

2016 AUTISM SOCIETY OF CALIFORNIA SURVEY REPORT

Examining critical issues among individuals and family members in the California Intellectual and Developmental Disabilities Community



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

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Thank You's and Acknowledgements

The artwork on cover of this report is an original done by an artist with autism, Grant Wisegarver. To reach the artist, you may contact him at grantw.art@gmail.com

Thank you to the Autism Society of America and all the committee members who worked on the National Outcomes Model. We appreciate the work you have done and the opportunity for us to continue this work in California.

A special thank you to Marcia Eichelberger, for the countless hours in assisting in the development of this survey and her unwavering commitment to improve outcomes for all. And to the rest of the ASC Executive Committee, Sandy Shove, Penne Fode, and Greg Fletcher for their unending support to improve the lives of all affected by autism.

Beth Burt
President,
Autism Society of California



The Autism Society of California (ASC) collaborates with other organizations to ensure individuals and families living with autism and other developmental disorders, are able to maximize their quality of life, to be treated with the highest level of dignity, and live in a society where their talents and skills are appreciated. As part of our endeavor, ASC has conducted online surveys every two years (2012, 2014) in our community to measure key areas across the lifespan. This year we focused on looking at two of the main service systems which serve adults in California (Regional Centers and Department of Rehabilitation) and nine Key Performance Indicators (KPI) with an emphasis on the adult population.

This year we broadened the reach of the survey to include not only individuals with autism and their families, but also individuals with Intellectual/Developmental Disabilities (I/DD) and their families. We are grateful to the individuals and families who participated in the survey as well as the policy makers, government agencies and other non-profit organizations who continue to strive for a higher quality of life for all.

2016 Survey Key Performance Indicators

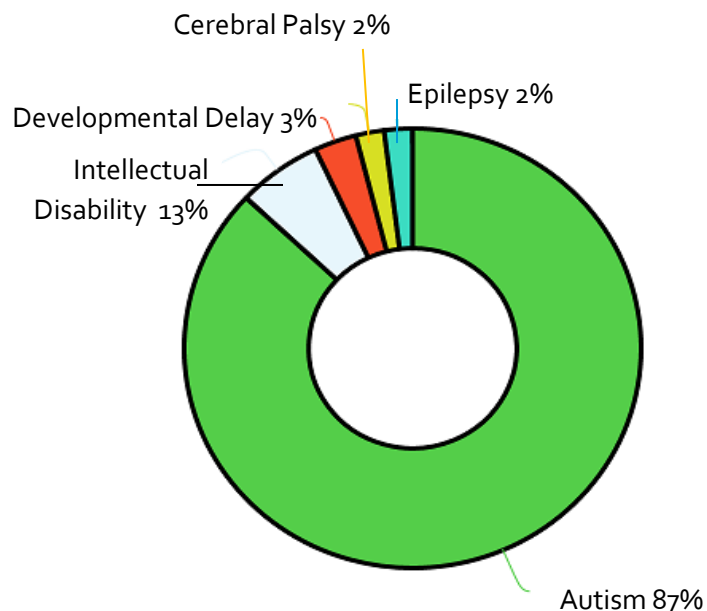
1. Service Systems
2. Autonomy and Self-Advocacy
3. Respect and Dignity
4. Communication
5. Health
6. Social Connections
7. Academic Success
8. Meaningful Employment with Fair Wages
9. Independent Living
10. Well-Being

The 2016 ASC survey was offered electronically in English and Spanish in July and August 2016 to individuals with developmental disabilities. Parents of children, family members of adults, and self-advocates were encouraged to participate. Overall 1,202 individuals participated in the 2016 ASC Survey. Participants were excluded who did not meet this criterion. In the end 1,172 surveys were analyzed. We find this survey 95% accurate with a +/- 3%

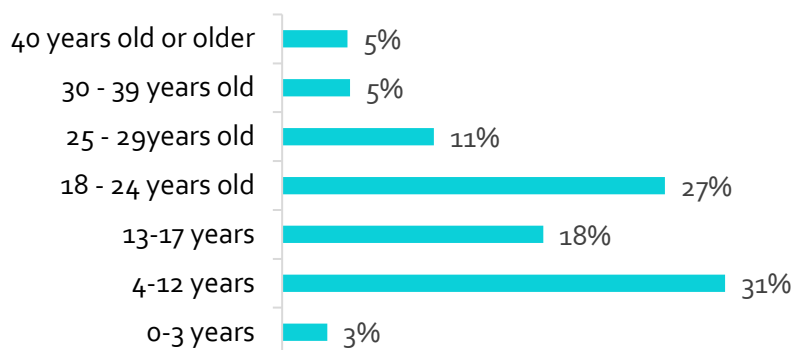
Data limitations: While we made every effort to reach out to nonprofit organizations for all developmental disabilities, 87% of the survey respondent's primary diagnosis was autism.

Additionally, individuals from 30 counties in California participated, but the predominant numbers of individuals were from Southern California. And while the survey was offered in both English and Spanish, the survey garnered 26% participation from Hispanic families compared to the reported Hispanic population of 39% California's population (CA Governor's Budget Summary – 2015-16). Conversely, Caucasians were overrepresented in the survey (53% Survey respondents compared to 38% of California population).

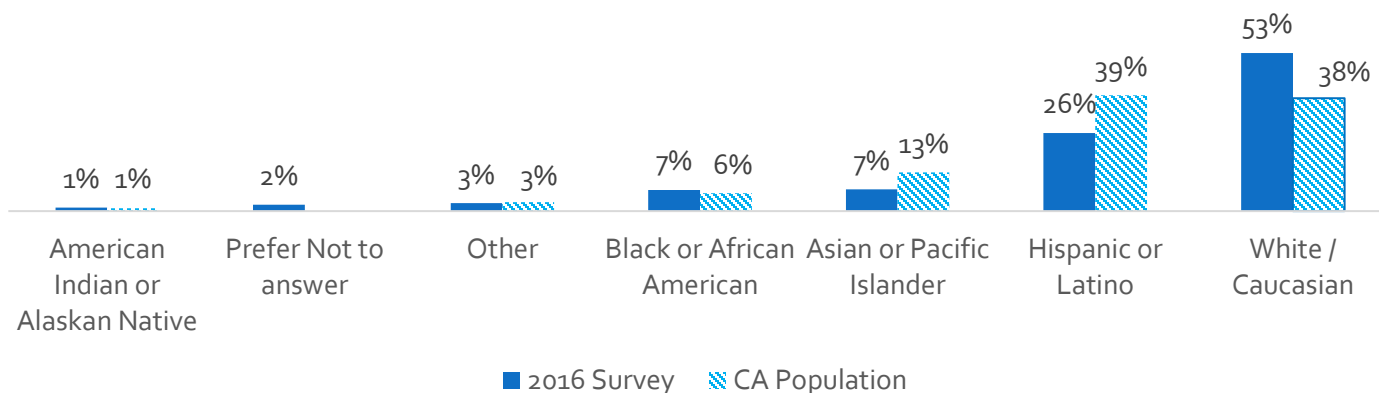
Breakdown of Individuals Surveyed



Age of Individuals with DD Represented in 2016 Survey



Survey Ethnicity Compared to CA Demographics



78% survey takers
are currently Regional
Center clients



While individuals from all 21 Regional Centers participated in the survey, geographic regions were not represented proportionately: 67% of the Survey respondents were from Southern California, 12% from Central California, and 21% from Northern California.

