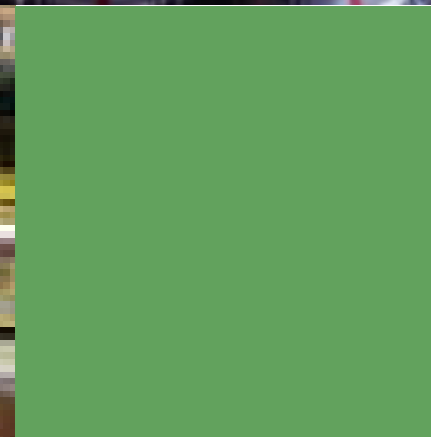
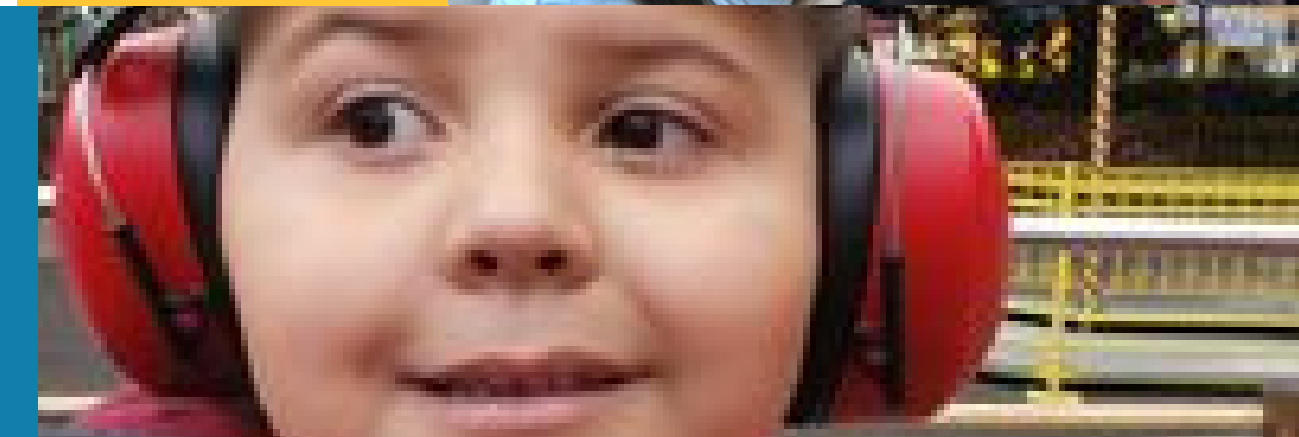
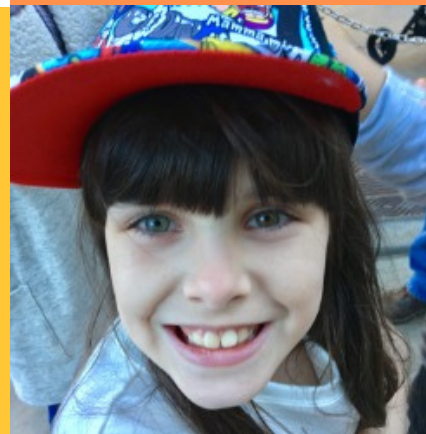


# The Impact of COVID-19 on the California ID/DD Community

May 2020 Survey







# Why This Survey

We want to thank the families who took the time to share how COVID-19 has affected their daily lives.

It was our hope to capture how COVID-19 has disrupted medical, educational and Regional Center services for our community, to understand the barriers for re-integration and what individuals and families are looking for to help them feel safe as we look toward the future.

We realize the issues we face are not necessarily unique to our intellectual and developmental disability (ID/DD) community, but it is important that policymakers and leaders are aware that our community may be substantially affected in a different way.

We will get through this together!

*Beth Burt*, President, Autism Society of California

*Marcia Eichelberger*, Co-Chair, Public Policy Committee, Autism Society of California



# Who Participated

Electronic survey from May 9 to May 19, 2020

1,093 participants: 5% individuals with disabilities and 95% family members

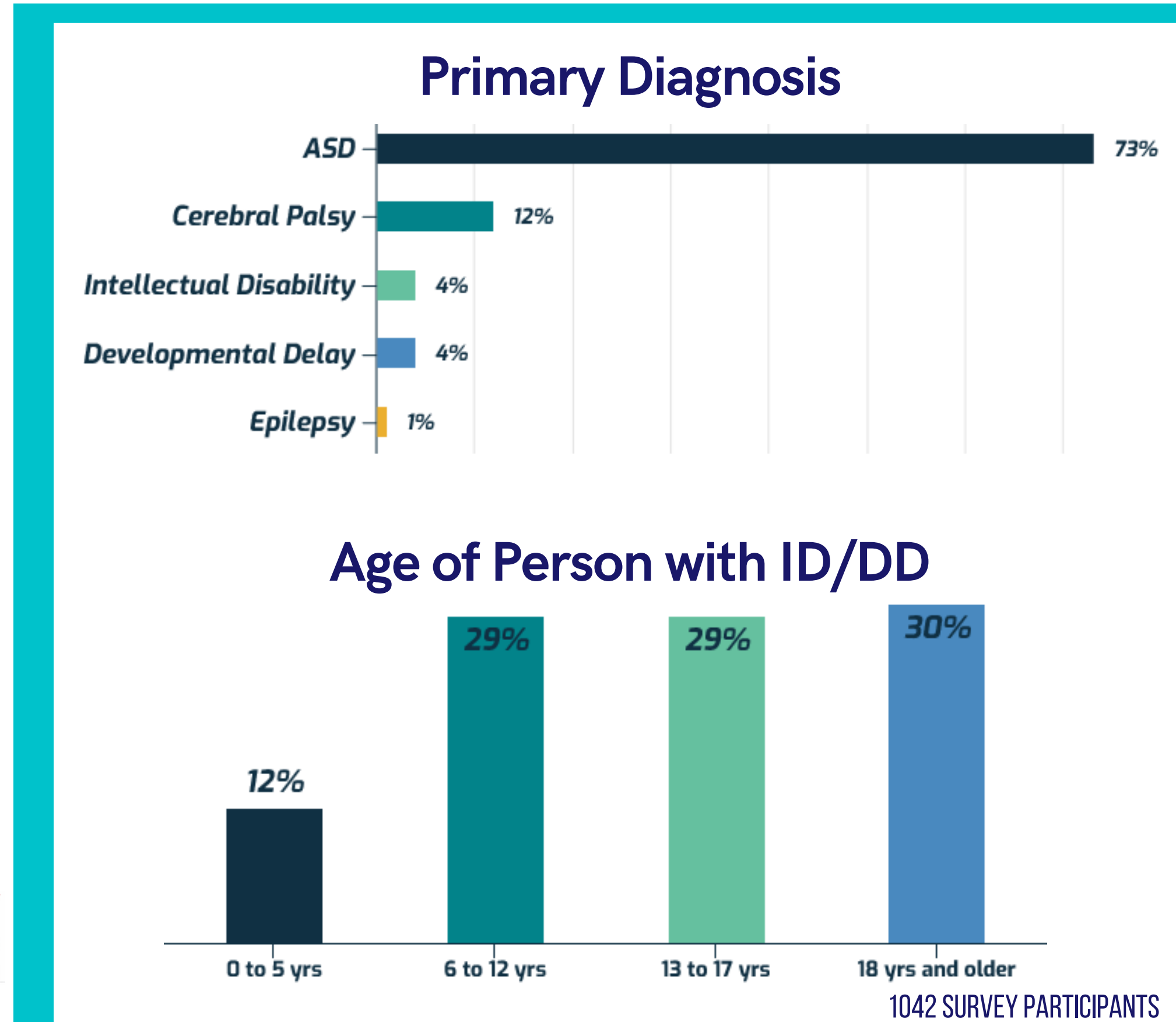
86% Regional Center clients

73% of survey respondents indicated the person with ID/DD had a primary diagnosis of autism

72% of survey participants lived in Southern California (Los Angeles, Riverside, San Bernardino, San Diego, Santa Barbara, and Ventura Counties) compared to 49% of the population.<sup>1</sup>



1. US Census QuickFacts Population Estimates July 1, 2019 [www.census.gov](http://www.census.gov)



# Who Participated

## Ethnicity (Multiple Responses Allowed):

50% of survey respondents identified as white.

43% identified as Hispanic

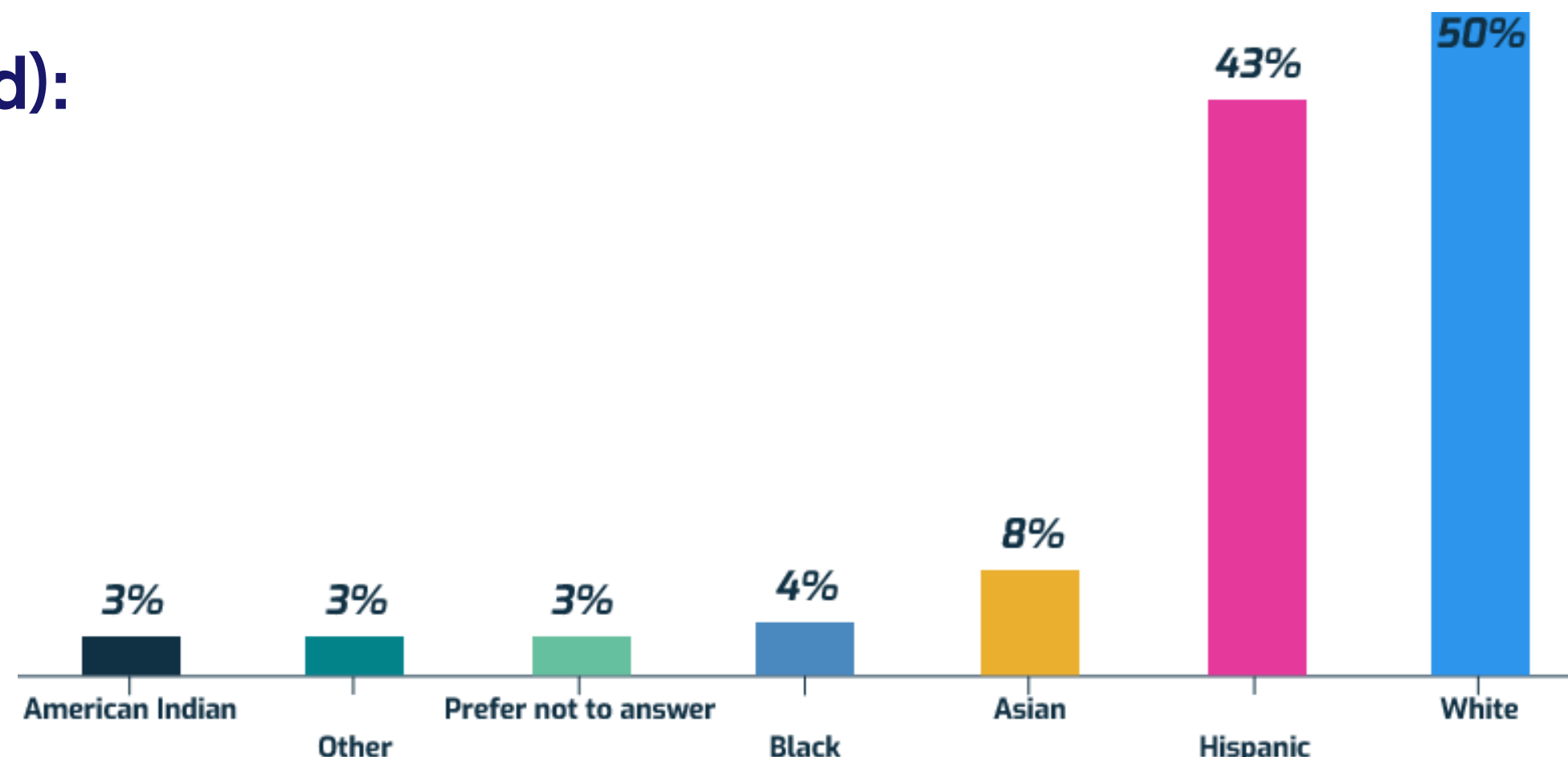
8% as Asian

4% as Black

3% preferred not to answer

3% other

3% American Indian



Language spoken at home - English: Survey Respondents - 86% (California 58%)<sup>2</sup>

