



 **AUTISM SOCIETY**
Inland Empire

**THE IMPACT OF COVID
ON THE INLAND EMPIRE
AUTISM AND
DEVELOPMENTAL
DISABILITY
COMMUNITY
2020**

6 MONTHS OF SHUTDOWN

Autism Spectrum Disorder is a developmental disability that can cause significant social, communication and behavioral challenges. There is often nothing about how people with ASD look that sets them apart from other people, but people with autism may communicate, interact, behave, and learn in ways that are different from most other people.

Families and children and adults with autism often require routine, structure and support in life. It is common for a child to receive special education services at school with behavioral, speech therapy, and occupational therapy services and then receive additional outpatient therapies such as behavioral, speech therapy, occupational therapy, physical therapy, mental health services and social skills training. Additionally, parents may have an outside caregiver come into the home to provide respite (childcare services) or IHSS (help with daily care). Suddenly, the normalcy of that routine and services was upended by COVID.

As Governor Newsom issued the California Stay at Home Order on March 19, 2020, the Autism Society Inland Empire reached out to our community to determine what the most pressing needs were. We worked to develop new services, educate our community, and advocate quickly to meet those needs.

This report summarizes the key findings of the last 6 months of survey completed by Inland Empire families.

**1 IN 54 CHILDREN
ARE DIAGNOSED
WITH AUTISM**

**IN THE INLAND EMPIRE
THERE ARE OVER 15,000
CHILDREN/ADULTS WITH
AUTISM AND ANOTHER
60,000 FAMILY MEMBERS
AFFECTED**

SURVEY INFORMATION

Surveys were conducted once a month from March - September 2020 and were distributed electronically in English and Spanish to individuals and family members in the Inland Empire Developmental Disability community (Autism, Cerebral Palsy, Epilepsy, Down Syndrome, Intellectual Disabilities and other disorders). Primarily our autism community responds to these surveys (92%). Surveys were kept brief to be conscious of the stress going on the families lives. Participants were given the option to enter their name for a chance to win a gift card.





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WHAT WE KNOW ABOUT COVID AND AUTISM

According to the Center for Disease Control, having a disability alone may not be related to higher risk for getting COVID-19 or having severe illness. However, there are other characteristics that make this population at a high risk for both contracting COVID and becoming seriously ill:

- Adults with disabilities are three times more likely than adults without disabilities to have heart disease, stroke, diabetes, or cancer than adults without disabilities.
- May have close contact with others who may be infected, such as direct support providers and family members
- May have trouble understanding information or practicing preventive measures, such as hand washing and social distancing
- May not be able to communicate symptoms of illness

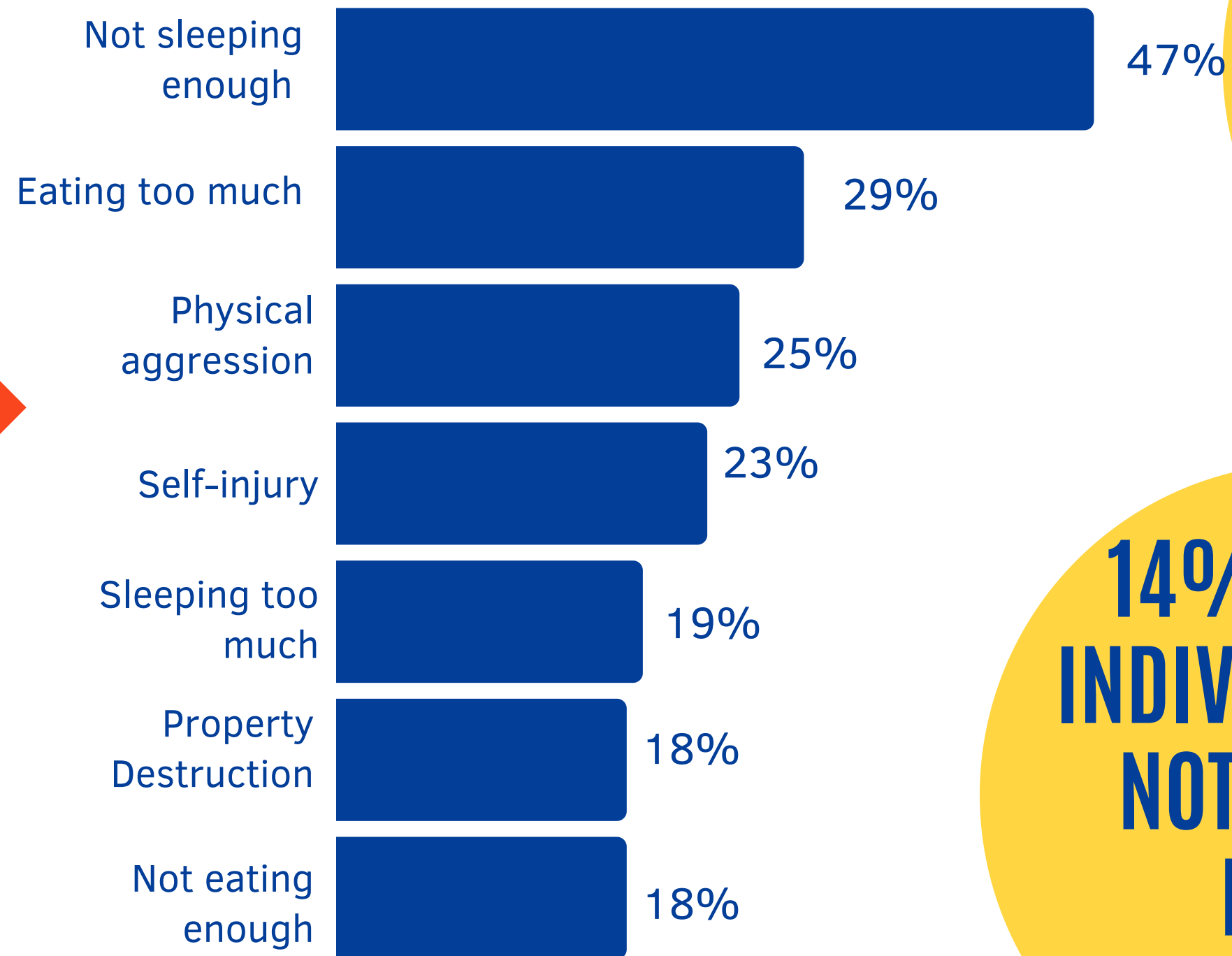
People with Intellectual Disabilities are 4x more likely to contract COVID and 2.5 times more Likely to Die of COVID¹

1. Shapiro, Joseph. "COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities" June 9, 2020

<https://www.wbur.org/npr/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili>

CHANGES IN BEHAVIOR

REPORTED CHANGES IN BEHAVIOR



OUT OF CONTROL BEHAVIORS AFFECTS 1 IN 4 FAMILIES

14% - 22% INDIVIDUALS DO NOT BENEFIT FROM TELEHEALTH

"Since the pandemic began, our daughter has had to go on three medicines (she never took anything before) for anxiety and to help her sleep. She has been psychotic at times but the medicine has definitely calmed her down. She has also regressed in her abilities to take care of her needs."

