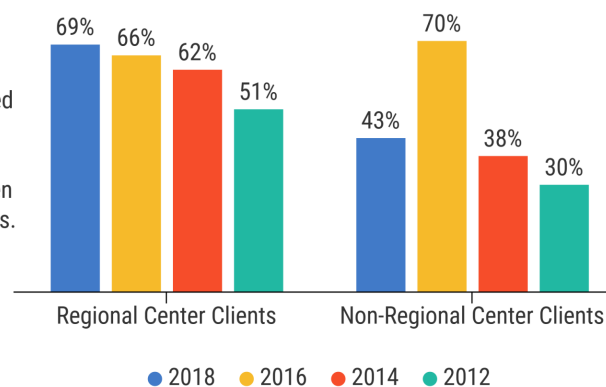
On July 1, 2012, the Autism Health Insurance Mandate, SB 946, (Steinberg) went into effect. This law states that California state-regulated health care plans fall under the guidance of the new Autism Health Mandate. The mandate declared there are no limits or caps on the number hours of Applied Behavior Analysis, nor are there caps on the dollar amount for coverage or age of access for these types of services. It is all determined individually by medical necessity. On January 21, 2016, the Centers for Medicare & Medicaid Services (CMS) approved State Plan Amendment (SPA 14-026) for the California Department of Health Care Services (DHCS) to provide behavioral health treatment (BHT), including ABA, as a Medi-Cal covered service for children under 21 years of age.

- In 2018, we still see a slight rise in Regional Center families who have accessed ABA services (69% in 2018 compared to 66% in 2016). However, there was a significant drop for non-Regional Center families accessing ABA services (43% in 2018 compared to 70% in 2016). This may be due to the fact that Medi-Cal families became eligible for these services in 2016 and there was a lot of communication with families. This graph illustrates newer, non-Regional Center families may not have the same amount of information about these services as they did in 2016. In fact, 47% of all families say they heard about ABA from their Regional Center caseworker, followed by 34% from their own research, and 25% by their doctor.
- 35% of all families representing all age groups reported they were currently receiving ABA services
- 70% of those accessing services were for a child 12 years old and under
- 46% of the families are accessing ABA through private health insurance, while 36% are accessing this treatment through Medi-Cal.

Autism Society of California's 2018 Survey Results Applied Behavior Analysis (ABA) Services for the Intellectual/Developmental Disability Community

In 2018, we still see a slight rise in Regional Center families who have accessed ABA services. However, non-Regional Center families accessing ABA services has dropped significantly since 2016. In 2016, ABA services became available through Medi-Cal and there had been a lot of communication with families. This graph illustrates newer, non-Regional Center families may not have the same amount of information about these services.

History of Accessing ABA Services

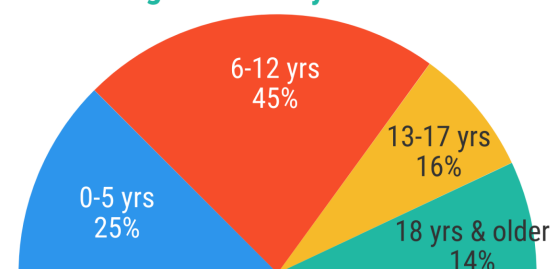


Snapshot of Who is Utilizing ABA Services in 2018

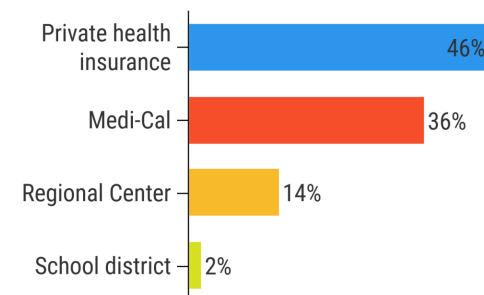
- 35% of the total survey respondents indicate they are currently receiving ABA services.
- 70% of those currently accessing services are for a child 12 and under.
- 46% of the families are accessing ABA through private health insurance, while 36% are accessing this treatment through Medi-Cal.



Ages Currently Served

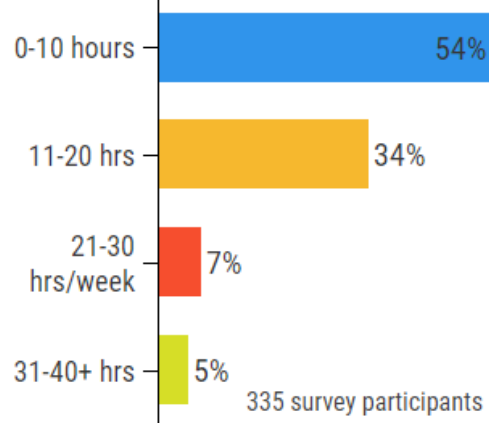


Primary Payor of Current ABA Services



ABA SERVICE QUALITY INDICATORS

Number of ABA Hours Received Each Week



54%

of families feel they are receiving the right amount of hours

323 survey participants

67%

of families report they are satisfied with the overall quality of their ABA Services