- Spanish: Survey Respondents 11% (California 29%)<sup>2</sup>

- Other languages: Survey Respondents 3% (California 15%)<sup>2</sup>

1104 SURVEY PARTICIPANTS

2. Languages in California (State)". Statistical Atlas. Archived from the original on August 15, 2018.





# What We Measured

- Health & Safety
- Medical Treatment
- Education
- Regional Center Services
- Adult Services
- Needs of the Community & Disparity



# Health & Safety Issues for the ID/DD Community During COVID-19

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California





**Families with loved ones with ID/DD are more vulnerable for serious illness due to COVID-19.**

**43%**

**child/adult with ID/DD considered higher risk for serious illness due to COVID-19**

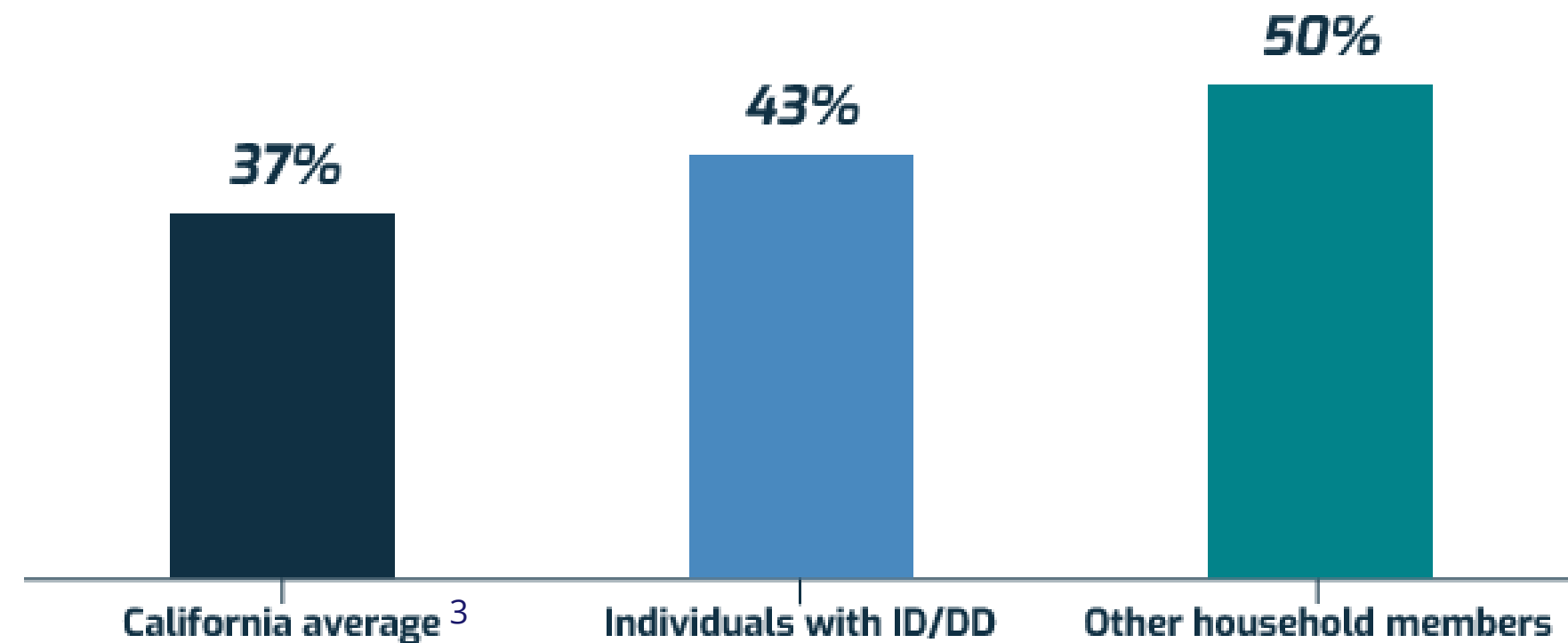
**50%**

**have another person in the household considered higher risk**

863 SURVEY PARTICIPANTS

Autism Society of California Survey respondents indicated that 43% of individuals with ID/DD were considered higher risk for serious illness due to COVID-19 using the Center for Disease Control (CDC) definition.

4







**Not all  
individuals with  
ID/DD can  
practice new  
safety skills.**



**1 in 6**

**Individuals with ID/DD (ages 6  
years and older) can not  
tolerate wearing a mask.**

**1 in 6**

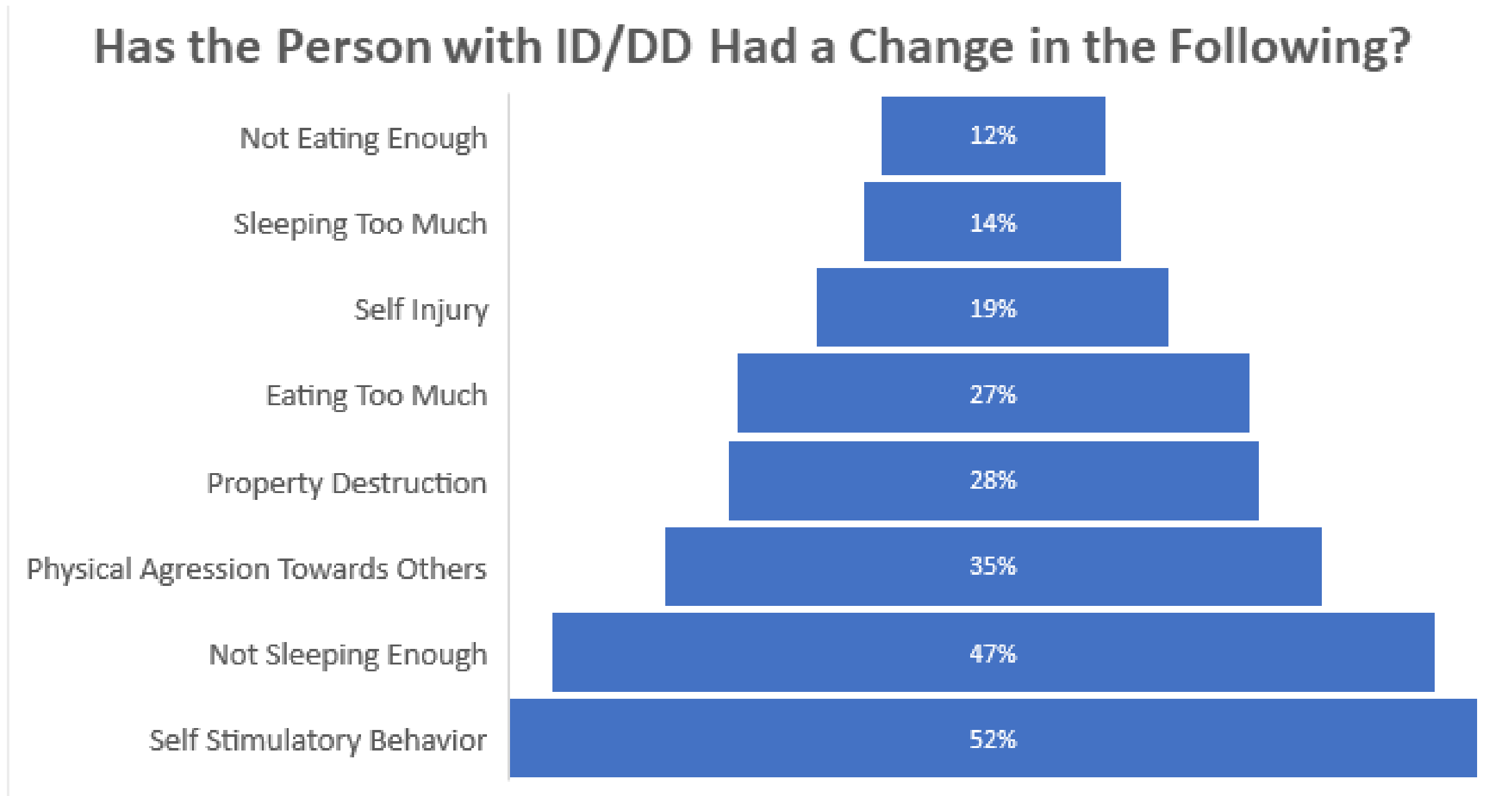
**Individuals with ID/DD (ages 6  
years and older) can not  
practice social distancing.**

**1 in 4**

**Individuals with ID/DD (ages 6  
years and older) touch their  
face or put things in their  
mouth.**



# Families report a dramatic increase in behaviors in the household.



820 SURVEY PARTICIPANTS

**Families with individuals with ID/DD may face additional challenges to access generic food resources like food banks and school lunches.**



**Survey participants report that 69% children/adults with ID/DD are picky eaters - only eating certain types, brands, or textures of food - so much so that it interferes with his/her diet.**

863 SURVEY PARTICIPANTS

**Disparity Issue: 6% of English speaking households and 19% of non-English speaking households do not have their basic food needs met.**

883 SURVEY PARTICIPANTS

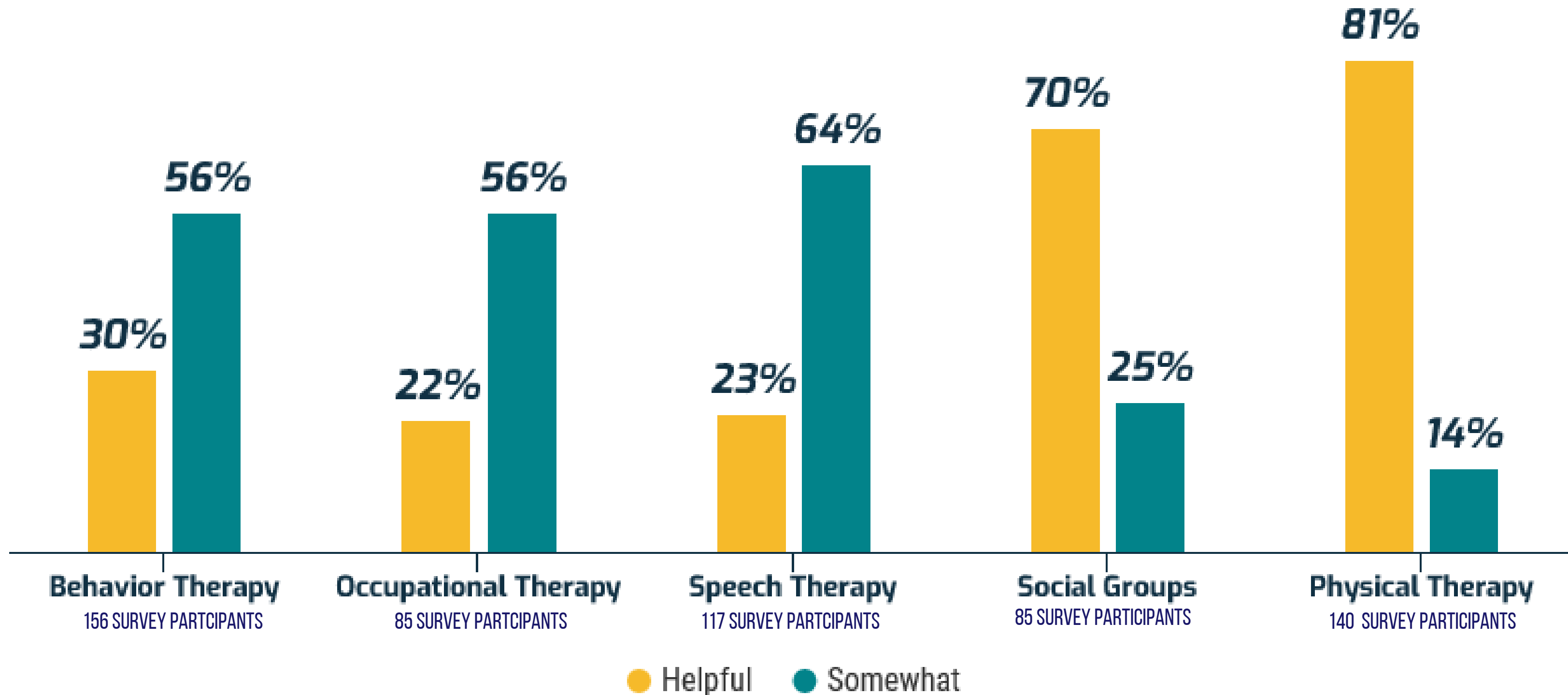


# How COVID-19 Affected Medical Treatments for the ID/DD Community



# Telehealth Was An Effective Option for Many

During COVID, if you are using telehealth, is the person with ID/DD benefitting from it?