Not only did families report an increase of behaviors, for most families services either ceased completely or converted to a telehealth model. While most families reported they received benefit from these services, depending on the type of therapy, 14-22% of families reported telehealth services were not effective.

THE AUTISM COMMUNITY'S DIFFICULTY IN FOLLOWING COVID SAFETY PROTOCOLS



Individuals with autism can face a variety of cognitive, communication, social and sensory challenges. These issues affect decisions families most basic decision such as attending school or programs, shopping in the community, and bringing medical professionals into their home.

- 39% will put things in their mouth or touch their faces
- 32% can not practice concept of social distancing
- 26% of the population can not tolerate wearing a mask at all
- 11% can not wash their hands frequently

Autism Society of California May 2020 Survey, Inland Empire population, 279 participants



COVID TESTING CHALLENGES

RIVERSIDE COUNTY
COVID TESTED

24.3%

POPULATION

As of 9/18/2020

SAN BERNARDINO
COUNTY COVID TESTED

26.4%

POPULATION

As of 9/18/2020

TESTED INDIVIDUALS
WITH AUTISM/DD IN THE
INLAND EMPIRE

15%

POPULATION

Sept 2020 Survey

FAMILY MEMBERS OF
INDIVIDUALS WITH
AUTISM/DD IN THE INLAND
EMPIRE

16%

POPULATION

Sept 2020 Survey

The Autism Society Inland Empire September 2020 COVID Survey showed that individuals with autism and other developmental disorders and their family members were less likely to get tested than the general population in the Inland Empire. We would suggest because this population can exhibit aggressive behavior and testing through a nasal swab may seem unimaginable. Interestingly, family members are also not being tested. This raises concerns about the health of parents and caretakers. More information to identify barriers and solutions is needed.

Riverside County DPH reported 600,554 tested as of 9/18/2020 - <https://www.rivcoph.org/coronavirus>