347 survey participants

45%

of families who speak a language other than English report ABA provides translation so parents can understand the training

66 survey participants

82%

of families report cost does not prevent them from accessing the recommended number of hours

342 survey participants

Additionally, the 2018 Autism Society of California Survey looked at various quality indicators for current ABA services and found:

- 54% of families report they receive 1-10 hours a week of ABA services; 34% receive between 11-20 hours a week of ABA services; 7% receive between 21 - 30 hours a week in services; and 4% receive more than 31 hours a week.
- 54% of families feel they are receiving the right number of hours.
- 26% feel they are receiving too few hours (323 respondents).
- 67% of families are satisfied with the overall quality of ABA services they are receiving (347 respondents). 45% of families who speak a language other than English reported the ABA services to provide translation or a translation service to train parents or family members during supervision meetings (66 respondents).
- 82% of families indicated that cost does not prevent them from accessing the recommended number of hours compared to 9% who feel the cost is a factor (342 survey respondents).
- 41% of families report they would like to receive services on the weekend (264 respondents).

This information raises a number of concerns for the Autism Society of California:

- because over half of the families reported receiving less than 10 hours a week of ABA treatment. This stands in stark contrast to what is typically recommended by professionals in terms of the intensity of the number of hours that should be provided. The Autism Society of California strongly encourages individuals with autism and their families to work closely with independent and trusted medical professionals (i.e. their family physician, psychologists familiar with autism, etc) in determining the appropriate number of ABA hours to be provided in order to meet their individualized needs. Research indicates that greater treatment intensity (number of hours) leads to more successful outcomes.
- Although insurance companies are mandated to provide interpreters for patients, less than half of the non-English speaking families are receiving translation services to assist them during the parent training component of the treatment plan. One possible reason for this is that parents may be unaware of their right to translation. In addition, due to a shortage of bilingual service providers, parents may be choosing to move forward with the services of an English speaking provider rather than delay the start of services until they can be provided with a bilingual provider. Whether it is using tele-interpretation services or incentivizing more BCBA's and interventionists who speak threshold languages, all families need access to parent training in order to provide this appropriate and medically necessary treatment.

Department of Rehabilitation

Autism Society of California's 2018 Survey Results Dept of Rehabilitation Services

Respect

62%

of the 146 participants felt the the Dept of Rehabilitation employees treated the individual with I/DD with courtesy and respect. This is an increase from 48% in 2016.



Met the Needs

23%

of the 146 survey respondents felt the Dept of Rehabilitation met their needs. This is an increase from 20% in 2016.



Awareness

32%

of the 156 participants who did not access the Dept of Rehabilitation services, 32% of individuals and families said they don't know what services the Department of Rehabilitation can offer or what they do.



336 Survey Respondents

 **AUTISM SOCIETY**
Improving the Lives of All Affected by Autism
California

While the 2018 Autism Society of California Survey showed improvement in the delivery of Department of Rehabilitation services, there is still need for improvement. The Autism Society of California applauds the new requirements and collaboration with the Department of Rehabilitation, but calls for additional funding to ensure services are being provided in a timely fashion, with respect, and are meaningful to our population.

Families continue to be frustrated with Department of Rehabilitation vendors, and in turn with Department of Rehabilitation, who do not demonstrate an understanding of the needs of the I/DD population. There needs to be a significant pool of vendors who can provide the Discovery process and customized employment for this population. There must be an investment in training, capacity building and sustainable rates to the vendors so they can make a shift to customized employment and better outcomes. Otherwise, we will continue this tragic cycle of poverty, unemployment and low expectations for adults with I/DD.

"...the few things we tried since High School just failed. I don't remember if anyone suggested DOR.

My son has self motivational issues and is not enticed by earning money. He also has severe problems with starting a program and then being exited. It tears his soul."

"The regional center said they would set up an appointment [with the Department of Rehabilitation] but no one called. I constantly called about this but no calls were returned. I gave up and look for job or schools on my own..."