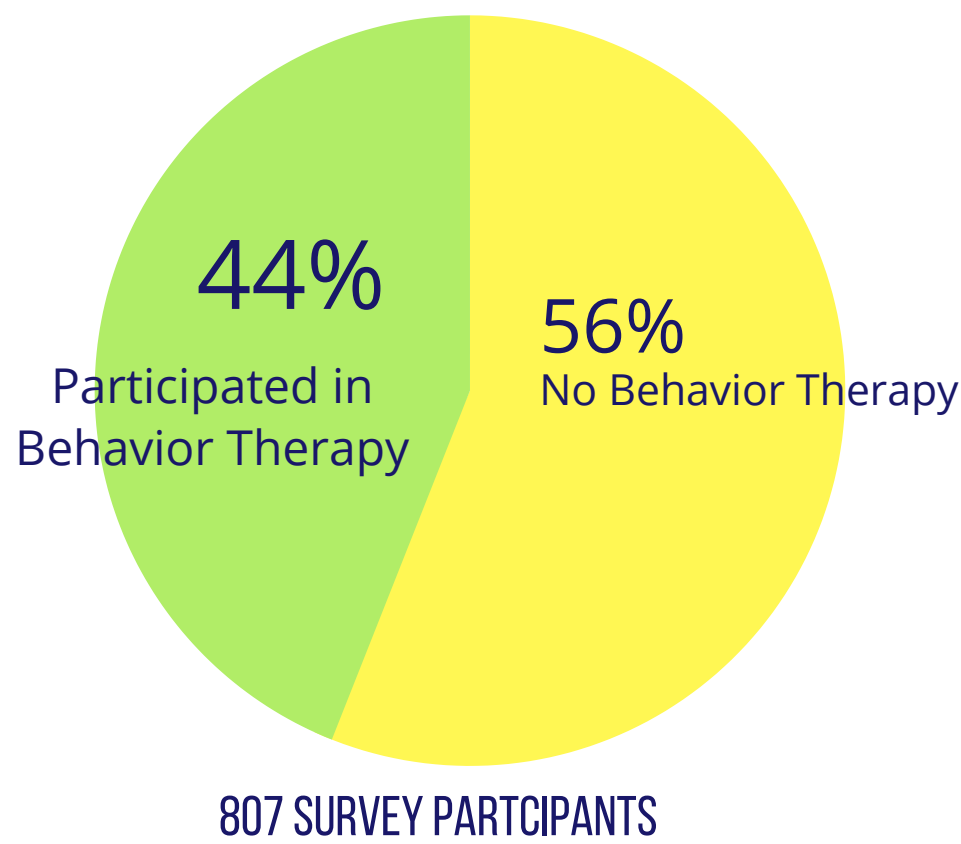




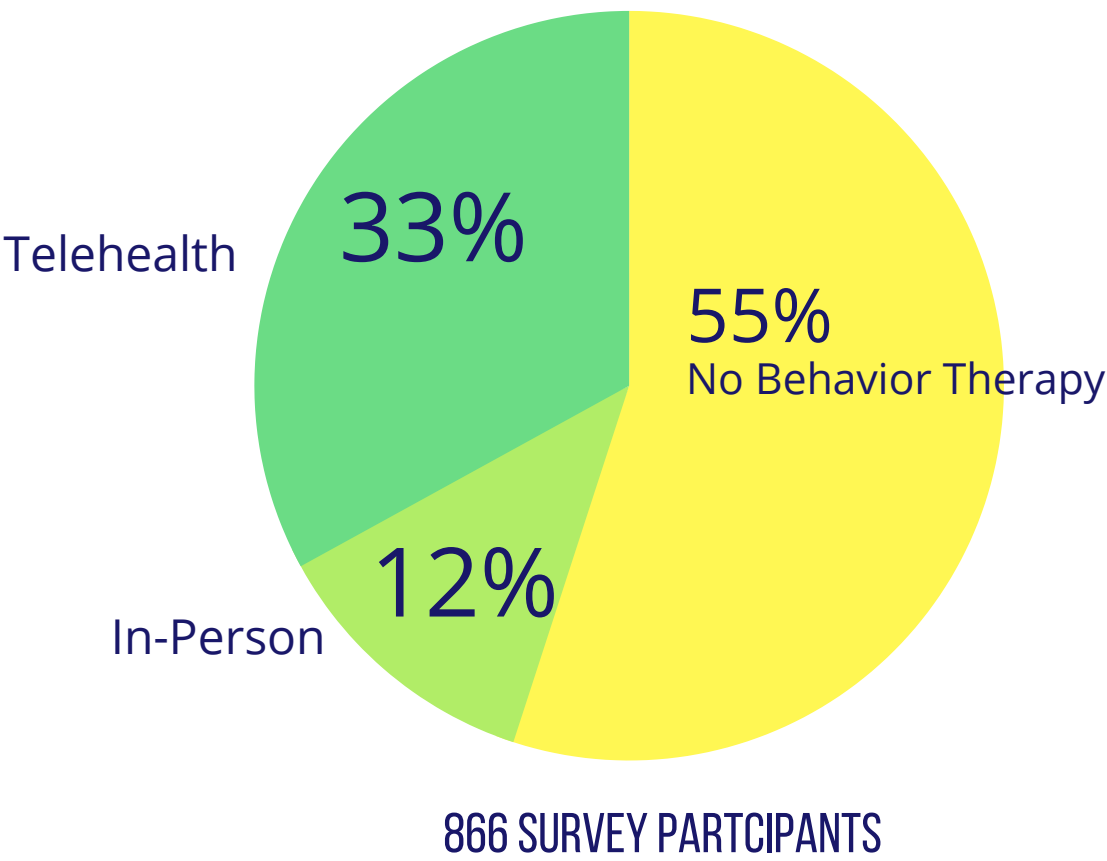
# Medical Treatment - Behavior Therapy

Families reported that they were able to maintain behavior therapy throughout the COVID-19 crisis. Additionally, more families plan on using behavior therapy in August than had used pre-COVID-19.