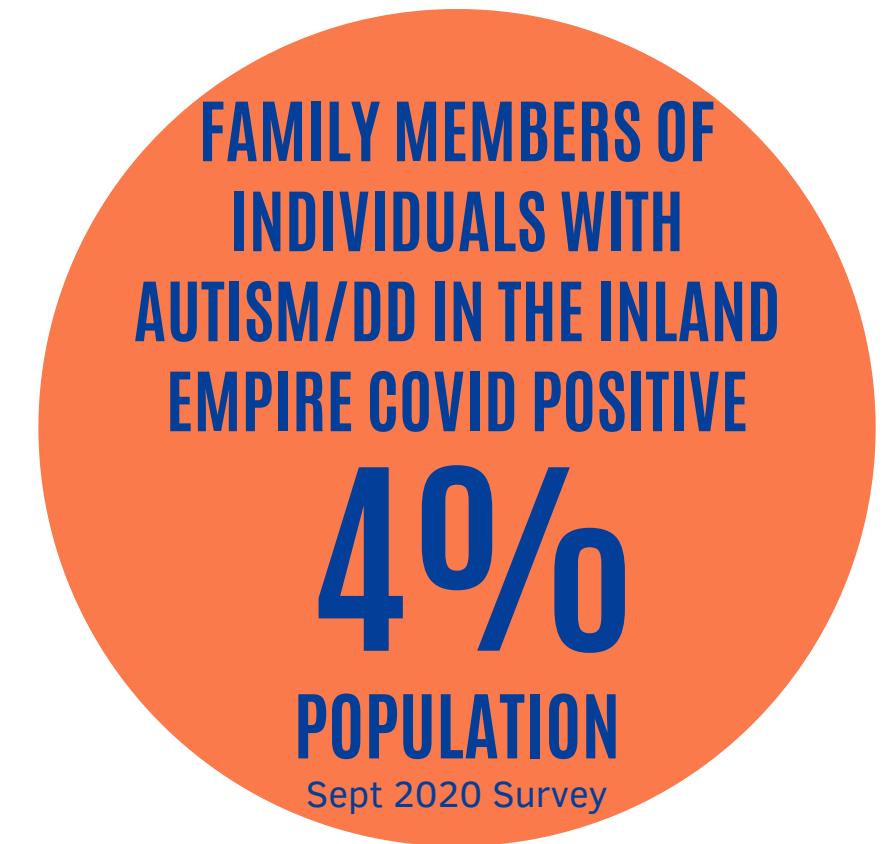
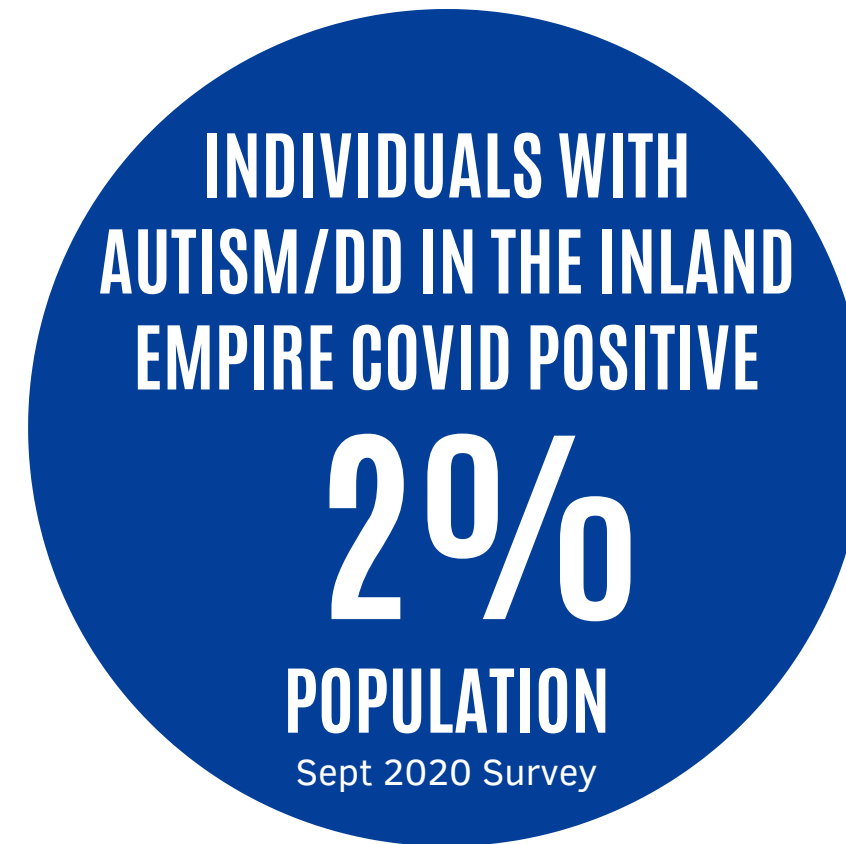
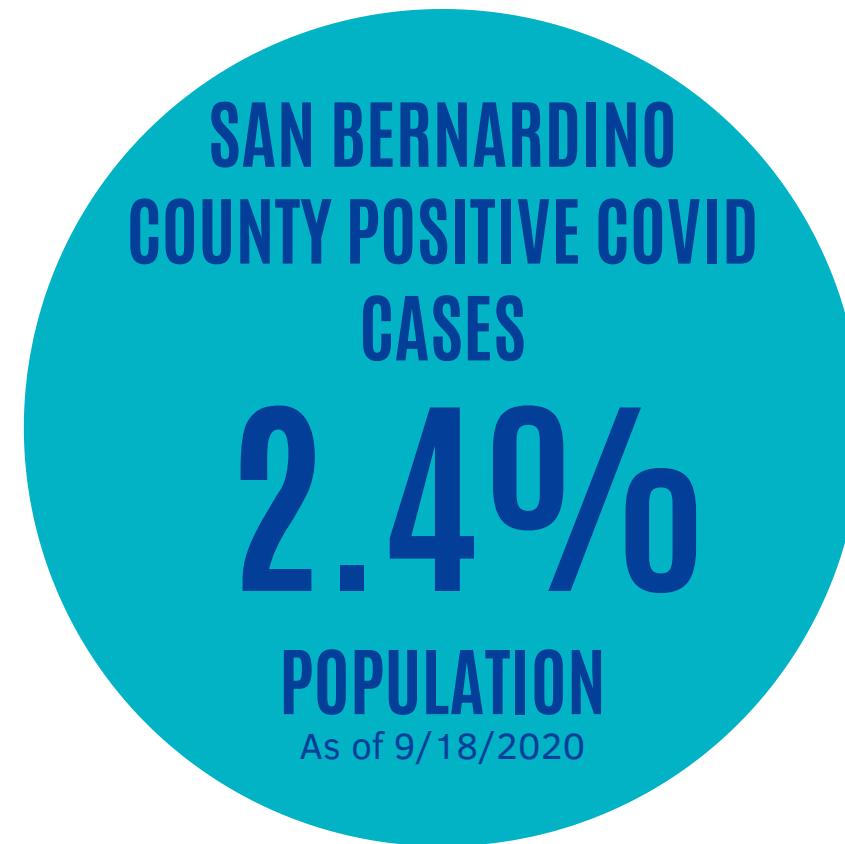
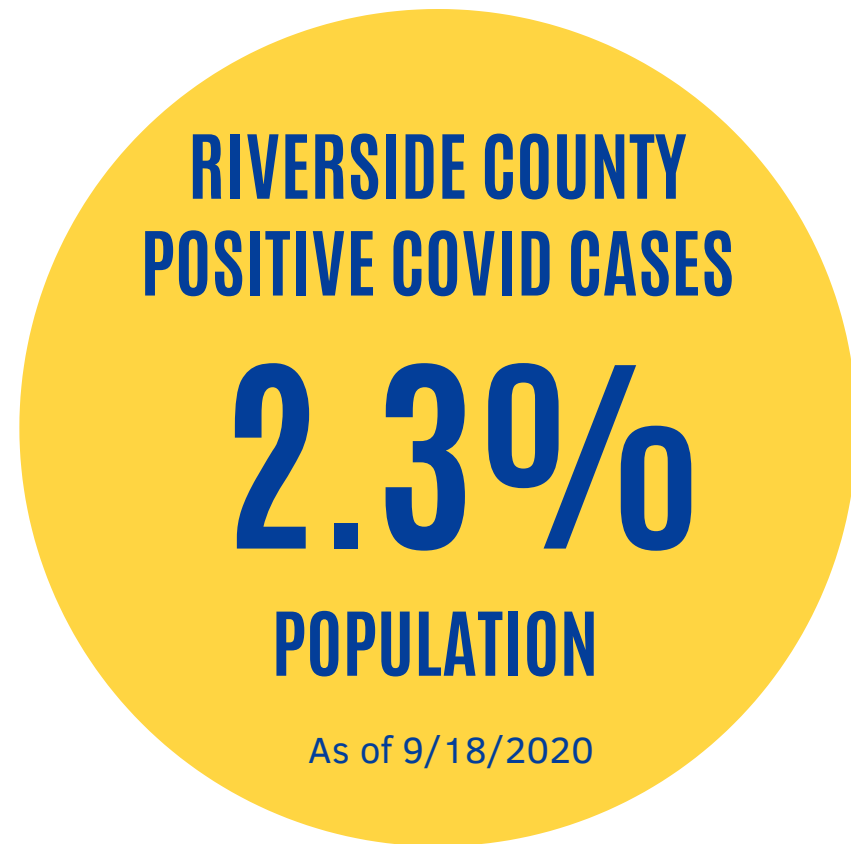
Riv Co Population Census Quick Facts Riv County population 2,470,546 - <https://www.census.gov/quickfacts/fact/table/riversidecitycalifornia,riversidecountycalifornia/PST045219?>

San Bernardino DPH reported 575,953 PCR tests as of 9/19/2020 - <https://sbcph.maps.arcgis.com/apps/opsdashboard/index.html#/44bb35c804c44c8281da6d82ee602dff>

San Bernardino Co Population Census Quick Facts Riv County population 2,180,085 - <https://www.census.gov/quickfacts/fact/table/sanbernardinocountycalifornia/PST045219?>

Autism Society Inland Empire Aug/Sept Survey - 346 participants

COVID CASES IN THE AUTISM COMMUNITY



- Individuals with Autism or Other Developmental Disability: 2% tested positive, 2% not tested but we think they had it
- Family Member of Individual with Autism or Other Developmental Disability: 4% tested positive, 3% not tested but we think they had it

Riverside County DPH reported 56,681 positive cases as of 9/18/2020 - <https://www.rivcoph.org/coronavirus>

Riv Co Population Census Quick Facts Riv County population 2,470,546 - <https://www.census.gov/quickfacts/fact/table/riversidecitycalifornia,riversidecountycalifornia/PST045219?>

San Bernardino DPH reported 52,827 positive cases as of 9/19/2020 - <https://sbcovid19.com/>

San Bernardino Co Population Census Quick Facts Riv County population 2,180,085 - <https://www.census.gov/quickfacts/fact/table/sanbernardinocountycalifornia/PST045219> Autism Society Inland Empire Aug/Sept Survey - 346 participants