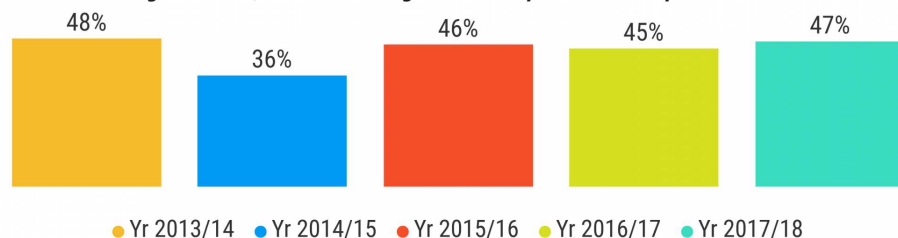
Autism Society of California's 2018 Survey

Education Indicators

for California's I/DD Population



**California Students with Autism as their Primary Disability,
Aged 14-21, Exit with a High School Diploma from Special Education**



The 2018 Autism Society of California reported a similar rate of graduation:

- 45% respondents over the age of 18 year reported graduating with a High School Diploma
- 52% reported receiving a Certificate of Completion or aging out of School
- 3% reported dropping out

313 survey participants



17%

reported feeling their loved one had the opportunity to explore different careers while in school

324 survey participants



32%

reported their loved one can write or discuss services or accommodations they need to be successful at a job

380 survey participants

AUTISM SOCIETY
Improving the Lives of All Affected by Autism
California

Education

The 2018 Autism Society of California Survey focused on the end result for education system - graduation rates and being prepared for employment.

Data from the California Department of Education was requested via a Public Records Request for graduation data for students with autism. Because the Regional Center and California Department of Education use different student classification methods, it was not possible to gather data on all individuals with Intellectual or Developmental Disabilities, therefore, only data for autism was requested.

Graduation data from the 2018 Survey was consistent with what the state reported. The Survey data showed a High School graduation rate of 45%, and the state showed 47% for the 2017/18 school year.

The 2018 Survey also showed that only 17% of individuals and families felt they had the opportunity to explore different careers while in school. Thirty-two percent (32%) reported being able to write or discuss services or accommodations they needed to be successful at a job.

This data is important when we are looking at supports for employment and college services in order to understand what experience and learning opportunities this population has had in the past. Department of Rehabilitation services assume that individuals who are "job ready" would know what jobs they want and can communicate the supports needed to be successful. The survey shows that a small percentage of our adult population has these skills.

Education

The Autism Society of California 2018 Survey shows the opportunity to attend college is important for approximately half of our adults. Only 25% of survey respondents reported that current college accommodations are sufficient for success. There is a large discrepancy between services and accommodations in high school and what is available in college. Many students with disabilities are unprepared for the challenges or how to navigate the college systems.

Whether it is pursuing community college classes like art or exercise, or pursuing a degree, individuals with Autism and other developmental disorders should have access, support, and the skills necessary to learn at post-secondary institutions.

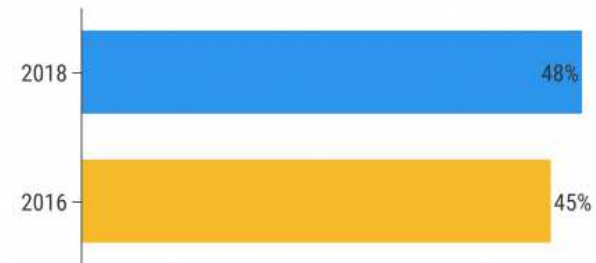
There is a need for better data collection including:

- Tracking and transparent reporting of the California High School graduation rates as measured by the percentage of students who begin in the 9th grade and graduate four years later by specific qualifying disability category (i.e. autism, learning disabled, other health impairment, etc).
- Collect and report completion rates at colleges by disabilities.
- More focus on high school and transition classes to help students succeed and be able to navigate college if that is the path they want to take.
- Develop meaningful and quality career exploration in high school and transition classes around the student's strengths.
- Plan to develop meaningful job skills including helping students understand what job accommodations/supports they would need to be successful.

Is the Opportunity to Attend College Important to You, a Person with I/DD?



Has the adult with I/DD attended or is attending college classes? (Academic or Non-Academic Classes)



Do you feel college accommodations are sufficient?



Autism Society of California's 2018 Survey Results 2018 Regional Center Indicators

Partnership



62%

of survey respondents felt they are a partner with their Regional Center in developing the IPP document and in determining the necessary services and supports for their family (918 respondents). The 2016 ASC Survey showed 59%

Communication



74%

report the caseworker returns calls or emails within 2 business days (918 respondents). The 2016 ASC Survey showed 68%.

Respect



85%

of the 914 survey respondents believe the caseworker treats the person with I/DD with courtesy and respect. This is the same as the 2016 ASC Survey.

Primary Language



95%

of the self advocates and families reported the IPP was conducted in their primary or preferred language (917 respondents). This compares to 94% in 2016.

14%

of the self-advocates and families indicated there are services written into the IPP or IFSP that they are not receiving. (911 total respondents)

7%

of the self-advocates and families reported the Regional Center caseworker refused to write down services they requested on the IPP. (907 total respondents)

Regional Center Services

The 2018 Autism Society of California Survey showed improvement from our 2016 Survey in Key Performance Indicators:

- 62% of individuals and families surveyed felt they were a partner with Regional Center in developing their IPP and determining necessary services (up from 59% in 2016).
- 74% reported the caseworker returns calls or emails within 2 business days (up from 68% in 2016).
- 85% believe the caseworker treats the person with I/DD with courtesy and respect (this is the same as reported in 2016).
- 95% report that the IPP was conducted in the client's primary or preferred language (compared to 94% in 2016).