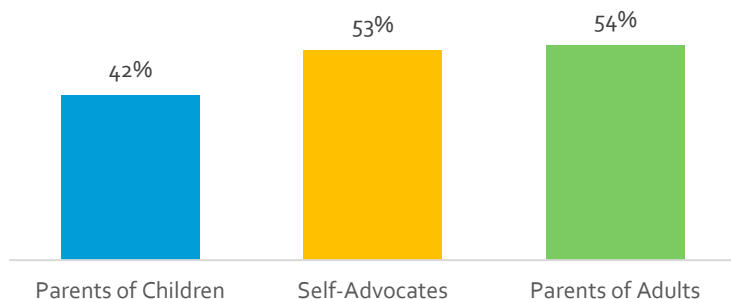
As part of the Autonomy and Self-Advocacy goal (KPI #2), the survey measured how many individuals were familiar with what a person-centered plan is (46% overall) and are familiar with the Self-Determination program (38% overall).

46%
Overall know what a
person-centered plan is

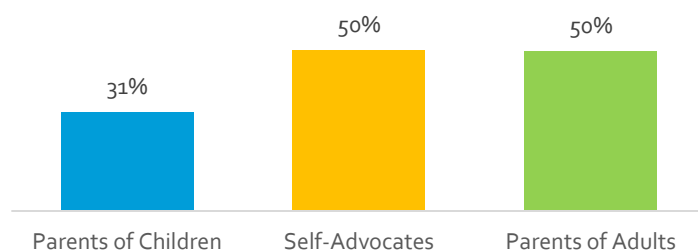
38%

Overall are familiar
with the Self-
Determination
program

I know what a person-centered-plan is

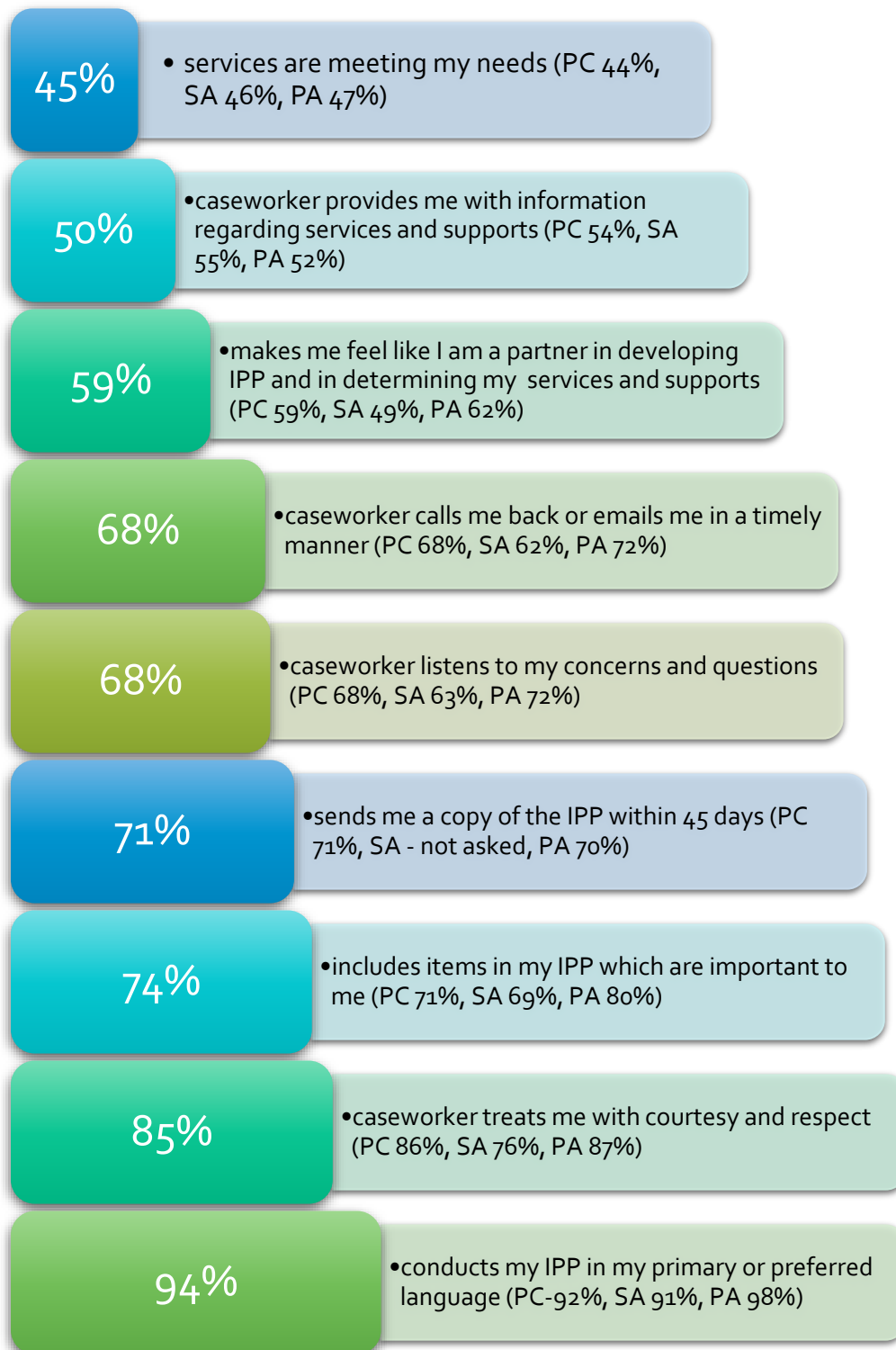


I am familiar with the Self-Determination program



Regional Center Key Performance Indicators

Key: The number to the left is the overall results. Percentages in the comments correlate to PC- Parents of Children; SA- Self Advocates; PA- Parents of Adults



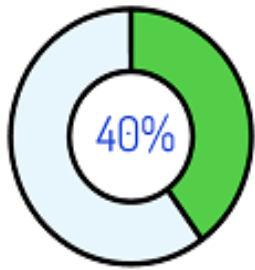
This was a new area of focus for the survey. Not only was this an opportunity to gather baseline data on the major system designed to serve this population, but it also gave us an opportunity to measure if individuals and families felt empowered to be self-sufficient and make decisions for their life (KPI #2), and felt respected (KPI #3).

Overall data was compiled using actual numbers (not averages of averages). Additionally, we have included data for the sub-groups.

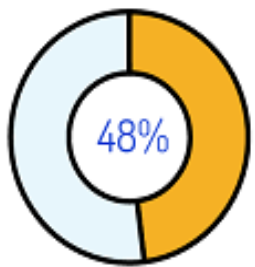
Only two of the nine areas had an overall rating of over 80%.

The data stayed consistent within a +/- 3 % except for two areas: Self-advocates reported a much lower rate of feeling like a partner in determining services and supports and feeling their caseworker treats them with courtesy and respect.

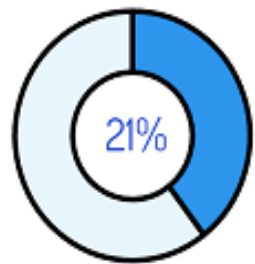
Department of Rehabilitation Services



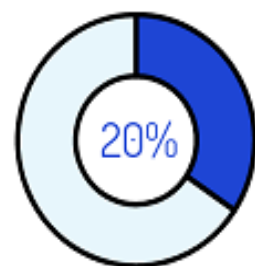
Number of adults with I/DD who have attempted to access DOR



Felt the Dept of Rehabilitation treated the individual with I/DD with courtesy and respect



Felt they were a partner in developing the Plan for Employment and was given choice in employment

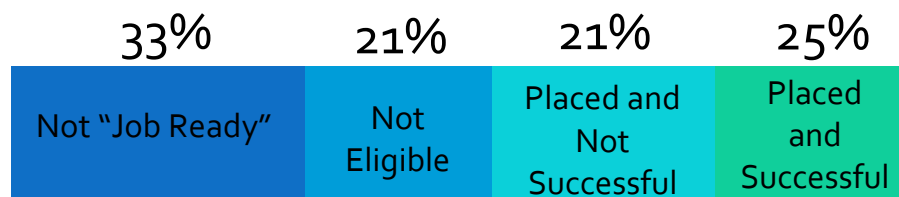


Believe DOR met the needs of their family member

Department of Rehabilitation (DOR) is another agency which individuals with intellectual and developmental disorders may be able to access to provide vocational services. Only parents of adults with an I/DD were asked about these services which resulted in a smaller sample size (355 participants).