EMERGENCY FOOD RESPONSE

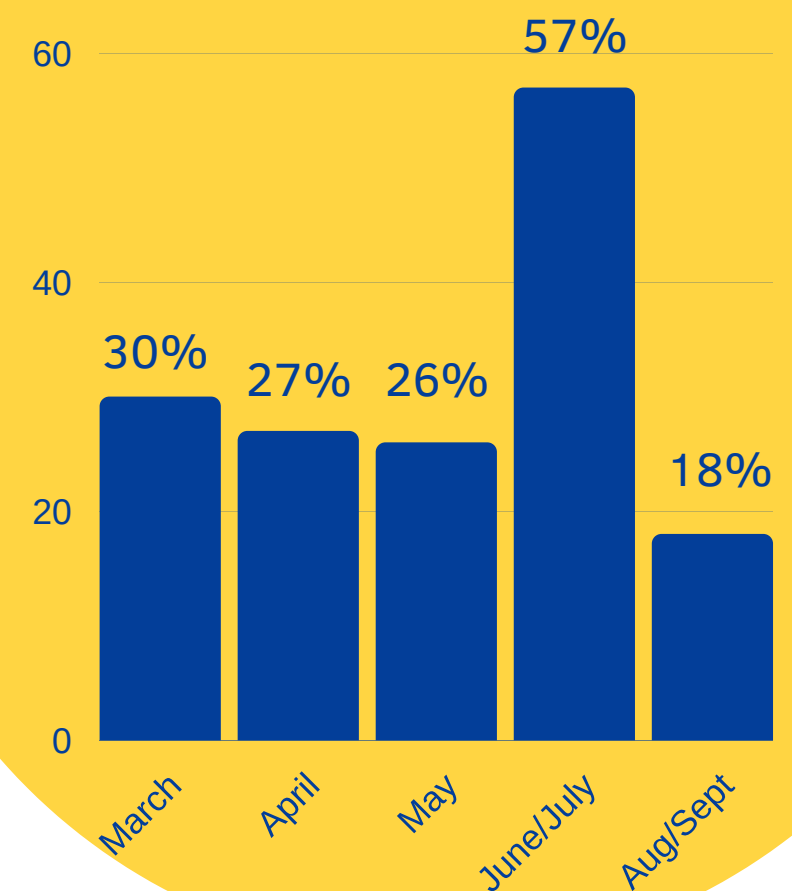
One of the devastating effects to families was the loss of jobs and income. Some families with children with autism faced added challenges. Sixty-nine percent (69%) of families reported their loved ones who had a restricted diet; they only ate certain textures, tastes, and brands. Furthermore, 25% of children/adults with autism were showing aggressive behaviors. These factors played a significant roll in families not being able to access generic resources like food banks and school lunches.

We are grateful to donations by No Hungry Kids, the Inland Empire Community Foundation, the Magnon Foundation, the Albertson's Nourishing Neighbors Foundation, the Inland Regional Center CAC, and private donors which has allowed the Autism Society Inland Empire to provide over \$30,000 of food to 680 community members.

In September, we are starting to see the need for food to decrease to pre-COVID levels.



NEED FOR FOOD



BASIC NEEDS

NEED FOR MASKS AND PPE

Thanks to the generous donation and partnerships from the California Department of Developmental Disabilities (DDS), the California State Council on Developmental Disabilities (SCDD), Inland Regional Center, Riverside County, and EasterSeals Southern California, over 200,000 masks have been distributed to local families in the Inland Empire.

The September 2020 Survey also showed that this is an area of disparity; 44% of Spanish speaking families indicated this was a priority to them compared to 25% of English speaking families.

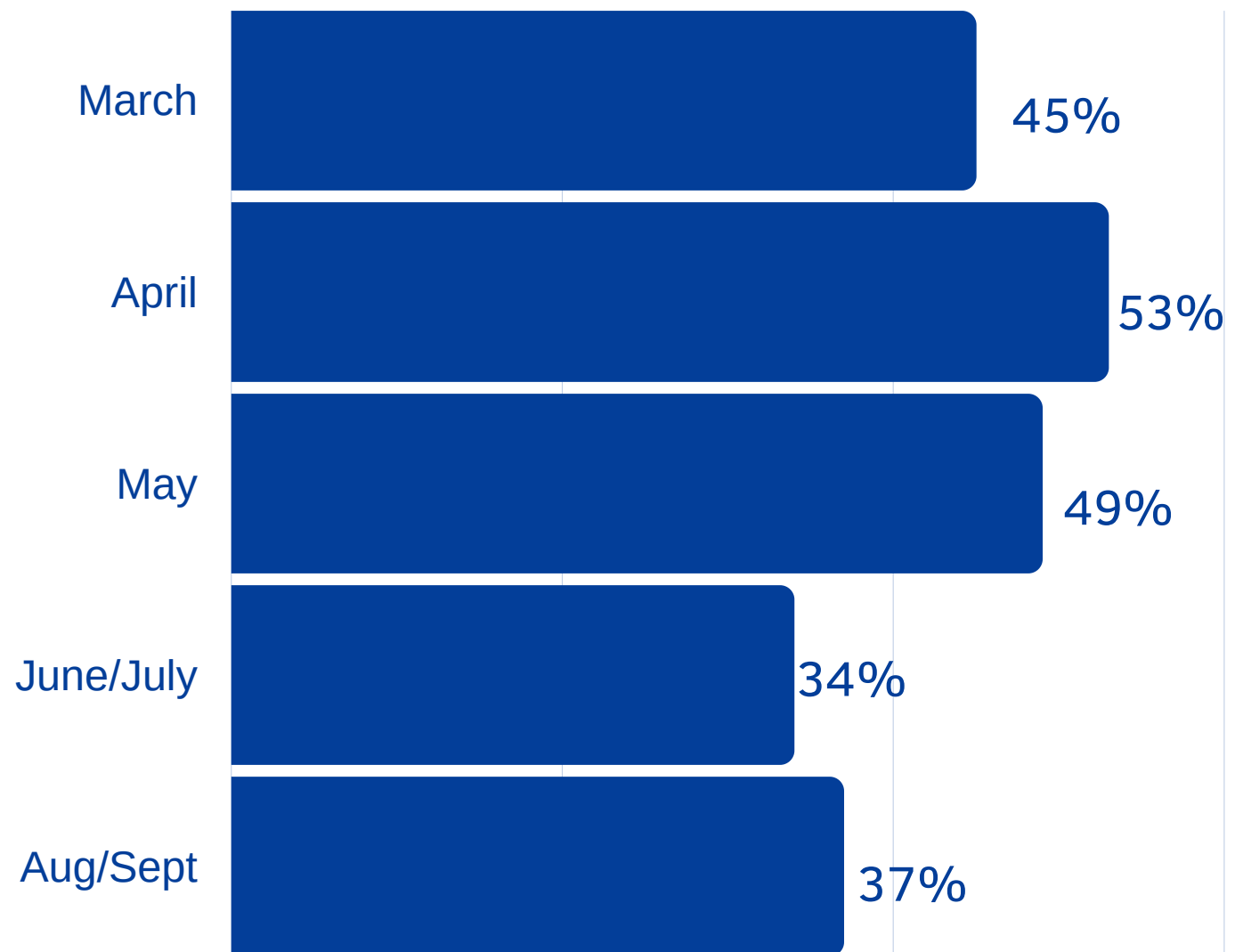
29%

of families identified PPE as a need for their family in the Autism Society Inland Empire September Survey