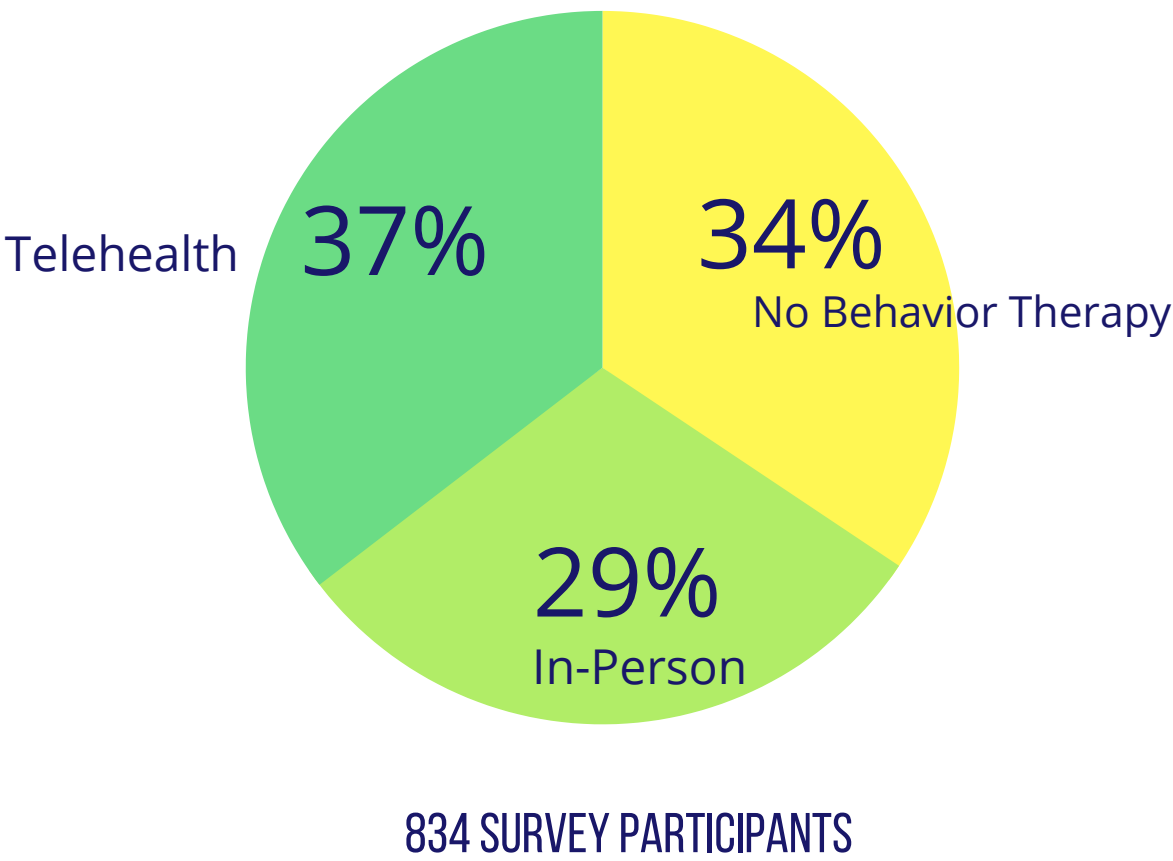
Before COVID-19



During COVID-19



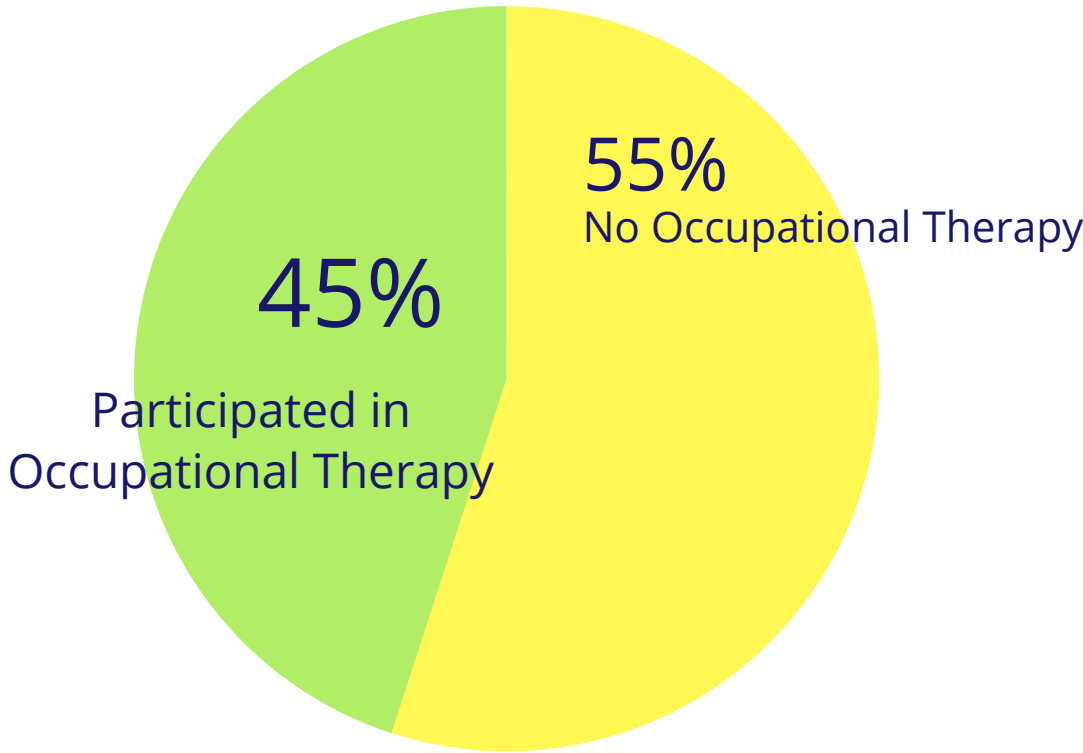
Projected Aug 2020



# Medical Treatment - Occupational Therapy

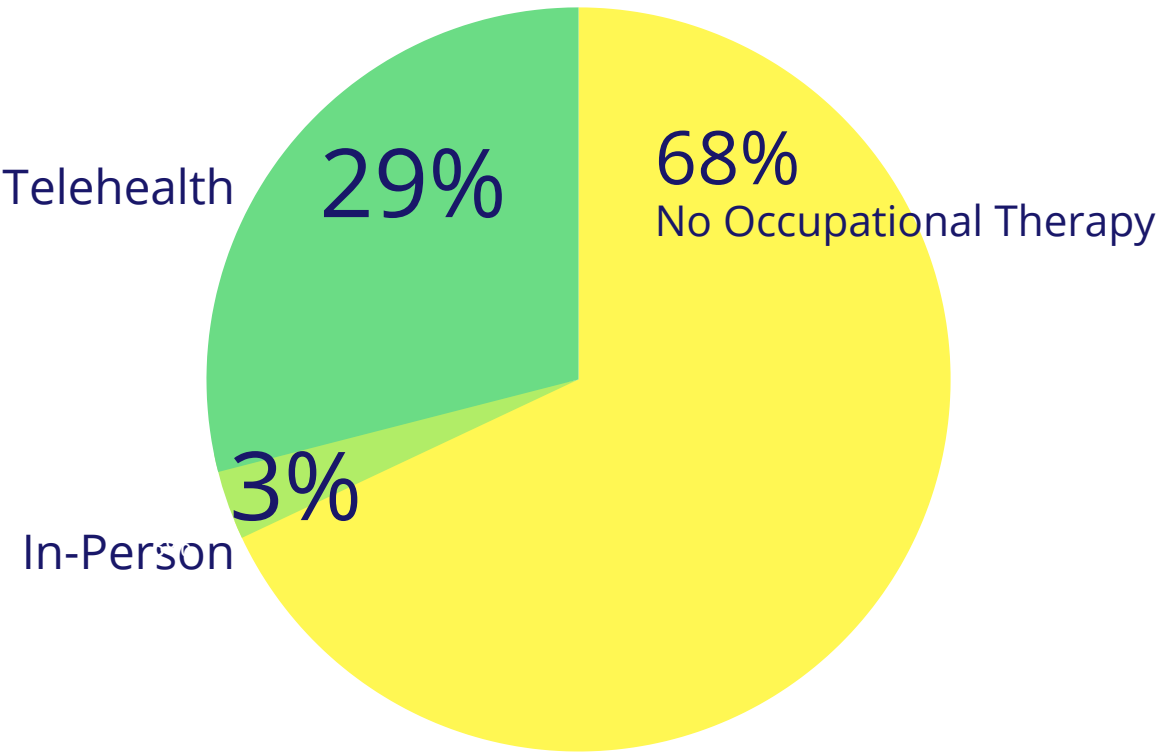
Families reported a loss of access to Occupational Therapy services during COVID-19. More families plan on accessing Occupational Therapy in August than prior to COVID-19.

Before COVID-19



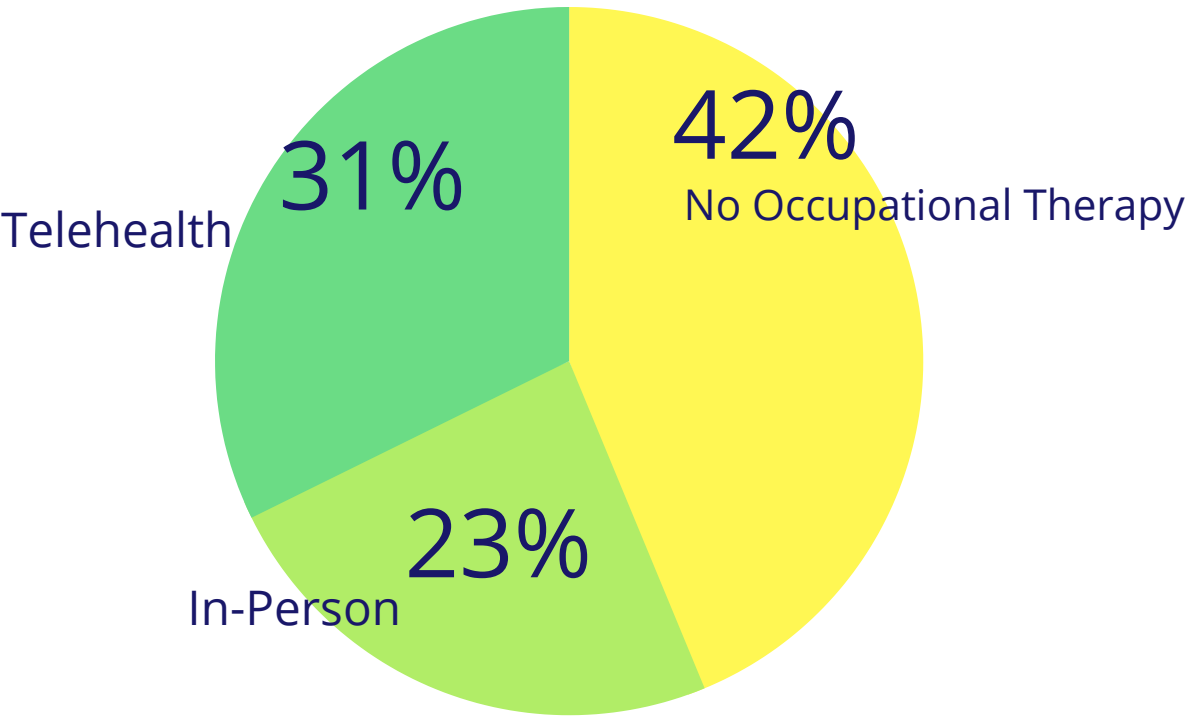
807 SURVEY PARTICIPANTS

During COVID-19



821 SURVEY PARTICIPANTS

Projected Aug 2020



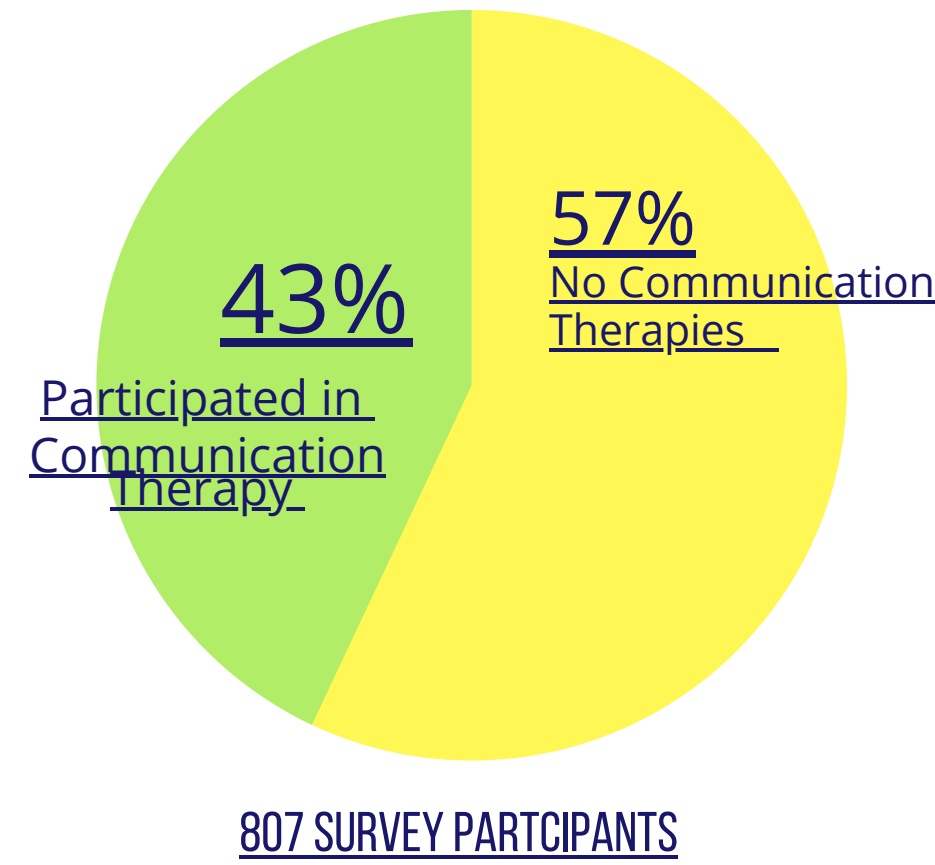
801 SURVEY PARTICIPANTS



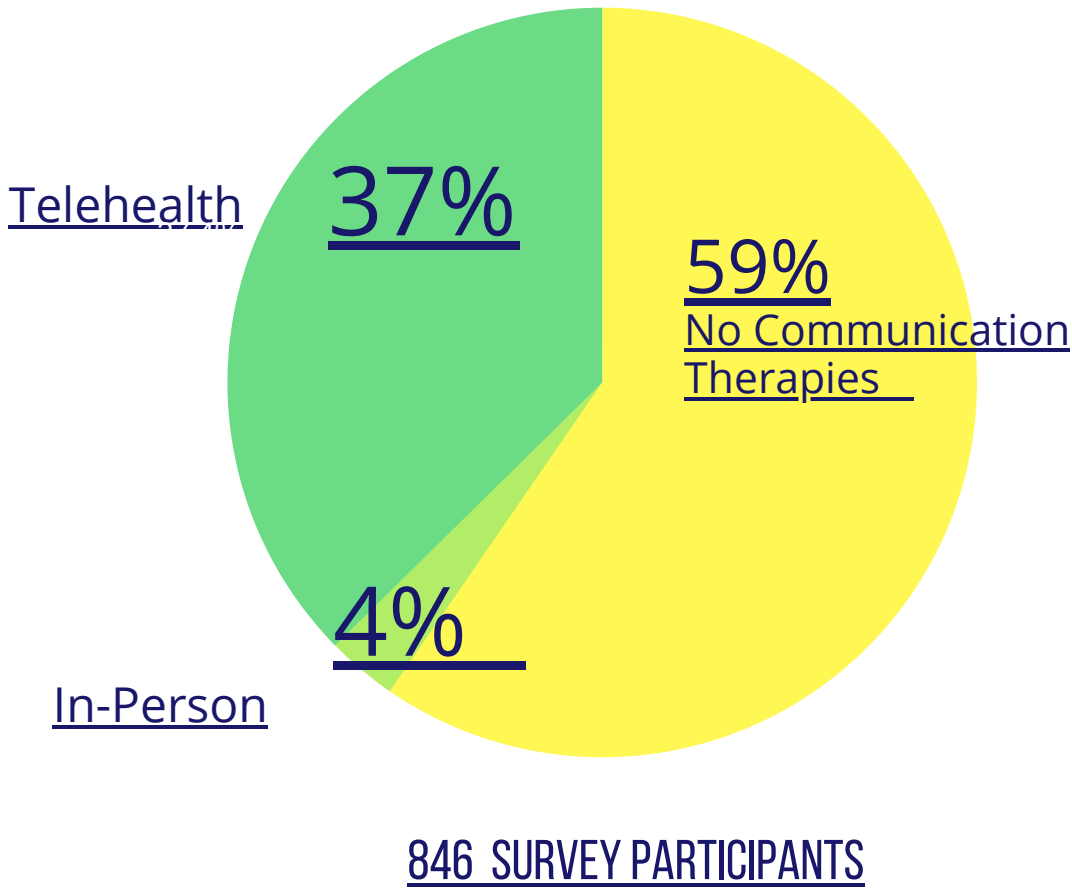
# Medical Treatment - Communication Therapies

Families reported that they were able to maintain communication therapy like speech and AAC therapies throughout the COVID-19 crisis. Additionally, more families plan on using communication therapy in August than had used pre-COVID-19.