The survey identified three areas of concern for self-advocates and family members:

1. There seems to be confusion and frustration around what services Regional Centers and their caseworkers should be providing. Families are unsure if Regional Centers should be paying for behavioral treatment, speech therapy, advocacy, conferences, etc. Self-advocates and families reported being unsure of what exactly the role of the Regional Center caseworker is.
2. Self advocates and families report a lack of information on timely topics such as the respite cap being lifted, self-determination and the Paid Internship Program (PIP). Only 1 in 3 Regional Center clients or family members felt they are receiving information from their caseworker.
3. Survey respondents report they are in crisis or on the brink of crisis due to the lack of resources. Even if it is a resource Regional Center is supposed to provide, more and more families are hearing there is no vendor for that service or there are long wait lists to get into an appropriate program.
 - 14% of individuals and family members advised there are services on their IPP or IFSP that are written but they are not receiving (911 respondents).
 - 7% indicated the Regional Center caseworker refused to write down services they requested (907 respondents).

Regional Center Services

Only 1 in 3 Regional Center clients or family members felt they are receiving information:

- Only 20% report their Regional Center case worker sends them information about resources in the community, events or training regularly; 28% advise they never receive information like this from their caseworker.
- Only 32% of survey respondents were aware the Respite Cap had been lifted and families are able to request additional hours if needed.
- Only 34% of individuals and family members were familiar with the Self-Determination program and felt like they made an informed choice.
- 31% of families and self-advocates over the age of 18 are familiar with the term Competitive Integrated Employment (CIE).
- 22% of families and self-advocates over the age of 18 reported their caseworker has reviewed employment and paid internship options with them.

"I don't know what's available. They seem to not offer much any more."

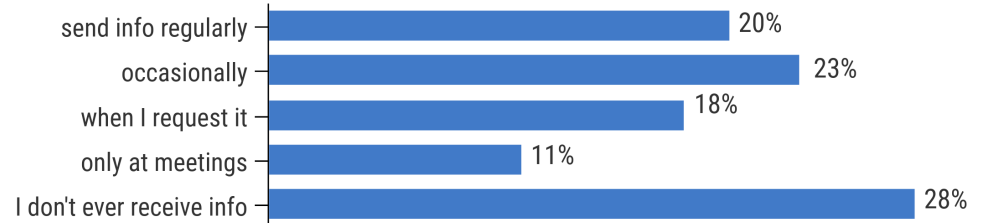
"I only see the [Regional Center] lady 1 x a yr for her to come to my house to check if my son still seems like he has autism (I guess) other than that I don't see or hear from my worker. An I'm not even sure what we have [the Regional Center] for because they don't really bother with us at all ."

"I has previously told our service coordinator that we were going to pursue residential housing and she agreed that it was a good idea...BUT this info did NOT appear in the finalized IPP."

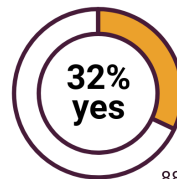
2018 Regional Center Performance Indicators

Does your Service Coordinator notify you about generic resources, events or trainings?

916 respondents

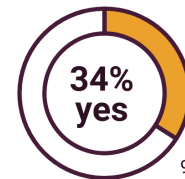


Are you aware that the Respite Cap has been lifted and you can call an IPP to request additional hours if needed?



880 respondents

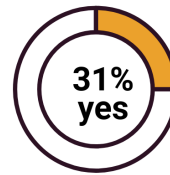
Are you familiar with the Self-Determination program and feel like you made an informed choice to participate in it if you wanted to?



917 respondents

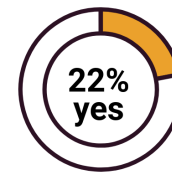
For families and self-advocates over the age of 18 years:

Are you familiar with the term competitive, integrated employment (CIE)?



526 respondents

Has your Service Coordinator reviewed employment and paid internship options with you?



370 respondents

Autism Society of California - 2018 Survey

Acknowledgements

Thank you to all the self-advocates and families who gave their time to complete this survey.

This report was co-authored by Beth Burt and Marcia Eichelberger. We are grateful for the generous financial support of the Hussman Foundation and Easter Seals Bay Area in helping make the 2018 Survey and Report possible and accessible to diverse communities. Thank you to the Autism Society of America and the leadership at each of the California affiliates: Autism Society Inland Empire, Los Angeles, San Diego, San Francisco, Ventura County, Coachella Valley Autism Society, and Kern Autism Network for their dedication to this project and serving our communities each and every day. Special thanks to Feda Almaliti and Penne Fode for their assistance.

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