NEED FOR EDUCATIONAL SUPPORTS HIGHEST PRIORITY FOR FAMILIES

NEED FOR FAMILIES: EDUCATION



The number one stressor for most families in the Inland Empire was the need for educating their student with autism and developmental disabilities. Routine disruptions and anxiety related to the virus and its impact.

However, the prospect of sending a special education student back to school, especially considering 1 in 6 students would not wear a mask or social distance presented a new dilemma for parents. Approximately 1/3 of parents have consistently reported they would not participate in person school.

- 33% (May 2020 California Survey: 927 participants)
- 31% (June/July Autism Society Inland Empire Survey: 196 participants)
- 37% (Aug/Sept Survey: 247 participants)

EDUCATION

On a scale of 1-10, 1 being extremely poor and 10 being excellent, Inland Empire special education parents gave distance learning a

4.2

Sept 2020 Autism Society Inland Empire Survey (221 participants)

 **AUTISM SOCIETY**
Inland Empire

Knowing that 14-22% of our population did not benefit from teleservices with medical professionals, it was a safe assumption that approximately the same percentage would have trouble engaging in online learning.

Most schools in the Inland Empire began distance learning mid-August and 2-4 weeks in, special education parents are reporting on a scale of 1-10, 1 being extremely poor and 10 being excellent, scored the distance learning process as 4.2.

The Autism Society Inland Empire receives calls daily from parents who are overwhelmed and stressed:

- *"My daughter can not follow along in class. I am the 1:1 aide and the teacher. I gave up my job and income to ensure my daughter has an education."*
- *"It's hard when you have to work away from home and have to leave her in the care of her older brother because they have no responsibility to connect her to classes or passion to be with her."*

Our organization advocated for and applauds the Guidance from the California Department of Public Health, updated Sept 4th which allows the return to school for some children in grades K-12 in groups of up to 14 students. The limited return to school applies to students needing special care, such those with disabilities, and is aimed at ensuring the students can access services like occupational therapy, speech and language services and individualized education programs. We feel this option should only be voluntary for all parties involved - educators, instructional assistants, service providers and families and look forward it to being one of the options available to parents.

We also believe more conversations need to happen about educational expectations and supports need to take place with all administrators, educators, service providers, students, and family members to ensure we are all working towards the same goals.

ACCESS TO TECHNOLOGY

16%

of school-aged families reported they still need a laptop

September 2020 Autism Society
Inland Empire Survey (239
participants)



"We have an outdated poorly pixelated lap top for two kids none for my nonverbal 4 yr old"

"A better support when there are laptop problem"

26%

families of school-aged children need a better internet connection

September 2020 Autism Society
Inland Empire Survey (239
participants)

DAY CARE

UNDER 17 YEARS -
DAYCARE AN ISSUE

50%

Sept 2020 Autism Society Inland
Empire Survey (248 participants)

OVER 18 YEARS -
DAYCARE AN ISSUE

24%

Sept 2020 Autism Society Inland
Empire Survey (62 participants)

Finding daycare for any family can be a challenge, but for a family who has a child with autism who may not speak, follow verbal instructions, and have violent meltdowns, finding a day care provider can be particularly challenging. Add in that these are children who also may not wear a mask or understand the concept of social distancing, the challenges seem unsurmountable. Parents are having to choose between their jobs and income and the well being of their child.

Additionally, many day care providers may only watch children under the age of 13 years. There is a need for services for children and adults who are disabled over the age of 13 years.