Only 40% of those surveyed have attempted to access this service – and for the families who did the results are disappointing – only 25% report being placed in employment and being successful. Over half were either deemed “not job ready” or not eligible for DOR services.

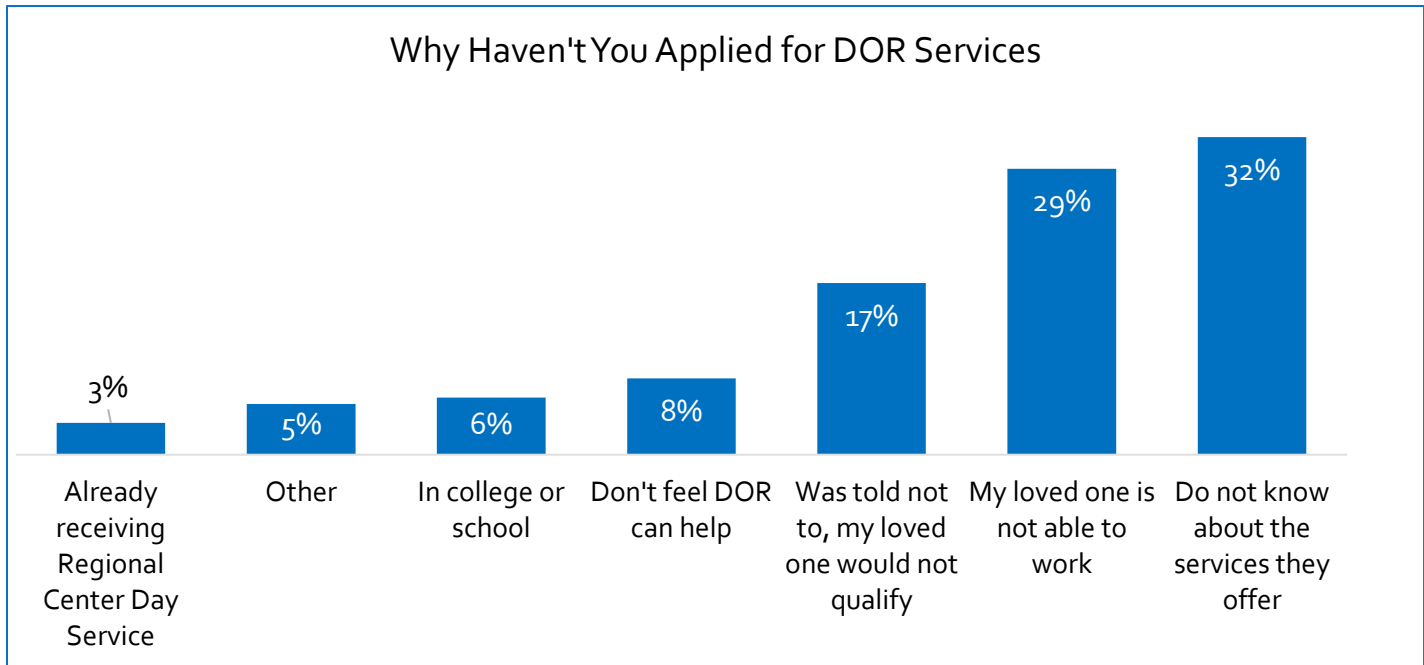
Result of Applying for DOR Services



Additionally, for the families with an I/DD loved one who had contact with the Department of Rehabilitation, the survey shows their frustration and disappointment:

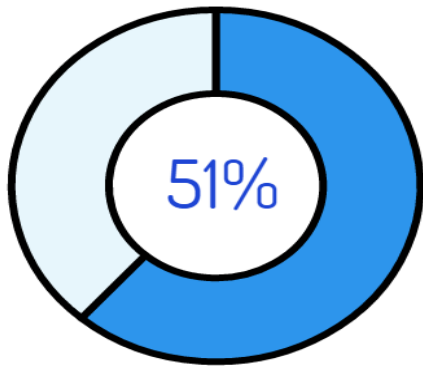
- 48% felt the person with I/DD was treated with courtesy and respect (KPI #3)
- 21% felt the person with I/DD was a partner in developing the Individualized Plan for Employment and was given a choice in employment
- 20% believe the DOR met the needs of their family member

For the 60% who did not try to access DOR services, we worked on identifying reasons why families did not attempt to access these services. Approximately one-third, 32%, were not aware of the services they offer; 29% believed their loved one is not able to work. There seems to be confusion on for whom and when DOR services should be accessed. Seventeen (17%) of parents reported they were told not to apply, that their loved one would not qualify; while a disappointing 8% believe DOR can help.



A third of the respondents felt compelled to make comments in this area expressing confusion on who and when DOR services should be accessed:

- *"As far as I know, they do not serve those with the most severe behavioral needs- Individuals who are minimally verbal and have a lot of SIBs."*
- *"do not believe they [DOR] have training or vision to design customized work opportunities and individually tailored support for persons with autism who have significant support needs"*
- *"they suggested more experience before trying the rehab service"*
- *"told by representative they are understaffed, beleaguered system and unlikely to be able to help my severely disabled son"*



Adults with I/DD who are conserved

AUTONOMY & SELF-ADVOCACY

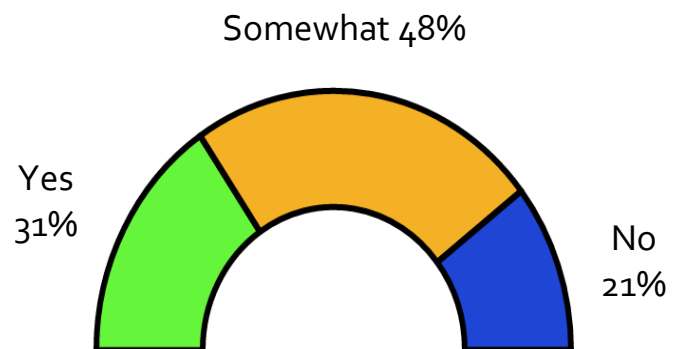
Another measure we looked at for Autonomy and Self-Advocacy (KPI #2) is the number of adults who were conserved (51%). This is not a statement that conservatorship is good or bad, only a baseline to estimate how many individuals are conserved.

Communication

People with autism and other developmental disorders should be able to express themselves and interact with others in a meaningful way (KPI # 4). We asked parents of adults if they believed their loved one, in making decisions about their life goals, felt their loved one was able to communicate what they want or do not want and make their intentions known (362 responded). 31% of parents of adults feel their loved one is able to communicate what they want/do not want regarding their life goals, 48% believe they can communicate somewhat and 21% believe their loved one is not able to communicate this information at all.

It is important to keep in mind communication plays a critical role for children and adults.