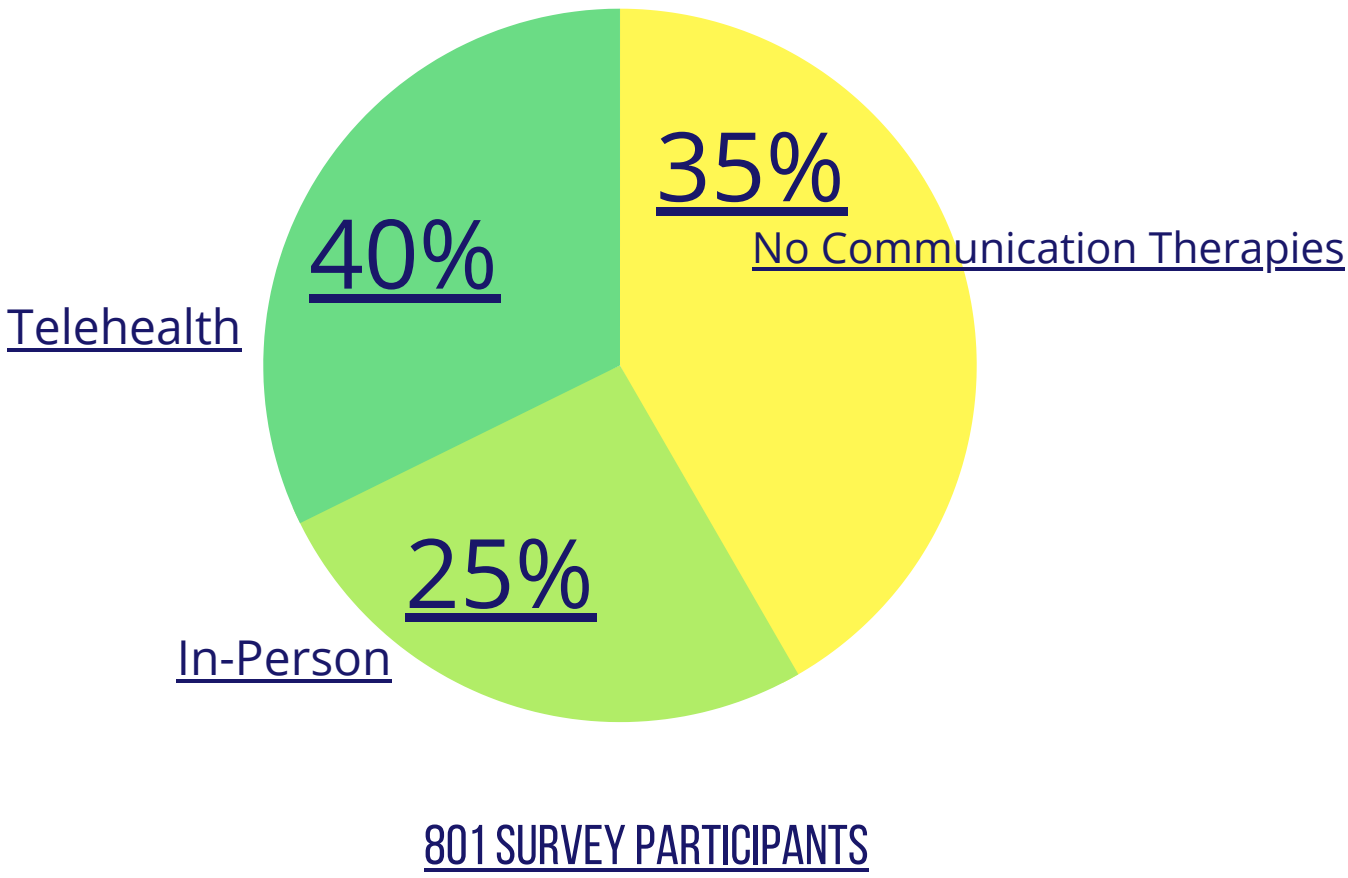
Before COVID-19



During COVID-19



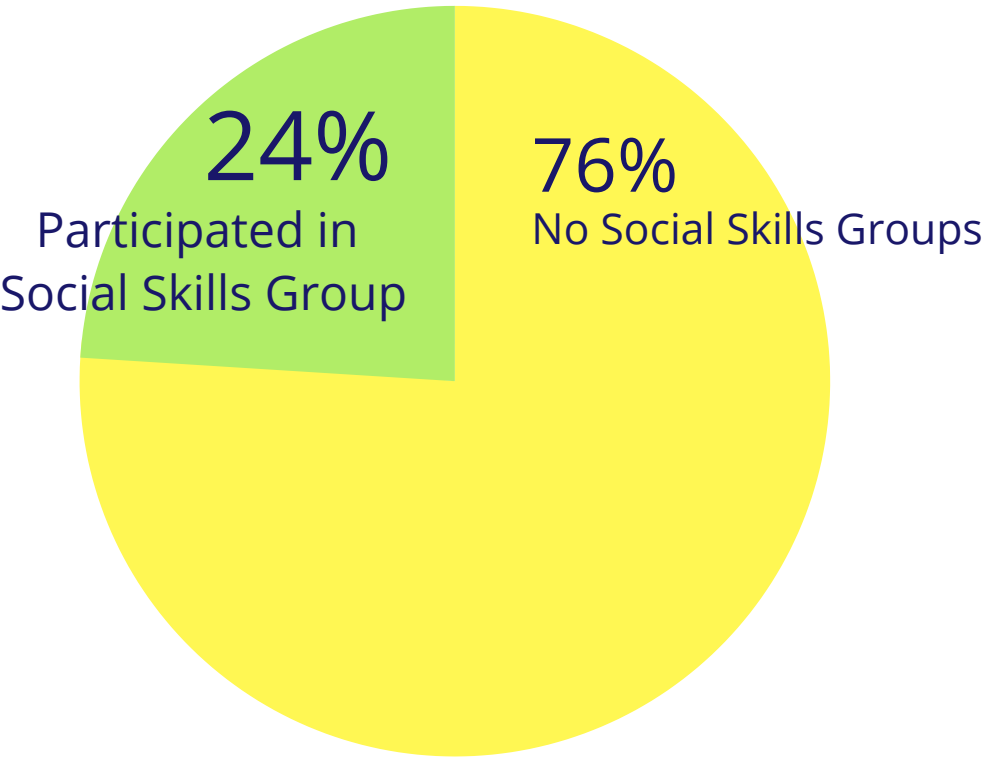
Projected Aug 2020



# Medical Treatment - Social Skills Therapies

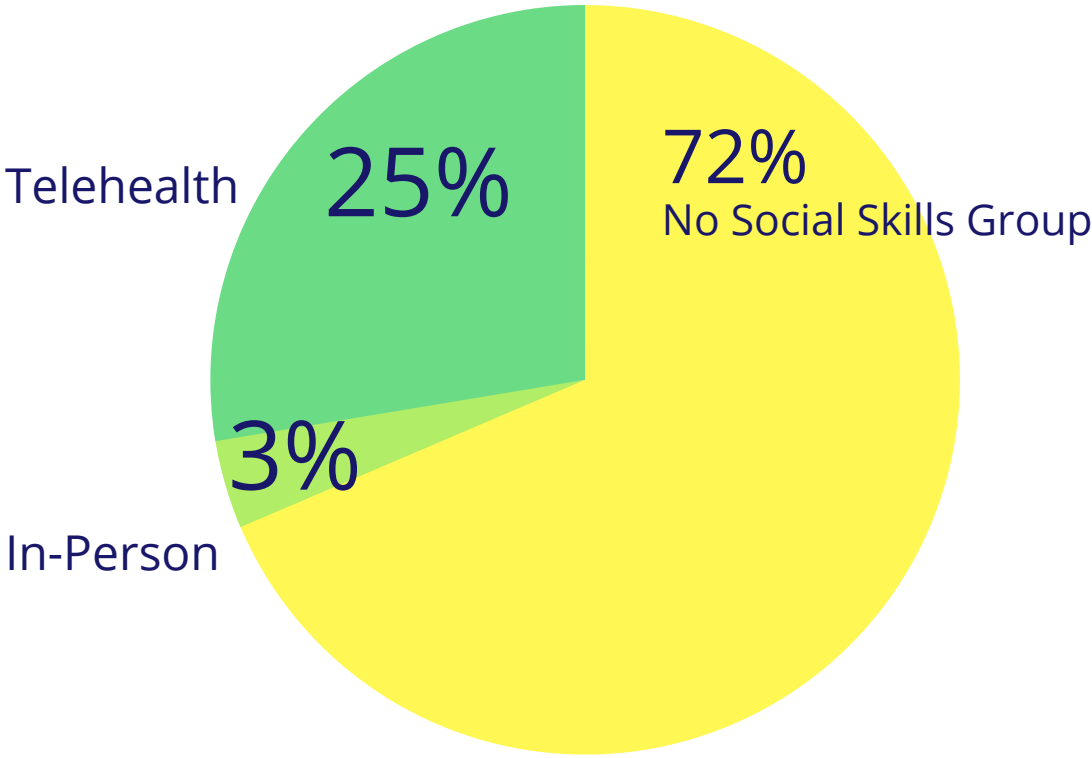
Families reported an increase of access to Social Skills Therapy services during COVID-19.  
More families plan on accessing Social Skills Therapy in August than prior to COVID-19.