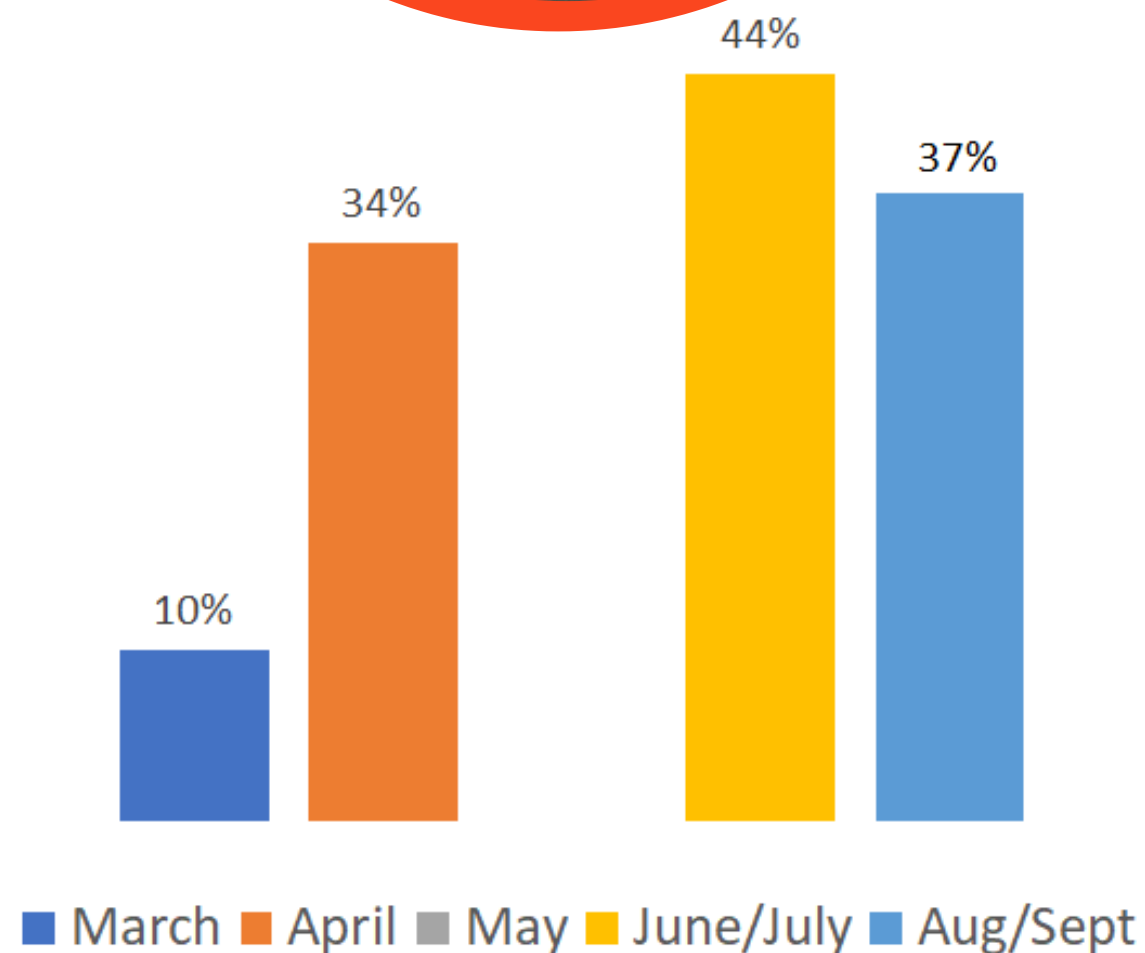


SOCIAL ISOLATION

The next major concern for parents is the need for social opportunities. There are many studies that show social engagement relates to the well-being of individuals including children and adults with Autism.

The Autism Society Inland Empire responded by creating new online programs that appeals to all ages and often can include family members. These programs were offered free of charge for the first 6 months to families, but will not shift to a small fee with scholarships available to those who cannot afford the fees,

"I wished my son would take an interest in anything and move forward. His depression and anxiety is debilitating."



AUTISM SOCIETY INLAND EMPIRE VIRTUAL SOCIAL PROGRAMS

- Bedtime Stories - every Thursday night, all ages
- Fun Friday's - every Friday afternoon, all ages
- Art Classes - every Wednesday, all ages
- Rancho Adult Group - twice a month on Friday nights
- Anime Club - adult group every other week
- Movie Club - adult group every other week
- Role Playing Game Club - adult group Sat night's
- Talk to Me Tuesday - support group for parents, professionals and adults with Autism, every Tuesday
- Support Group for Parents of Adults

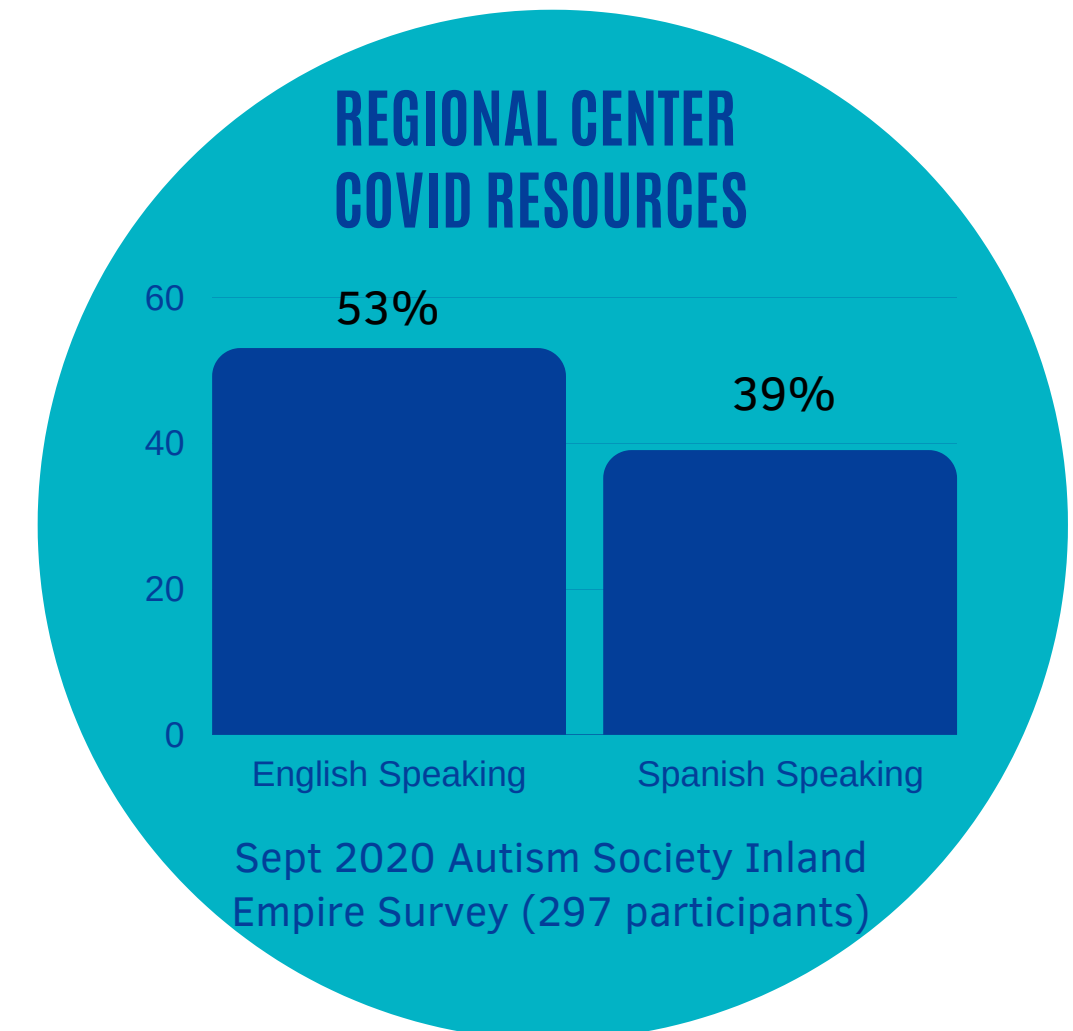
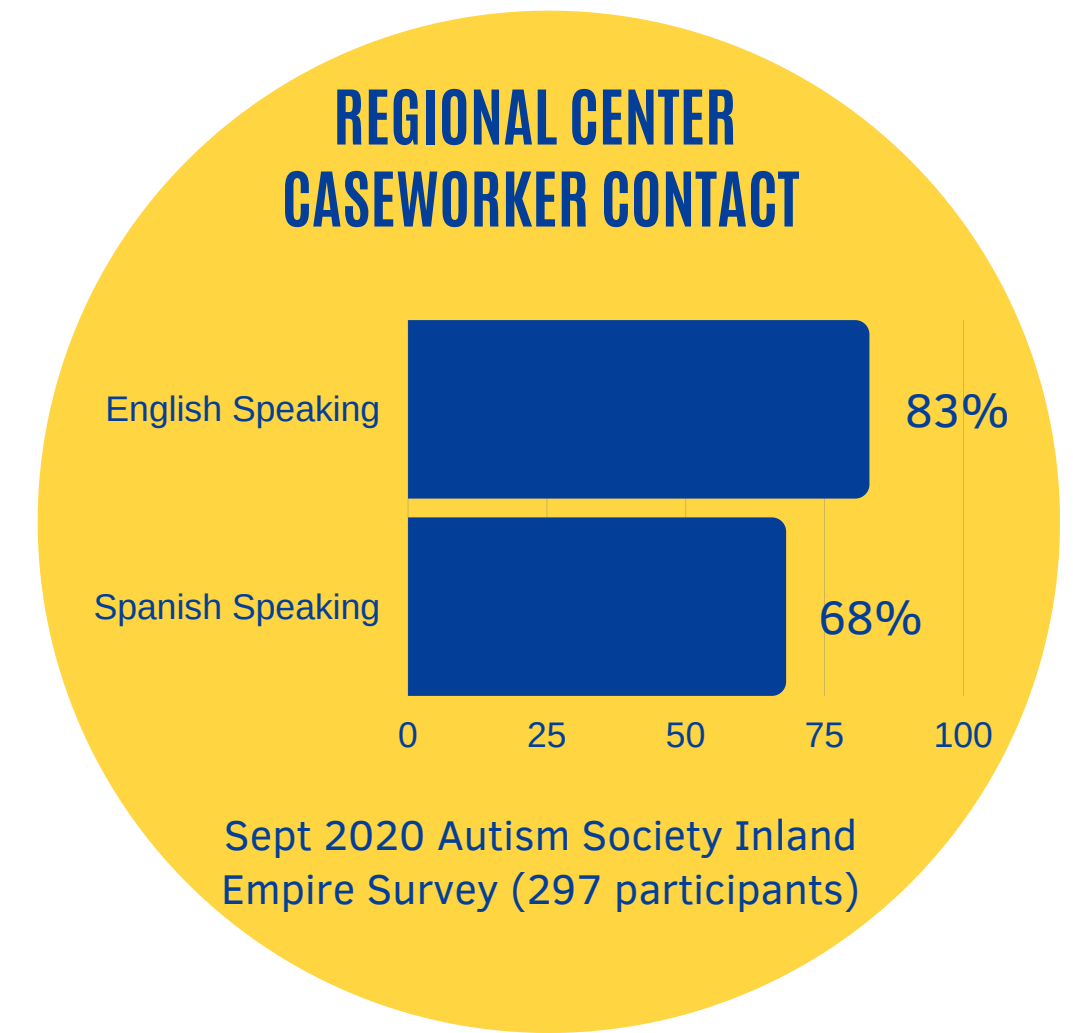
REGIONAL CENTER SERVICES