Parents Who Feel Their Loved One Can Communicate Their Life Goals

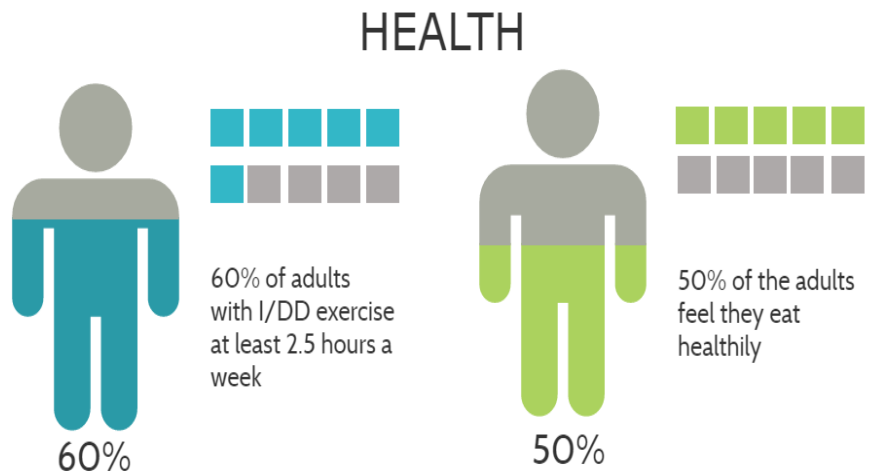


"There are too many days of frustration, and unable to communicate we as a family just keep guessing and guessing and we only get try this, try that, we've tried everything we've ever been told and it doesn't get us out of the crisis."

"I can not seem to navigate normal life so it's always a crisis. I try to communicate what I need or want to say but it never comes out right or effectively. My life is nothing what I hoped or dreamed and despite all my hard work I can't make it better. I have children. I don't want them to grow up and have this life."

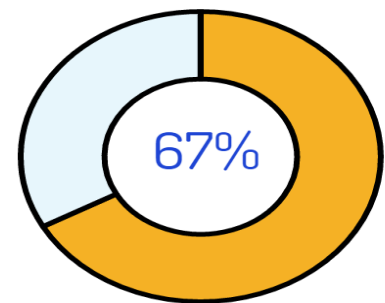
HEALTH

We believe individuals with ID/DD should feel and be well physically, and have access to the services they need to stay healthy (KPI #5). Sixty percent (60%) of adults reportedly exercise at least 2.5 hours a week and 50% report they eat “healthy.”



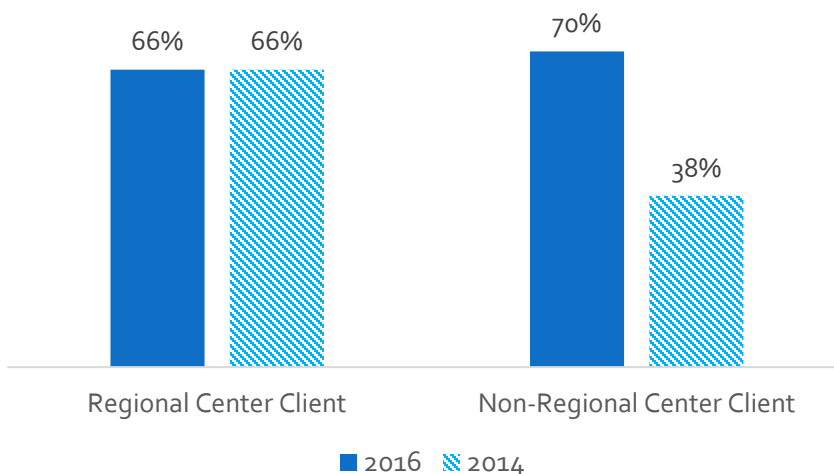
Autism Insurance Mandate

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. Behavioral Health Treatment (BHT) must be provided for individuals with autism. Behavioral health treatment (BHT) includes applied behavior analysis (ABA) and other evidence-based behavior intervention programs. BHT is considered one of the most effective approaches to help individuals with ASD. Medi-Cal is legally required to provide this coverage as of 2015.



of parents with a child under the age of 18 years with Autism have tried to access Behavioral Health Treatment through their medical insurance

Regional Center vs Non-Regional Center Clients Who Applied for BHT 2016 vs 2014

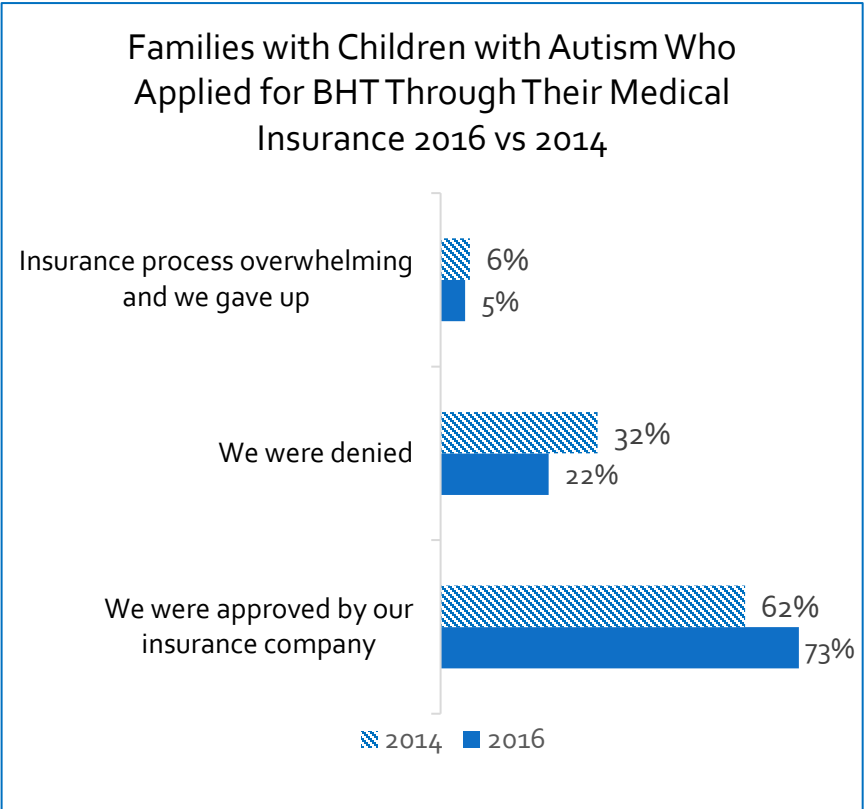


We consider this another KPI for health (KPI #5) and are happy to report this is an area where we saw progress. In our 2014 Survey 66% of Regional Center families and 38% of non-Regional Center families had applied or were in the process of applying for BHT services. We are happy to report in 2016, when we looked at families with a child with autism under the age of 18 years, 70% of non-Regional Center families and 66% of Regional Center families were pursuing BHT therapy through their medical insurance.