Before COVID-19



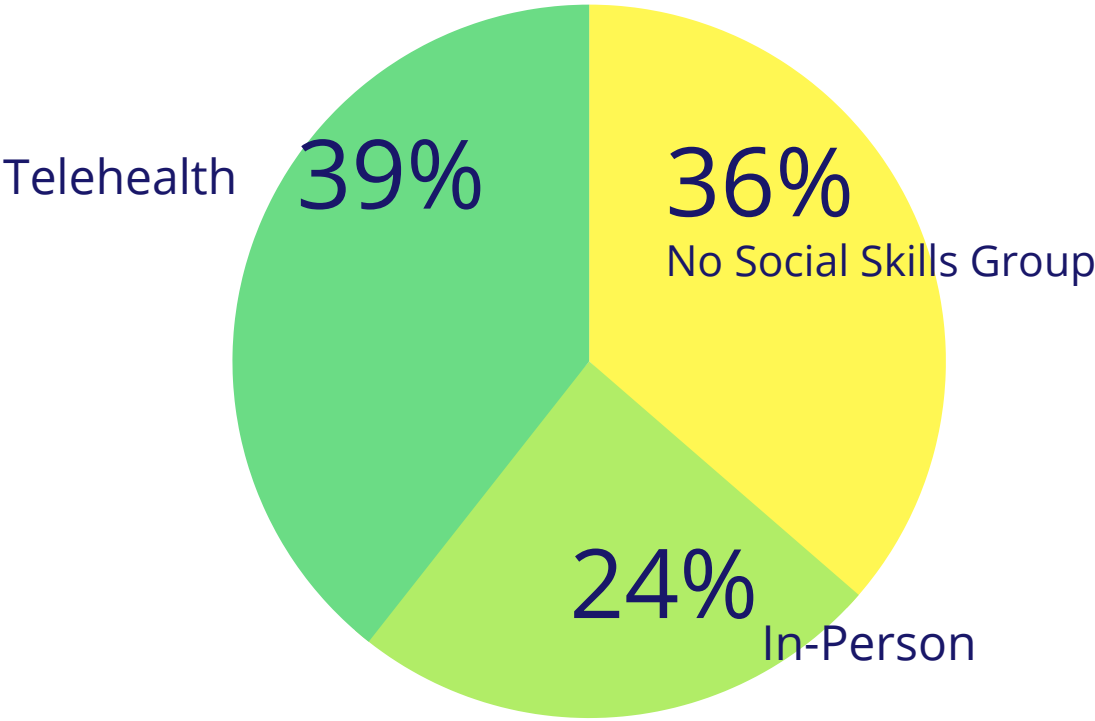
807 SURVEY PARTICIPANTS

During COVID-19



817 SURVEY PARTICIPANTS

Projected Aug 2020

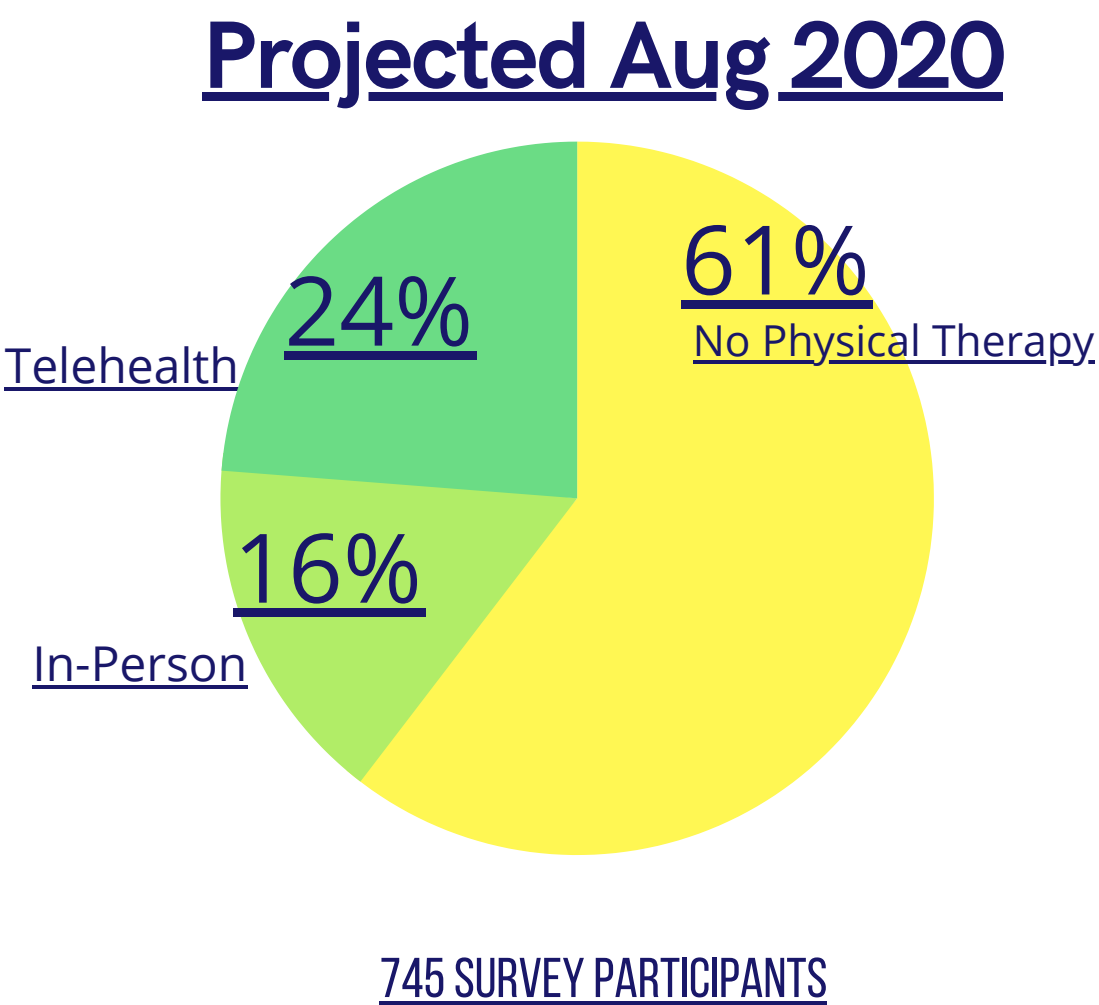
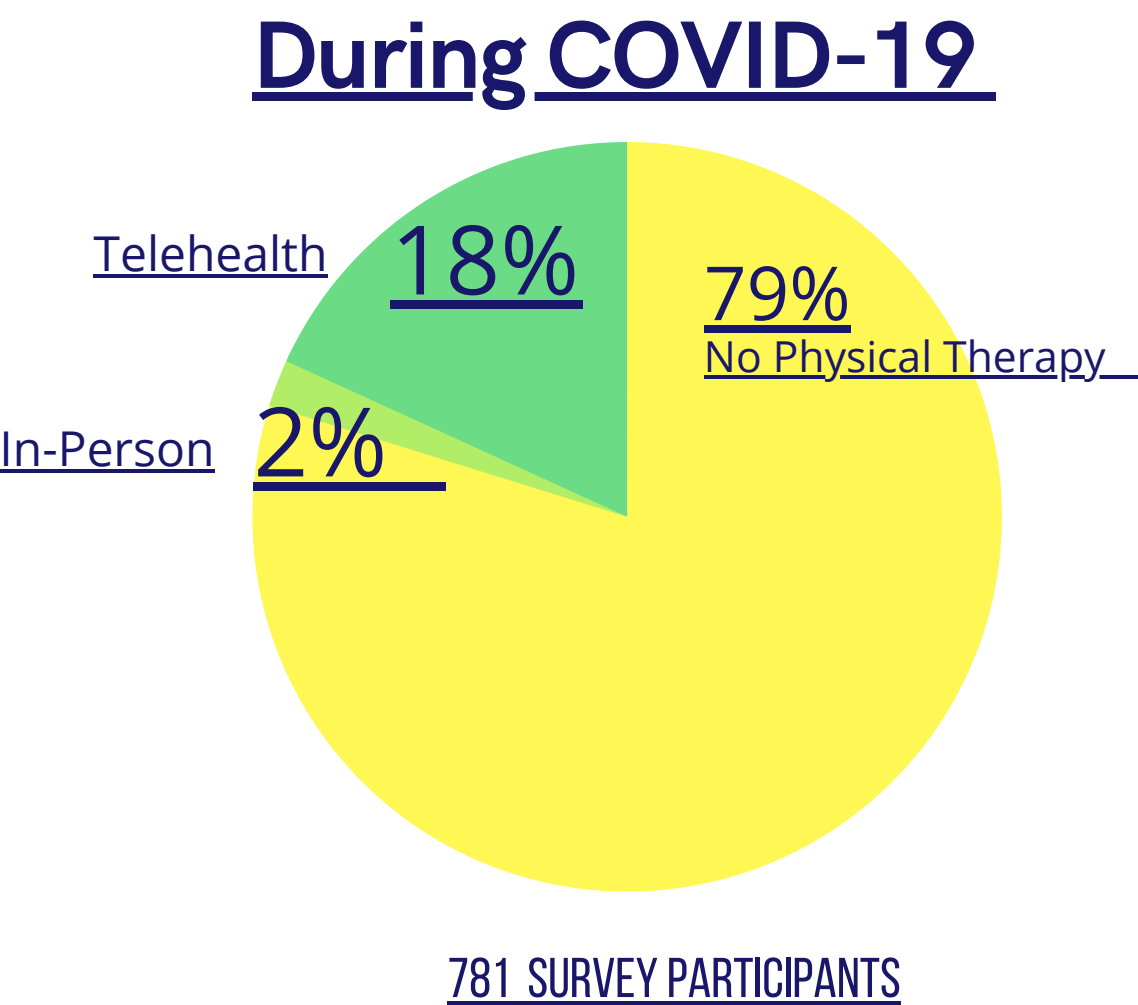
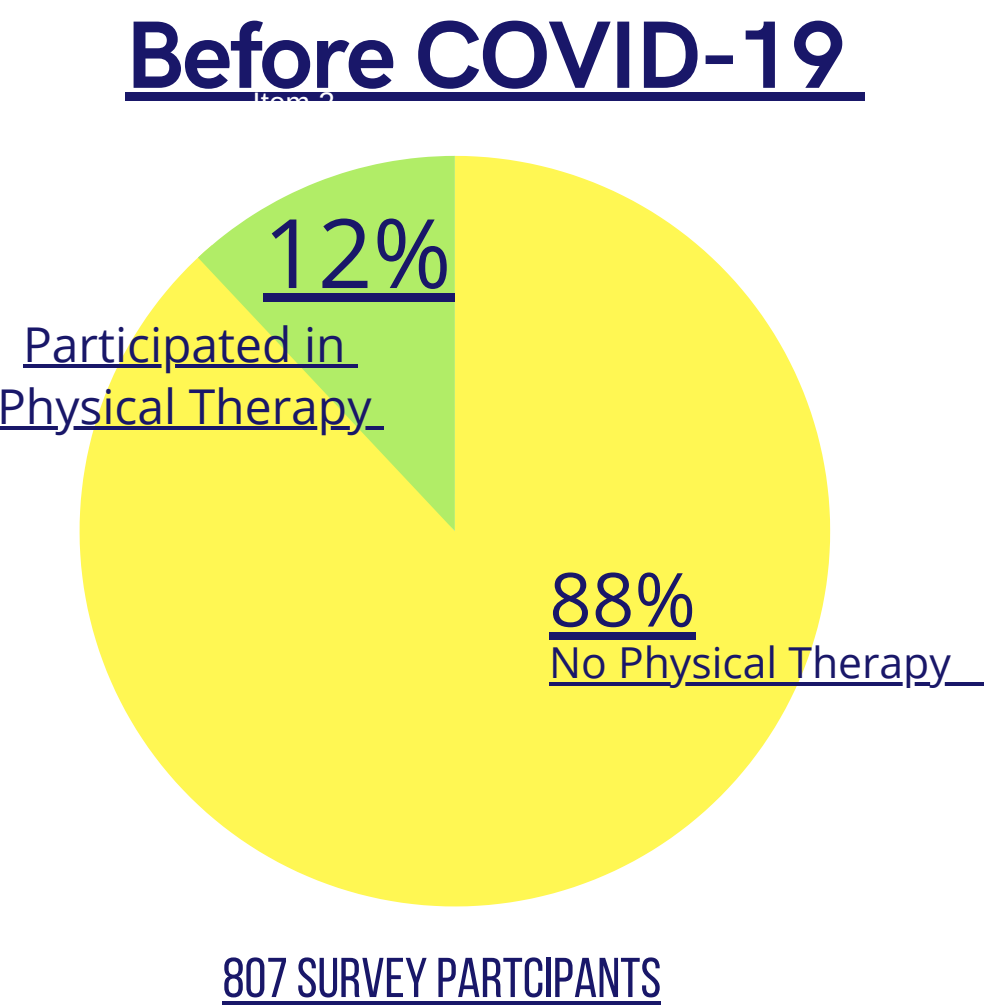


801 SURVEY PARTICIPANTS



# Medical Treatment - Physical Therapies

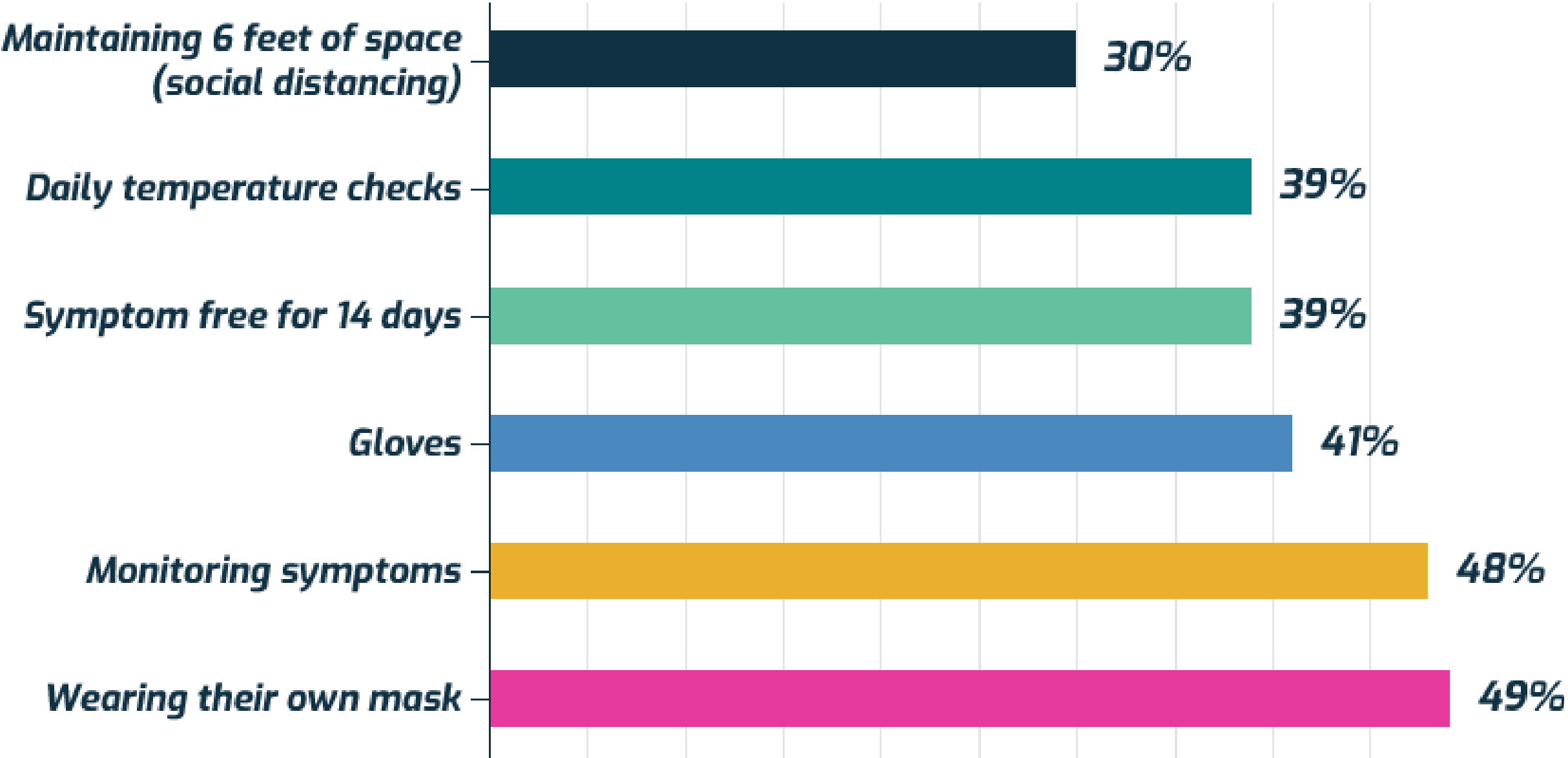
Families reported an increase of access in Physical Therapy services during COVID-19. More families plan on accessing Physical Therapy in August than prior to COVID-19.