APPROXIMATELY 80% OF SURVEY RESPONDENTS ARE REGIONAL CENTER CLIENTS

DISPARITY ISSUES

- In the September 2020 Survey, a total of 21% of families report their Regional Center caseworker have not contacted them. However, when the data was analyzed by language spoken, there was a disparity: 32% of Spanish speaking families advised they were not contacted compared to 17% for English speaking families.
- Similarly, when families were asked if the caseworker has provided COVID related resources or supports to your family, 61% of Spanish speaking families indicated they had not versus 47% of English speaking families.



REGIONAL CENTER ADULT SERVICES

On a scale of 1-10, 1 being extremely poor and 10 being excellent, Inland Empire parents gave current adult services

6.4

September 2020 Autism Society Inland Empire Survey (72 participants)

31%

of families with adults advise they need a better internet connection to participate in online programs

September 2020 Autism Society Inland Empire Survey (93 participants)

23%

of families with adults advise they need a laptop to participate in online programs

September 2020 Autism Society Inland Empire Survey (93 participants)



REGIONAL CENTER EMPLOYMENT AND DAY SERVICES

As of 2018, the California Department of Developmental Services reported that only 4% of the adult autism population was employed at a job which paid minimum wage or more. This was an increase from 2% employment in 2016.

Many individuals and families are very concerned about their loved one in the community at a job, volunteering, or participating in a day service due to:

- Many individuals with Autism and other Developmental Disabilities have co-existing conditions that make them more susceptible to complications from COVID. ((Autism Society of California May 2020 Survey, 279 participants)
- 1 in 4 individuals can not tolerate wearing a mask and 1 in 3 social distancing at all. For many who can tolerate it, they may need constant reminding and may not be able to tolerate it for more than an hour at a time. (Autism Society of California May 2020 Survey, 279 participants)
- Many adults rely on public transportation which have reduced bus schedules and a limit on the number of riders which could impact time at a bus stop or on a bus.

The Autism Society Inland Empire commends the California Department of Developmental Services in promoting Alternative Service Delivery Models and hopes that the vendors providing these services will develop new service delivery methods that can provide meaningful interaction, and build new skills for employment and independence.