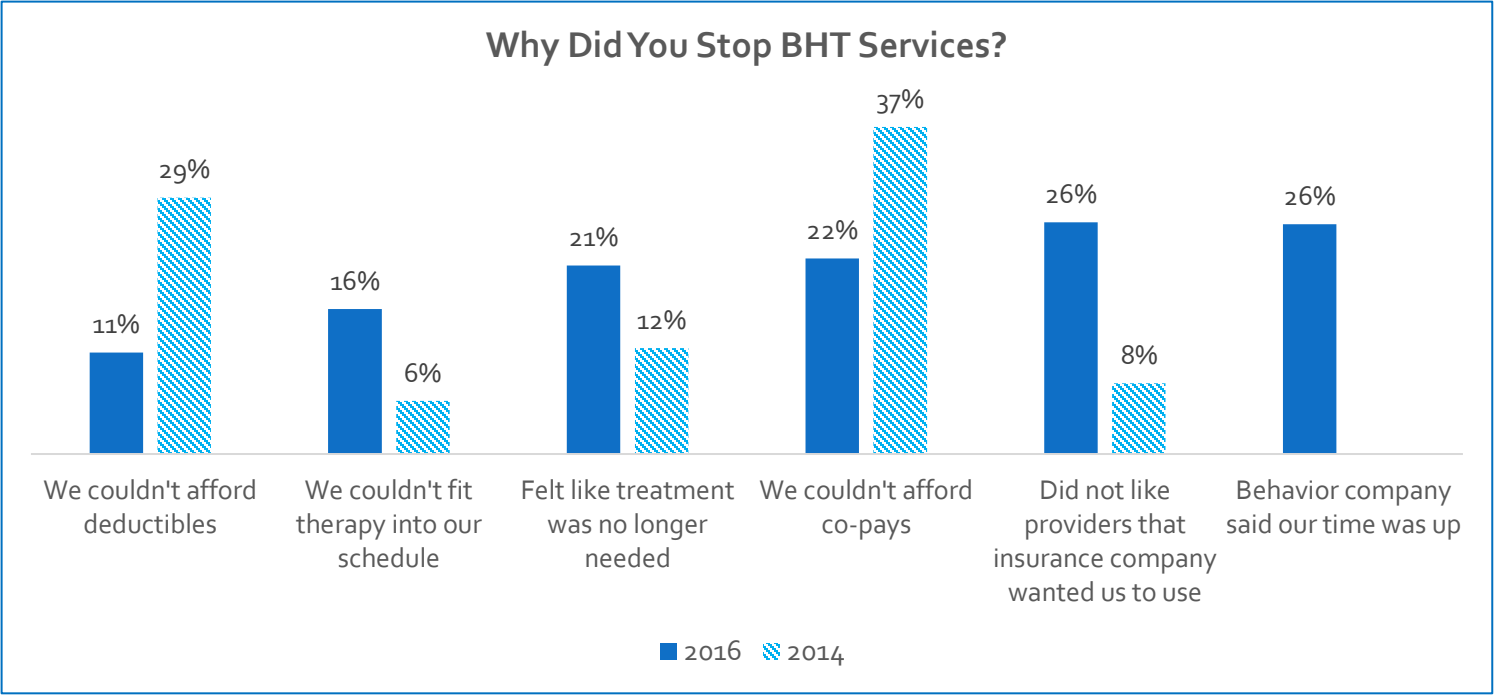
Additionally, we saw progress in the number of cases which are being approved by the insurance companies. In 2014, 62% of the requests were being approved without having to go through the appeals process. In 2016, respondents reported that number increased to 73%,

For those who were denied for BHT services by their health insurance plan, only 6% of the families in 2016 appealed the decision, compared with 21% in 2014.

We also looked at reasons why families were stopping BHT services. In 2014, two-thirds of families discontinued these important services because of financial



hardship. In 2016, only one-third of the families had to stop services because of financial hardship. However, we saw a dramatic increase of families who did not like the providers the insurance companies wanted them to use as the main reason (26% in 2016 compared to 8% in 2014).



SOCIAL



46%
adults have
friends who
they talk online
with



23%
feel like the
adult has
enough friends
or social
opportunities

SOCIAL CONNECTIONS

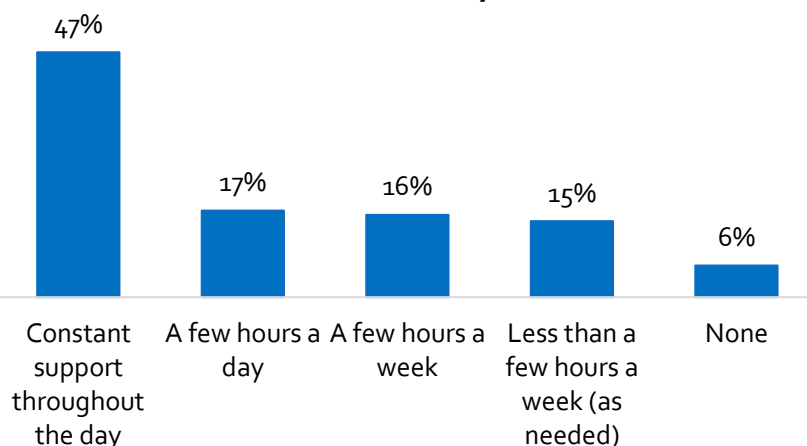
Individuals with autism and other I/DD should have friends, supporters, and ties to the community (KPI # 6). This is an area of need which many organizations hear about often from individuals and parents – the need for meaningful social interaction and opportunities. Unfortunately, only 23% of self-advocates and parents of adults feel like the adult has enough friends or social opportunities.

Additionally, we surveyed the number of adults who have friends they talk to online to see if technology played a role in social connection. Even though 46% of adults talk online with friends, it still does not seem to be enough to quench the thirst for more social opportunities.

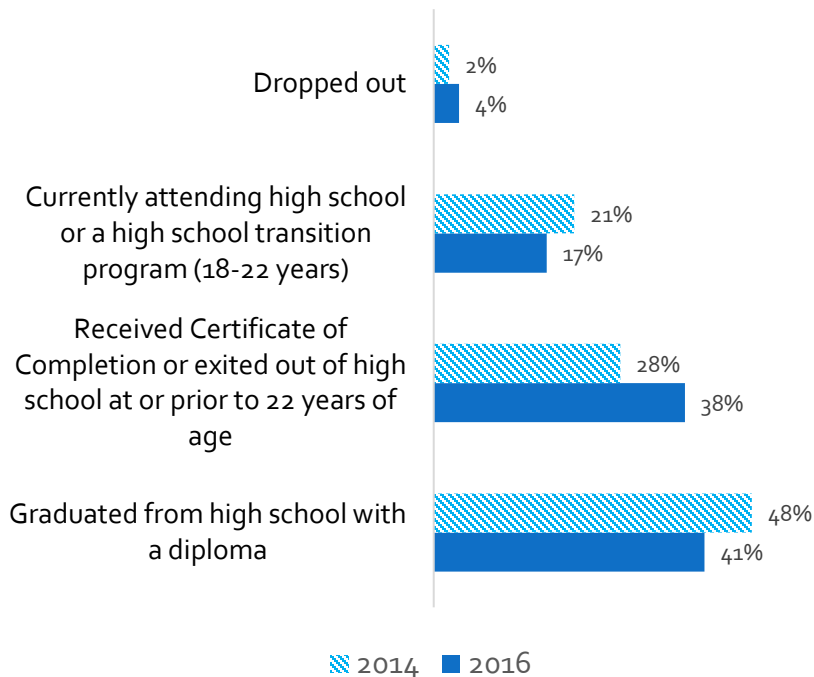
SUPPORT NEEDED

47% of parents report the adult needs constant supervision due to significant deficits in self-help skills, and/or some limitations in physical coordination and mobility, and/or exhibits disruptive or self-injurious behavior prohibiting them in being included as part of their local community (shop, go on social outings, have a job, live). In fact, 65% of the time, the parent or a family member is the one accompanying the adult in the community.

How Much Support Needed For Your Loved One to be Part of the Local Community?



High School Experience 2016 vs 2014

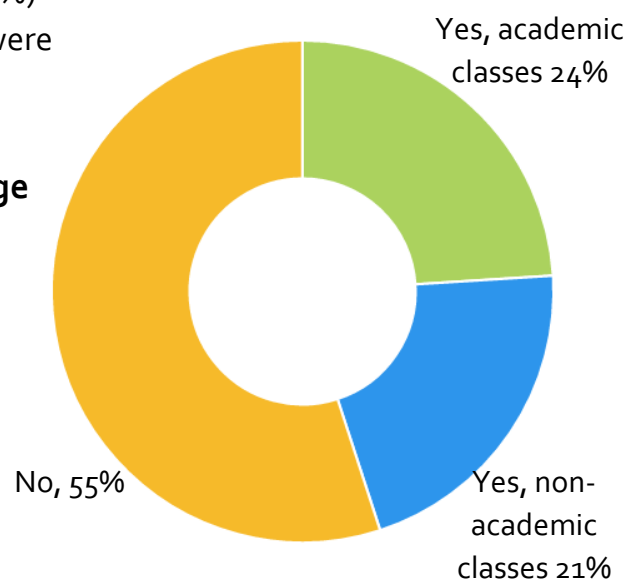


Academic Success (KPI #7) is defined as individuals with autism and other developmental disabilities should have the opportunity to participate in school to their fullest capability and be able to learn in an environment and manner that enables them to succeed.