# The Future of Medical Therapies

32% of families reported it doesn't matter what the medical providers do, they don't want a professional in their house, nor do they want to go to a clinic.

Actions families would like before allowing an outside service provider (for example ABA, speech, occupational therapy, respite, IHSS, etc) into your home or before visiting a clinic:

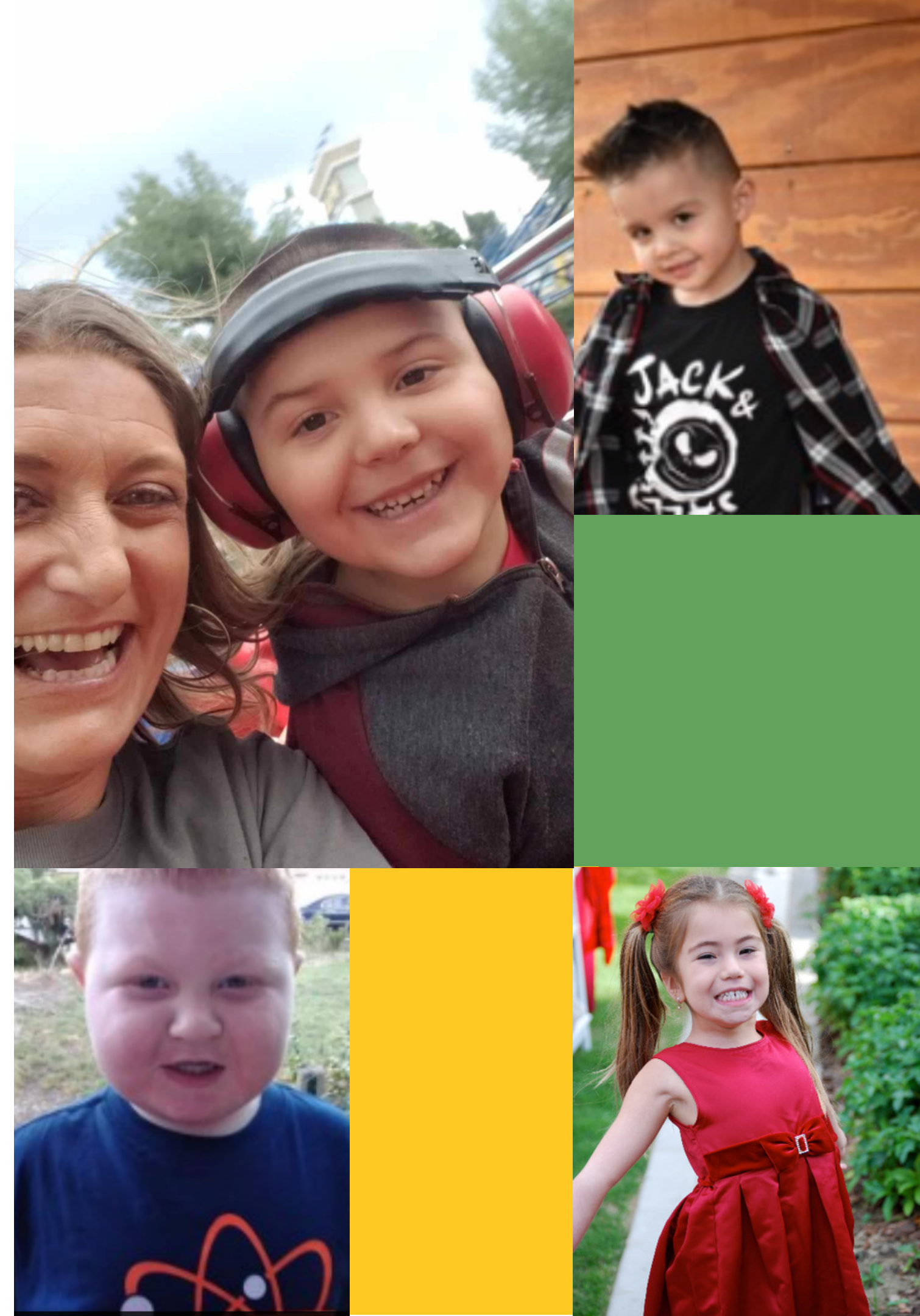


927 SURVEY PARTICIPANTS



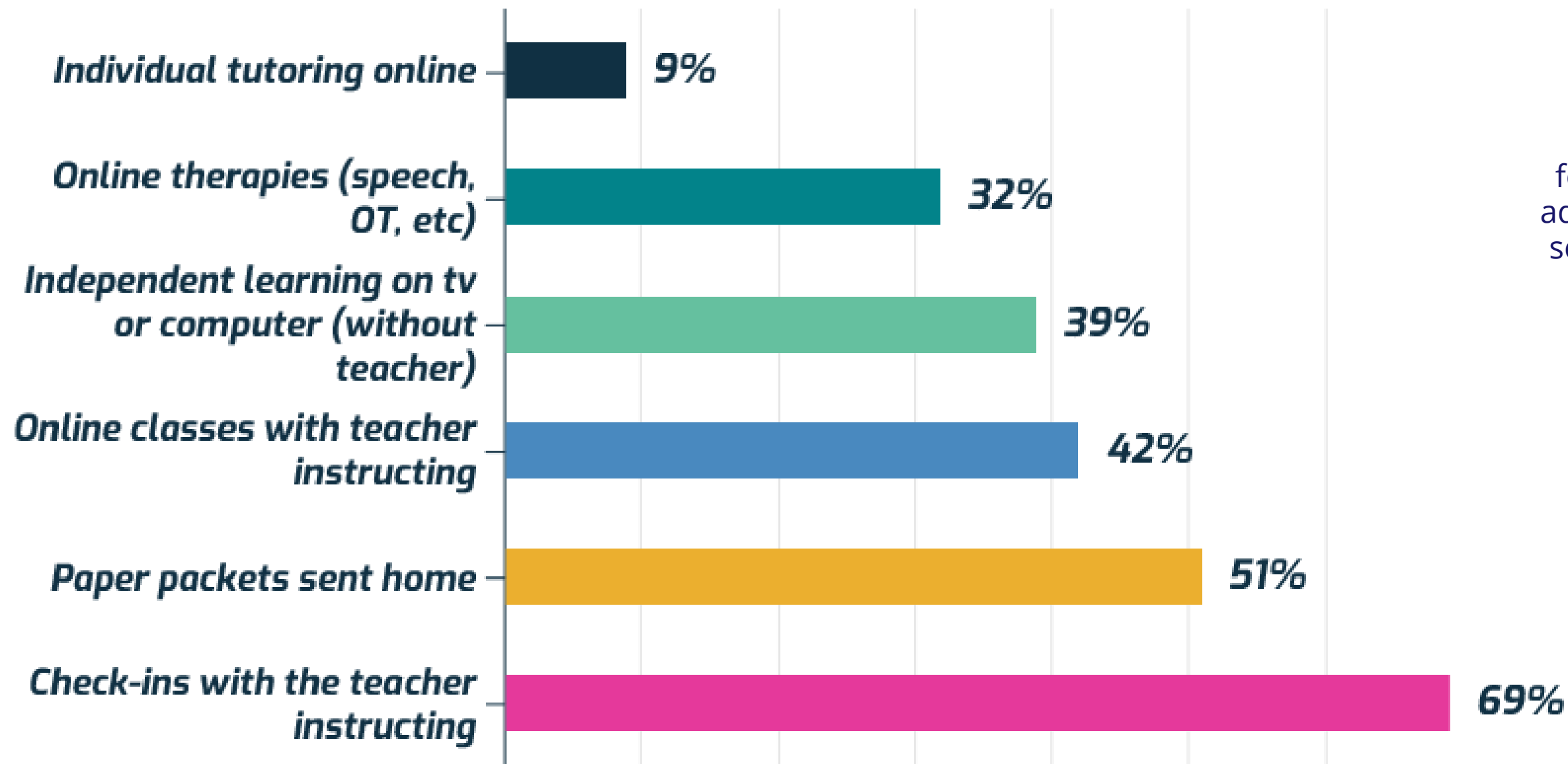
# K- 12 Education Issues for the ID/DD Community During COVID-19

 **AUTISM SOCIETY**  
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California



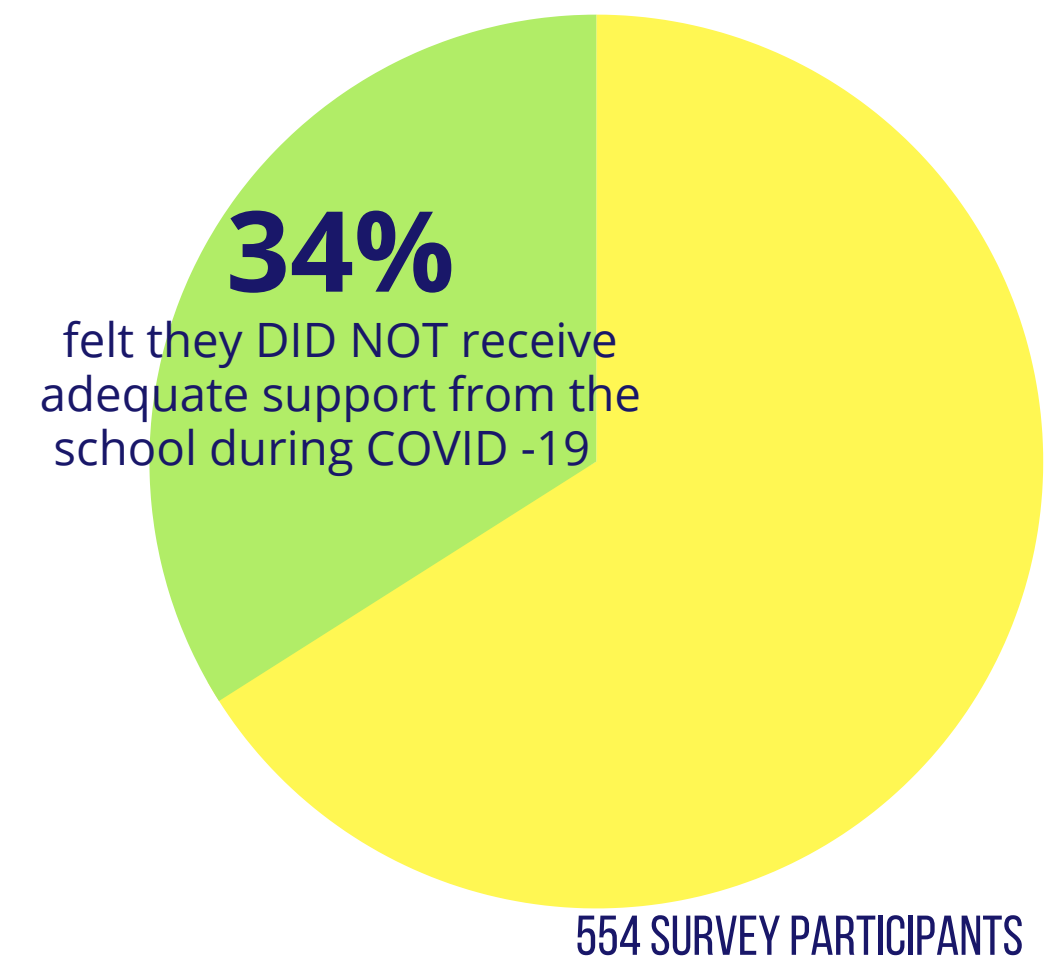
# 1 in 3 Families Did Not Feel Supported by Schools