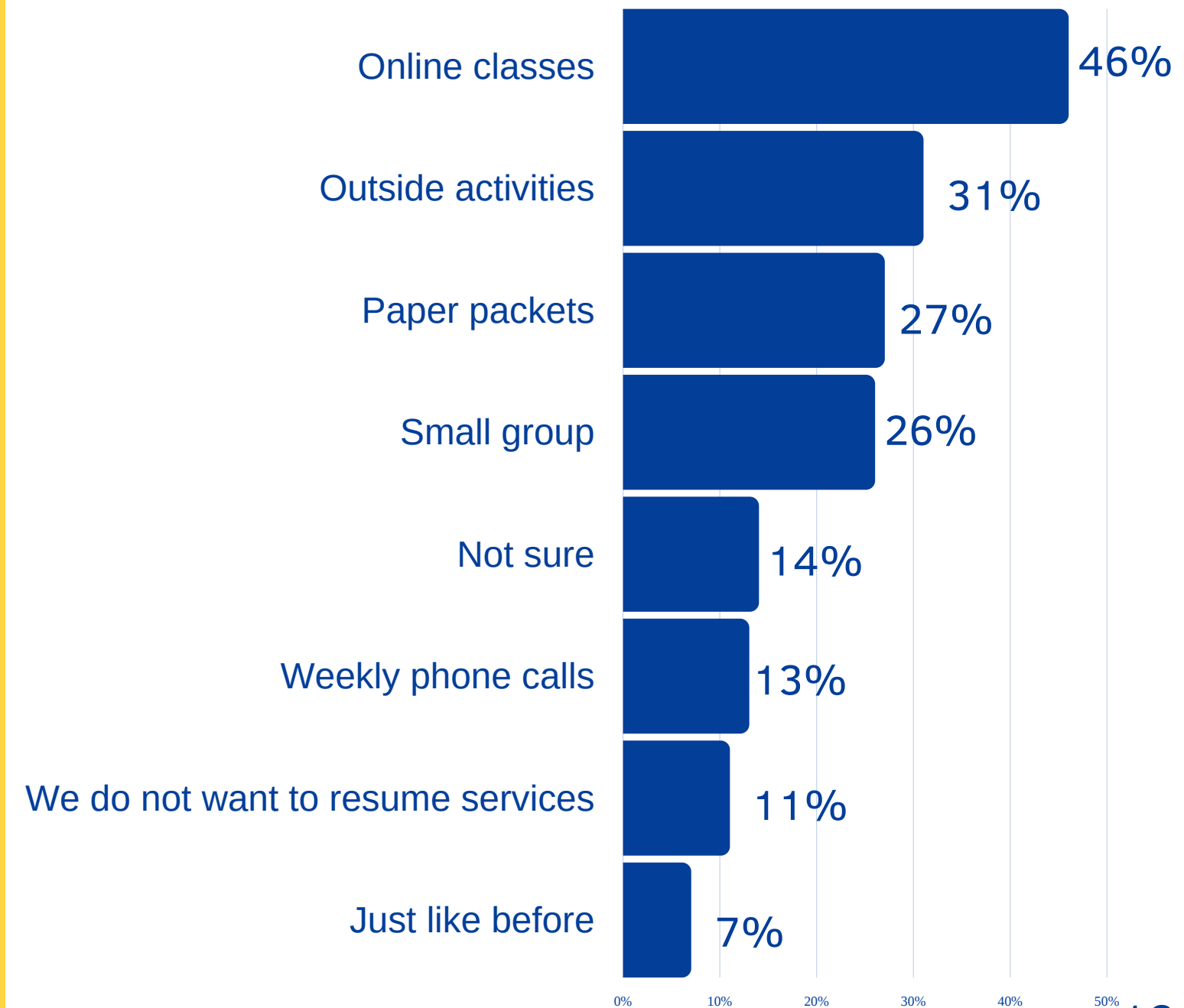
33%

of families indicated they would not agree to in-person day service or job program

May 2020 Autism Society Inland Empire Survey (62 participants)

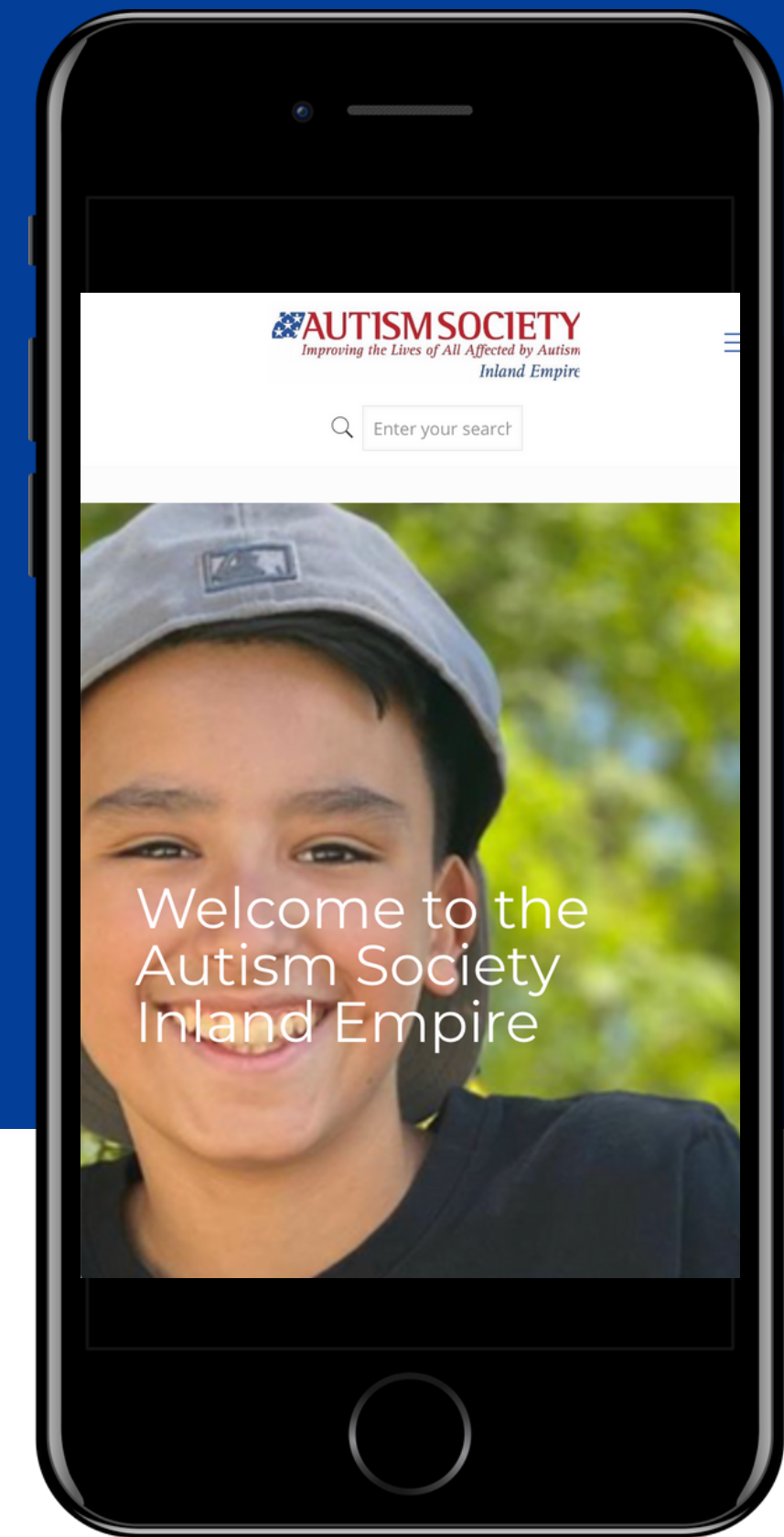
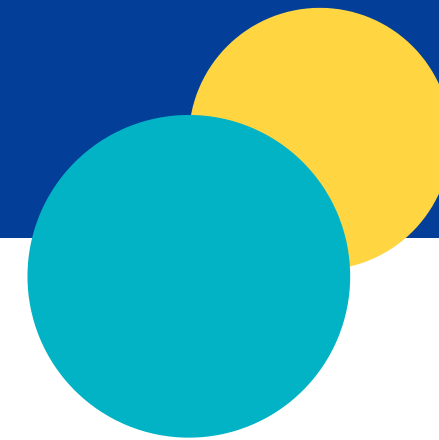
SEPTEMBER 2020 REQUESTED ADULT SERVICE DELIVERY

Sept 2020 Autism Society Inland Empire Survey (70 participants)



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 **AUTISM SOCIETY**
Improving the Lives of All Affected by Autism
Inland Empire