One of the ways we can measure this is by the number of adults who are graduating with a High School diploma (41% in 2016 compared to 48% in 2014) and the number of drop outs (4% in 2016 compared to 2% in 2014). Both of these measures seem to raise concern for individuals with I/DD in our public education system.

In 2014, we asked if adults were currently enrolled in college in which 29% of 2014 participants said yes. In 2016, we asked the question a little differently coming up with a different baseline; 45% of adults either were attending or have attended college classes. Twenty-four percent (24%) were/had been enrolled in academic classes while 21% were enrolled in non-academic classes.

Adults With I/DD Who Are Attending or Have Attended College



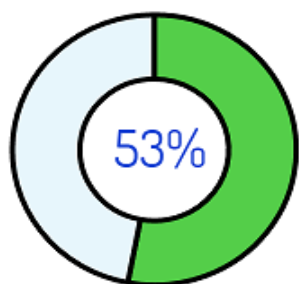
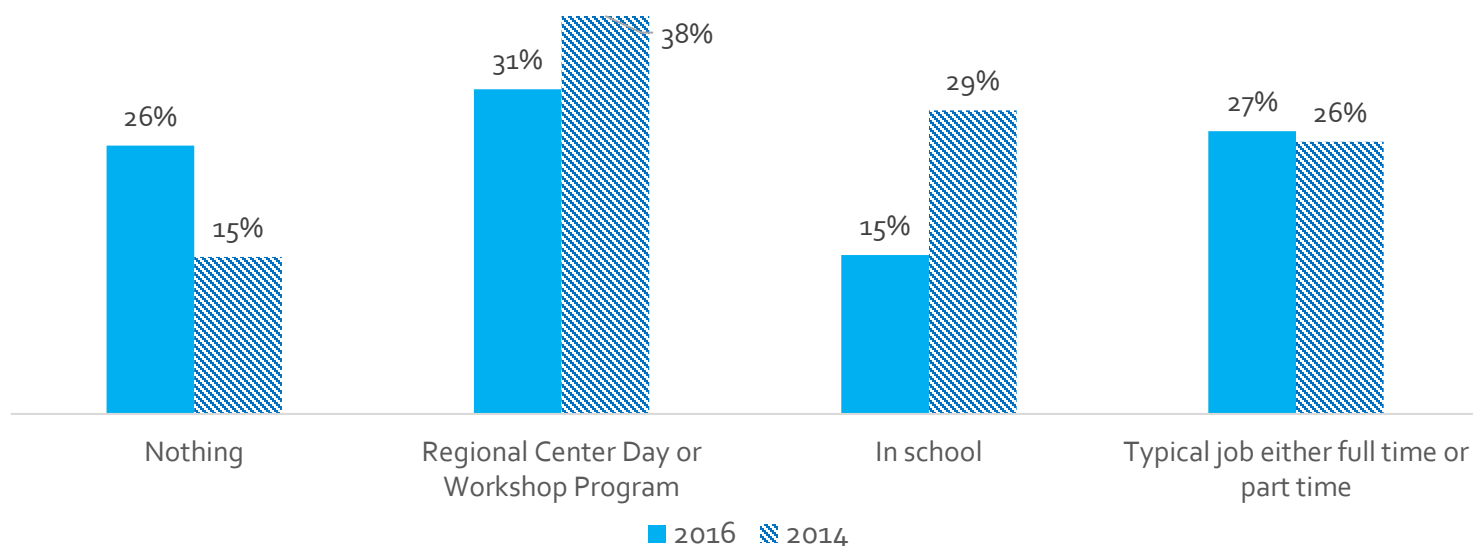
Meaningful Employment with Fair Wages

2016 ASC Survey

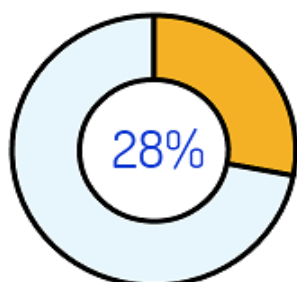
Individuals with I/DD should have the opportunity to do work which contributes to their communities, and should receive compensation befitting their position. Meaningful employment with fair wages is KPI #8. Long-term underfunding of the current vocational service systems has left Regional Centers, the Department of Rehabilitation, and service providers struggling to serve more people with fewer resources, which has resulted in higher caseloads and less customization of service options. Both Federal and State government agencies have acknowledged the need for better employment outcomes and data collection.

We compared the results from the 2016 Survey with the results we received from the 2014 Survey. Unfortunately, there was an increase in the number of adults who were at home doing nothing (26% in 2016 compared to 15% in 2014) and a decrease in the number of individuals in school (15% in 2016 compared to 29% in 2014). The number of individuals working either full-time or part-time stayed constant (27% in 2016, 26% in 2014).

What Does the Adult Do During the Day - 18 and older, Regional and Non Regional Center Clients



of the parents feel the day program/work their loved one does is meaningful



of the self advocates are happy with their job situation

Only 28% of the self-advocates are happy with their job situation while 52% of the parents of adults feel the work their loved one does is meaningful to them.

Another new measure for this survey is a baseline for the individuals who are working. Thirty-eight percent (38%) of adults (Regional Center and Non Regional Center) who are working reported they earn minimum wage or more. The average number of hours worked was 18.4 a week.

For individuals with I/DD who are employed:



The parent comments in this employment section reflects the broad need for services necessary to support our diverse community:

"My son's 1-1 aide in his Adult Day Program was going to leave due to low wages. I offered to pay her cash to supplement her wages, \$400 a month. She stayed, I'm thankful, but financially it's hard for me."

"I am grateful that my son has a job, but also think that he can do more. I do not think that he advocates for himself."

"Support for employment was difficult to get. He qualified for the service through DOR and [Regional Center], but no agencies had staff to support him, which means most of the support came from family members. I had to take a leave of absence from my work to assist him transitioning into employment. The job itself is very basic, but the pride in having a job, getting himself there and getting that check is priceless."

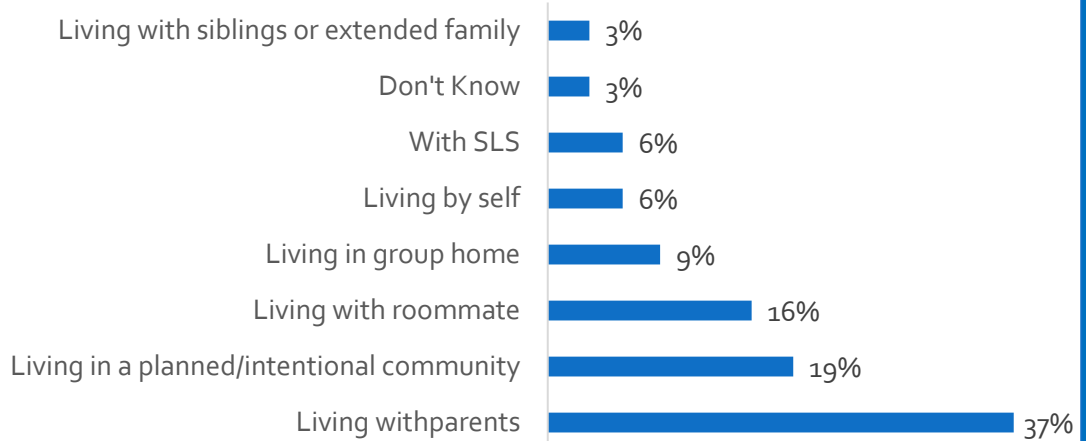
"Parents had to find the job and privately pay for the coach. What we are paying for the job coach will equal or exceed what is earned in pay. The system is not working at all in this regard".

"Employment is not something my son will ever have. (unless there is a medical break-through and things improve dramatically). We are grateful for his day program and their willingness to work with our son who has severe/classic autism."

"He loves "working" at [the Workshop]. He earns next to nothing but loves going there".

37% of parents believe living with them is the most appropriate place for their loved one to live

In 5 years, what type of living environment do you believe is most appropriate for your loved one?



Individuals with I/DD have the right to lead their own lives, and they should have support if they need help caring for themselves. Independent Living is KPI #9.

Long-term underfunding of the Regional Center service system, has left Regional Centers and service providers struggling to serve more people with fewer resources. Many families have real concerns about their loved one's ability to live in a group situation when communication, safety skills, and behavior issues are the norm. In fact, 42% of parents say that their loved one requires 24 hour support.

Over half the parents surveyed are concerned about how to pay for rent/mortgage expenses (62%), finding quality support staff (62%) and safety issues (60%). Compounding an underfunded system and an increased demand are new Federal Regulations, the HCBS rules, ensuring this will continue to be one of the "hot topics" for the I/DD community.

Housing and residential support is one of the most emotional issues for parents to consider. We had over 130 parents write comments regarding housing and housing supports.

"This is the most challenging issue for us. We feel that our son will eventually have to go into a group home as we get older, but it's an emotionally very difficult decision for us to make."

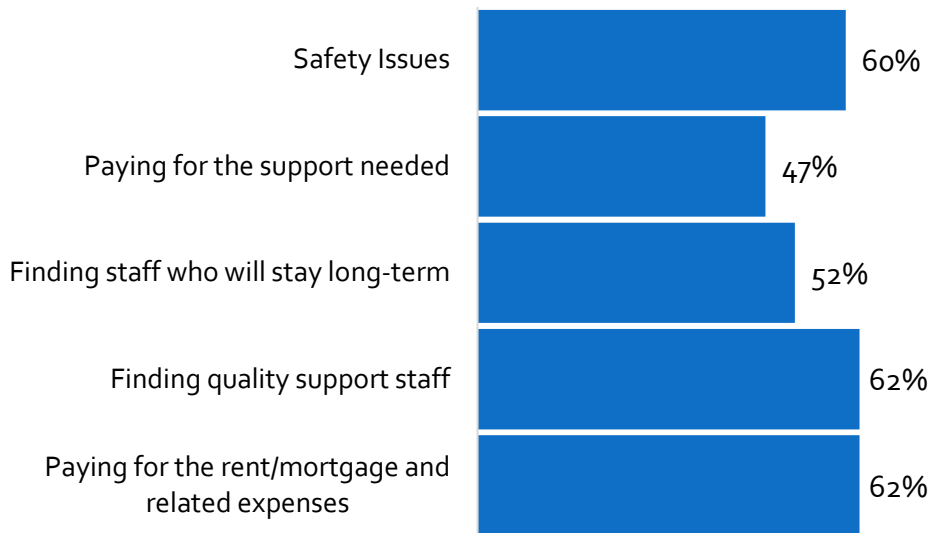
"He may appear high functioning but on occasion will unpredictably become enraged and self-harm himself"

"if i die, who will take care of my son? sibling will have their own lives, grandparents are elderly, i think my sister might care for him but it would be a financial burden on her"

"This is my biggest fear-he has no one to care/love him"

"I really don't know..... Would a group home sedate him too much? Are Staff trained in behavior challenges? What about wandering? Am fearful of abuse."

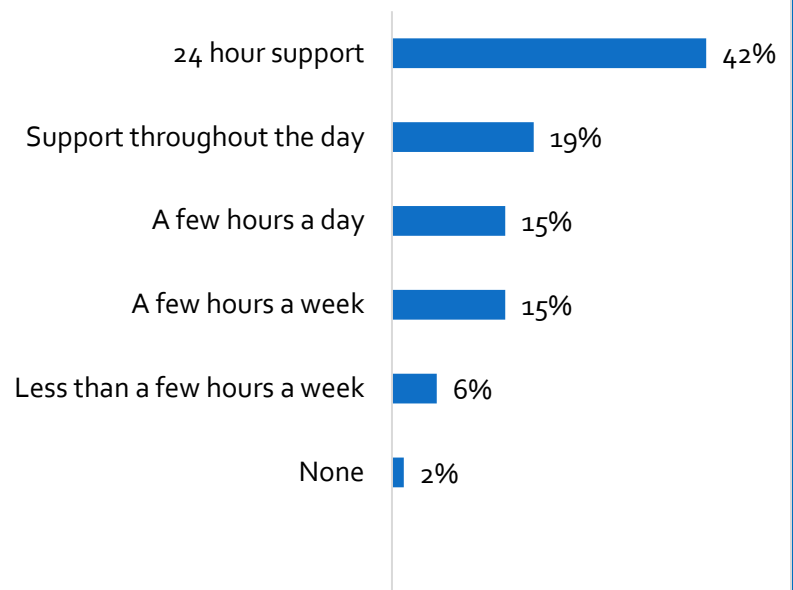
Parents Top Concerns Related to Housing



"I'm terrified about the future. My son needs to be encouraged, cajoled into going out, doing things. If left alone, he just stares at screens. I need to find somewhere for him where he will be encouraged to go out, be his best self. Supported when he has outbursts or is frustrated. And where he can live as independently as possible. And I haven't seen anything available that would suit his needs."

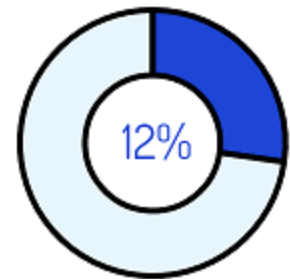
"He needs constant oversight and assistance by someone with a compassion and patience. He cannot cook, bathe, or brush teeth independently. His idea of socializing is repetitive joking (which he does with his mother) that most people would not understand or tolerate for long. He is prone to answering impulsively without thinking. If someone asks: "Did you have lunch yet?" or "Do you know where to go?" he is prone to saying Yes, when the answer is No. This is very risky for him."

If parent were no longer able to care for this person, how much support is needed to care for the individual in an ideal living situation?

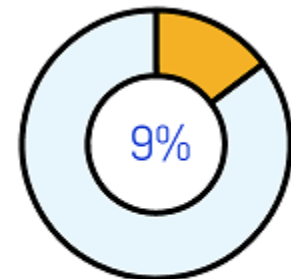


The Autism Society of California has defined well-being as individuals with I/DD should feel happy and enjoy life (KPI #10). This can be measured in a variety of ways. Our survey looked at how many families and individuals with developmental disabilities felt like they were in crisis. We did not define the word crisis and gave survey participants an opportunity to write in why they felt they were in crisis. We had almost 300 people respond to this section of the survey.

Twelve percent (12%) of parents with children under the age of 18 years felt like they are in crisis, while 9% of the Self-Advocates and family members with an adult with ID/DD feel they are in crisis.

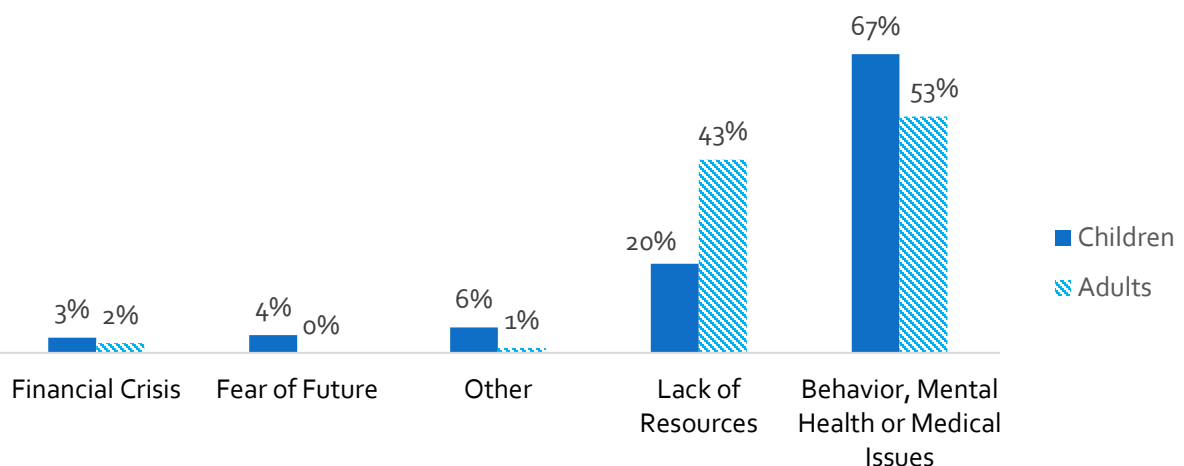


Parents with children under the age of 18 feel they are in crisis right now



Self-Advocates and family members with an adult with ID/DD feel they are in crisis right now

Reasons Given for Crisis



We compiled all the comments with regard to crisis and found they fell into five broad themes. We've included a few examples of the comments below to give readers an idea of the issues.

Comments from Parents of Children in Crisis	Comments from Self-Advocates and Parents of Adults in Crisis
67% of the comments indicated crisis was because of behavior, mental health or medical issues "We still need help with behavior. Child still has raging episodes where she is hitting, scratching, biting, throwing objects, lashing out at anyone. As she grows bigger, she just grows stronger and can inflict much more damage to herself and others." 20% indicated crisis was due to lack of resources "Our son is 12. He is almost a teen. He needs help he is frustrated, angry and needs services. We as parents are exhausted, sad and frustrated. MediCal has been a nightmare. With all of the paperwork and advocating for 12 years to fall between the cracks most everywhere even with our school system has been more stressful than caring for the spectrum child! Everyone says they can help but everyone has an agenda and if my square peg doesn't fit into the round hole we get nowhere" "There are too many days of frustration, and unable to communicate we as a family just keep guessing and guessing and we only get try this, try that, we've tried everything we've ever been told and it doesn't get us out of the crisis." 4% are worried about the future "Cause this is really hard, and lonely and scary. And we worry about the future of our son." 3% have severe financial pressures "She needs to be back on ABA services again, but I must work just to pay normal bills and so must my husband so fitting in the service is hard. We want it through the school district, but they won't provide it and fighting it is exhausting."	53% of the comments indicated crisis was because of behavior, mental health or medical issues "He has co-morbid mental health issues that make him depressed and anxious all of the time. He has said he wants to be dead." "I keep going to the emergency room because I tell my mom I want to kill myself and a am really unhappy" "He has strong outbursts and because he's large and difficult to restrain, it's hard to take him out. I feel like his life is getting smaller and smaller as he ages. I want him to be able to go out, find interests, friends. But it's getting harder and harder, the bigger and older he is." 43% of the comments crisis due to lack of support and services "He has no job and spends too much time in his room. He is not motivated to do anything other than stay up late, sleep in, and play games. He is about to turn 27 and has only a little it of job experience. He is dependable. He is intelligent. He could do so much. The lack of work and social interaction will no doubt further impact his self-esteem. His father reminds him that having had no job looks bad on applications. But his father does nothing. I am chronically forgetful myself. I am working on just being sane myself." "I have no friends other than my parents." "My husband and I are aging, and our daughter needs a housing solution that will survive our deaths, and be reasonably assured of surviving for the rest of her life. She would not understand if we suddenly disappeared, and, lacking an independent home in her community, she would be shipped off to some remote facility where she would lose family, friends, doctors, teachers, and everything and everyone she knows."

2016 Survey Key Performance Focus

1. Service Systems

- a. 45% of survey participants report Regional Center services are meeting their needs
- b. 20% believe DOR met the needs of their family member
- c. Only 40% of parents with adults and self-advocates have attempted to access Department of Rehabilitation services – and only 25% report being placed in employment and being successful.

2. Autonomy and Self-Advocacy. People with ID/DD have the right to make their own decisions.

According to responses from self-advocates and parents:

- a. 46% overall were familiar with what a person-centered plan is
- b. 38% are familiar with the Self-Determination program
- c. 51% of adults were conserved
- d. 59% report Regional Center makes them feel like they are a partner in developing IPP and in determining services and supports
- e. 74% report Regional Center includes items in their IPP which are important to them
- f. 47% of parents report the adult needs constant supervision due to significant deficits in self-help skills, and/or limitations in physical coordination and mobility, and/or exhibits disruptive or self-injurious behavior making it difficult for their loved one to be included as part of their local community (shop, go on social outings, have a job, live).

3. Respect and Dignity. Individuals with I/DD should feel respected by those around them.

- a. 48% felt the Department of Rehabilitation treated the individual with courtesy and respect
- b. 85% of all Regional Center clients surveyed feel their caseworker treats them with courtesy and respect

4. Communication. People with autism and other developmental disorders should be able to express themselves and interact with others in a meaningful way.

- a. 31% of parents of adults feel their loved one is able to communicate what they want or do not want and make their intentions known regarding their life goals, 48% somewhat and 21% believe their loved one is not able to communicate this information.

5. Health. Individuals with ID/DD should feel and be well physically and have access to the services they need to stay healthy.

- a. 60% of adults report exercising at least 2.5 hours or more in a typical week
- b. 50% of adults and parents feel the individual with ID/DD eats healthy

- 6. Social Connections. Individuals with I/DD should have friends and supports as well as ties to their communities.**
- a. 46% of adults have friends they talk to online
 - b. 23% Feel like the adult has enough friends or social opportunities
- 7. Academic Success. Academic Success is defined as individuals with autism and other developmental disabilities should have the opportunity to participate in school to their fullest capability and be able to learn in an environment and manner that enables them to succeed.**
- a. 41% of individuals with I/DD reported graduating High School with a diploma in 2016 compared to 48% in 2014
 - b. The number of High School drop outs was reported as 4% in 2016 compared to 2% in 2014
- 8. Meaningful Employment with Fair Wages. Individuals with I/DD should have the opportunity to do work which contributes to their communities, and should receive compensation befitting their position.**
- a. For all adults, Regional Center and Non-Regional Center, over the age of 18 year, there was an increase in the number of adults who were at home doing nothing (26% in 2016 compared to 15% in 2014) and a decrease in the number of individuals in school (15% in 2016 compared to 29% in 2014). The number of individuals working either full-time or part-time stayed constant (27% in 2017, 26% in 2014).
 - b. Those who work 38% receive minimum wage or more
 - c. Ones who work average 18.4 hours a week
 - d. 53% of the parents feel the day program/work their loved one does is meaningful
 - e. 28% of the self-advocates are happy with their job situation
- 9. Independent Living. Individuals with I/DD have the right to lead their own lives, and should have support if they need help caring for themselves.**
- a. 42% of parents say that their loved one requires support 24 hours a day
 - b. 62% of parents surveyed are concerned about how to pay for rent/mortgage expenses and finding quality support staff
 - c. 60% are concerned about safety issues
 - d. 37% of parents say living with their parents is the most appropriate place for their loved one to live
- 10. Well-being. Individuals with I/DD should feel happy and enjoy life.**
- a. 12% of parents with children under the age of 18 years felt like they are in crisis
 - b. 9% of the Self-Advocates and parents of adults felt like they are in crisis.