## Kind of Educational Services Received (Multiple Answers Allowed)



669 SURVEY PARTICIPANTS

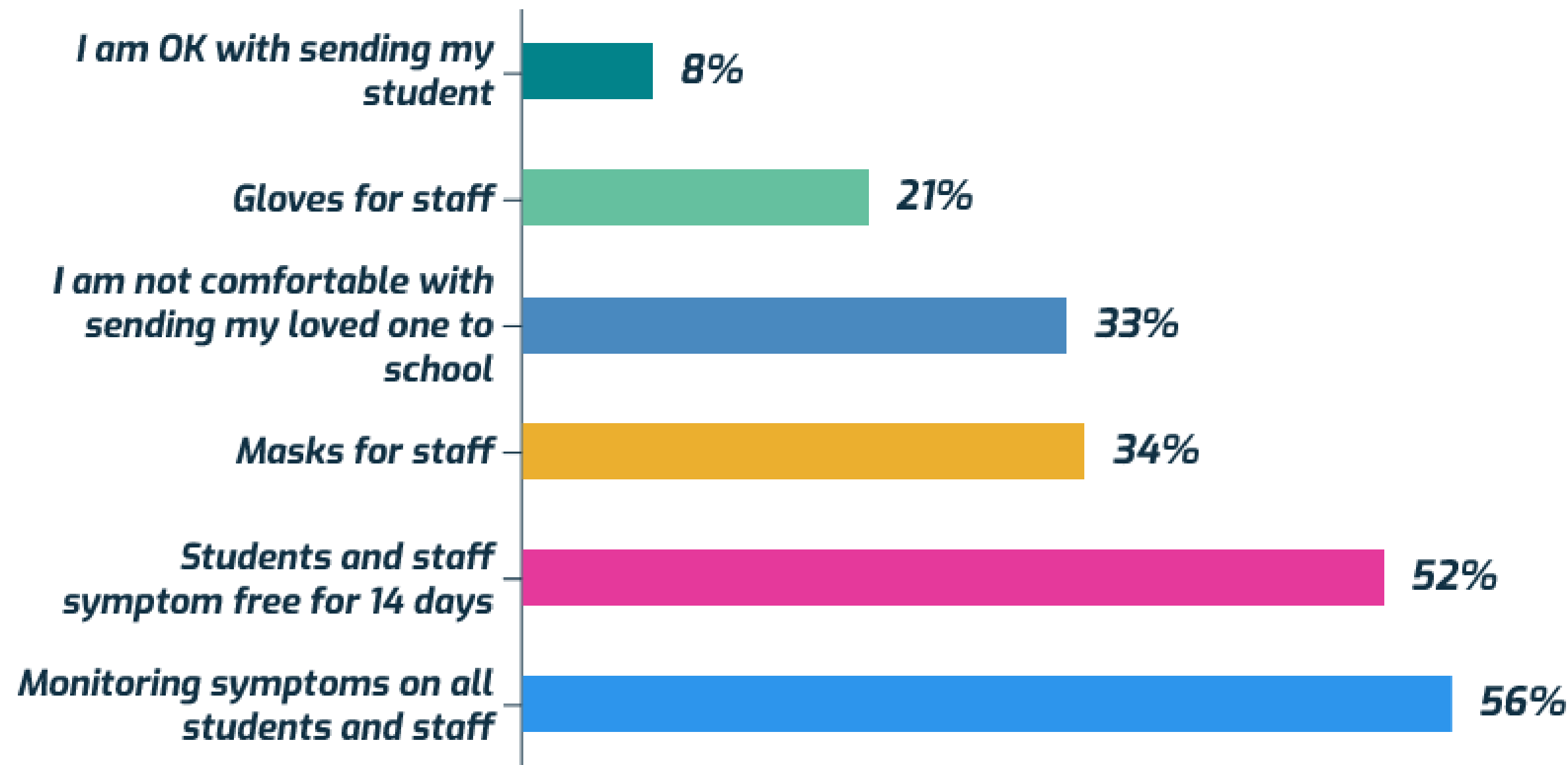
## School: Adequate Support During COVID-19



554 SURVEY PARTICIPANTS



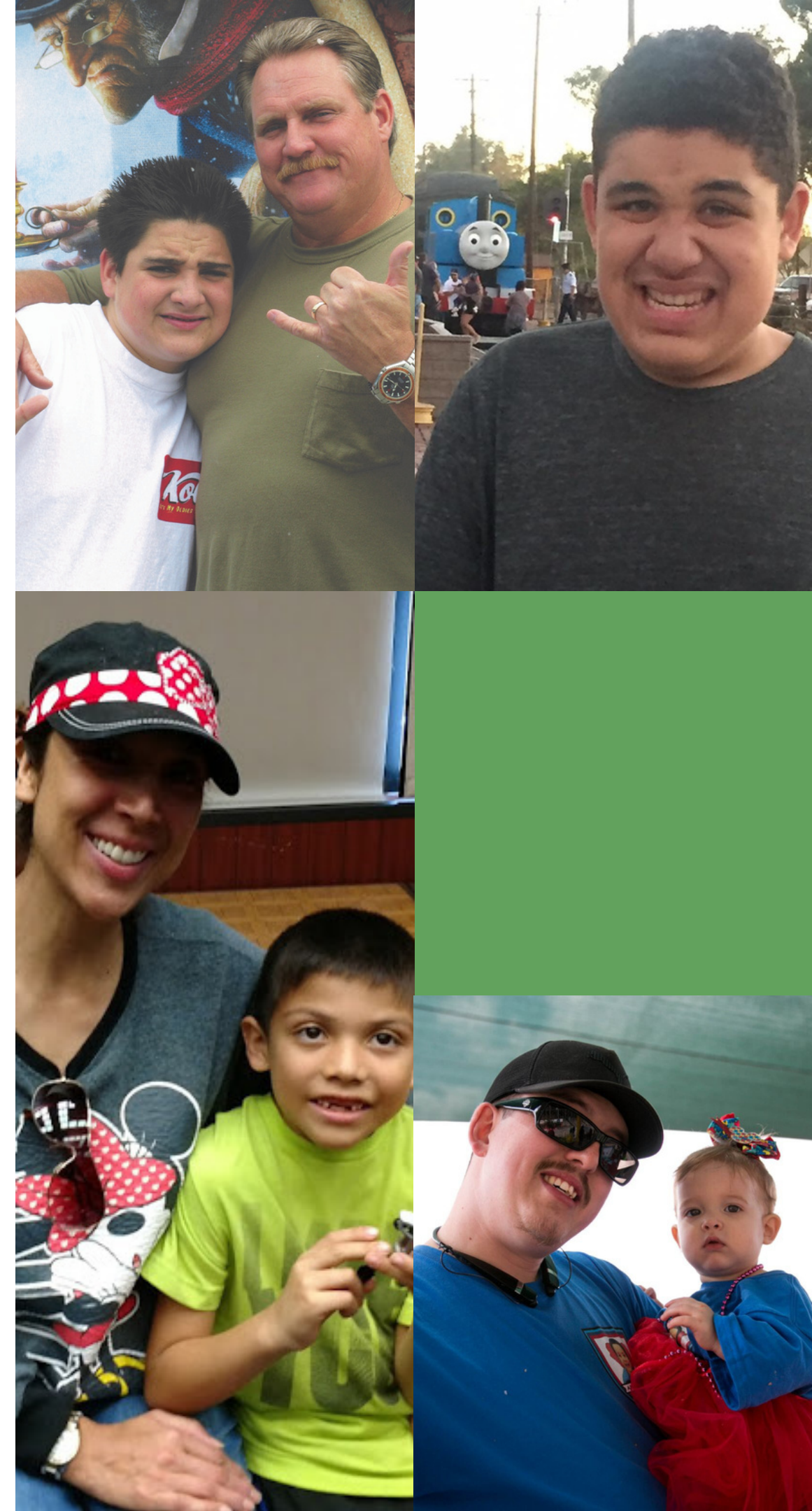
What would it take to make you feel comfortable before  
you let your loved one attend school?  
(Multiple Answers Allowed)



# The Future of Education

1/3 of families reported it doesn't matter what the school does, they will not be comfortable letting their loved one go back to school.

# Regional Center Services During COVID-19





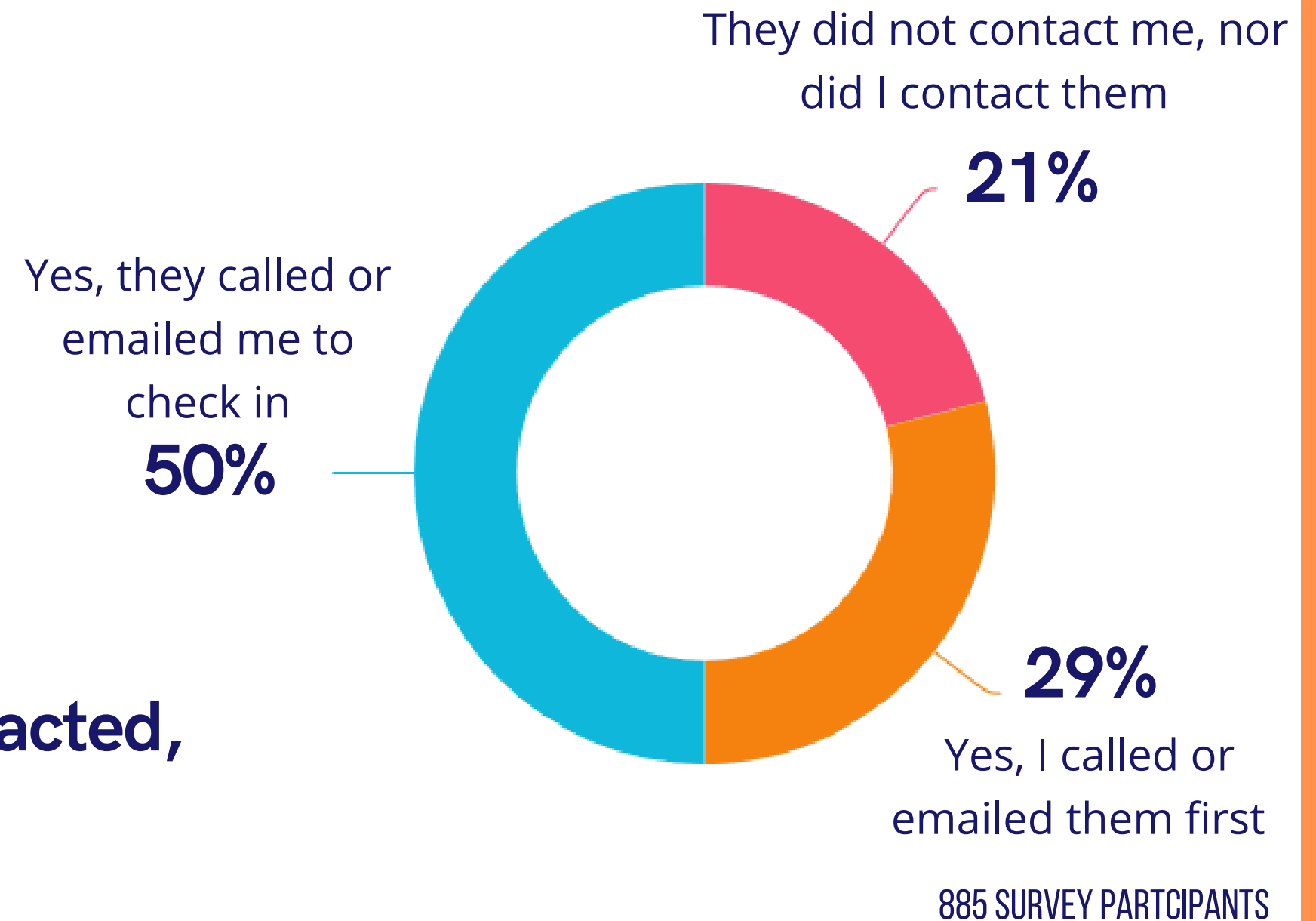
# Regional Center Caseworks Had Delays in Contacting All Families

**1 in 5 families did not hear from their caseworkers from March 19th to May 1st.**

**For individuals and families who were contacted, most had been contacted twice.**

25% - One time  
42% - Twice  
6% - Once a week  
10% - Every other week  
17% - Other

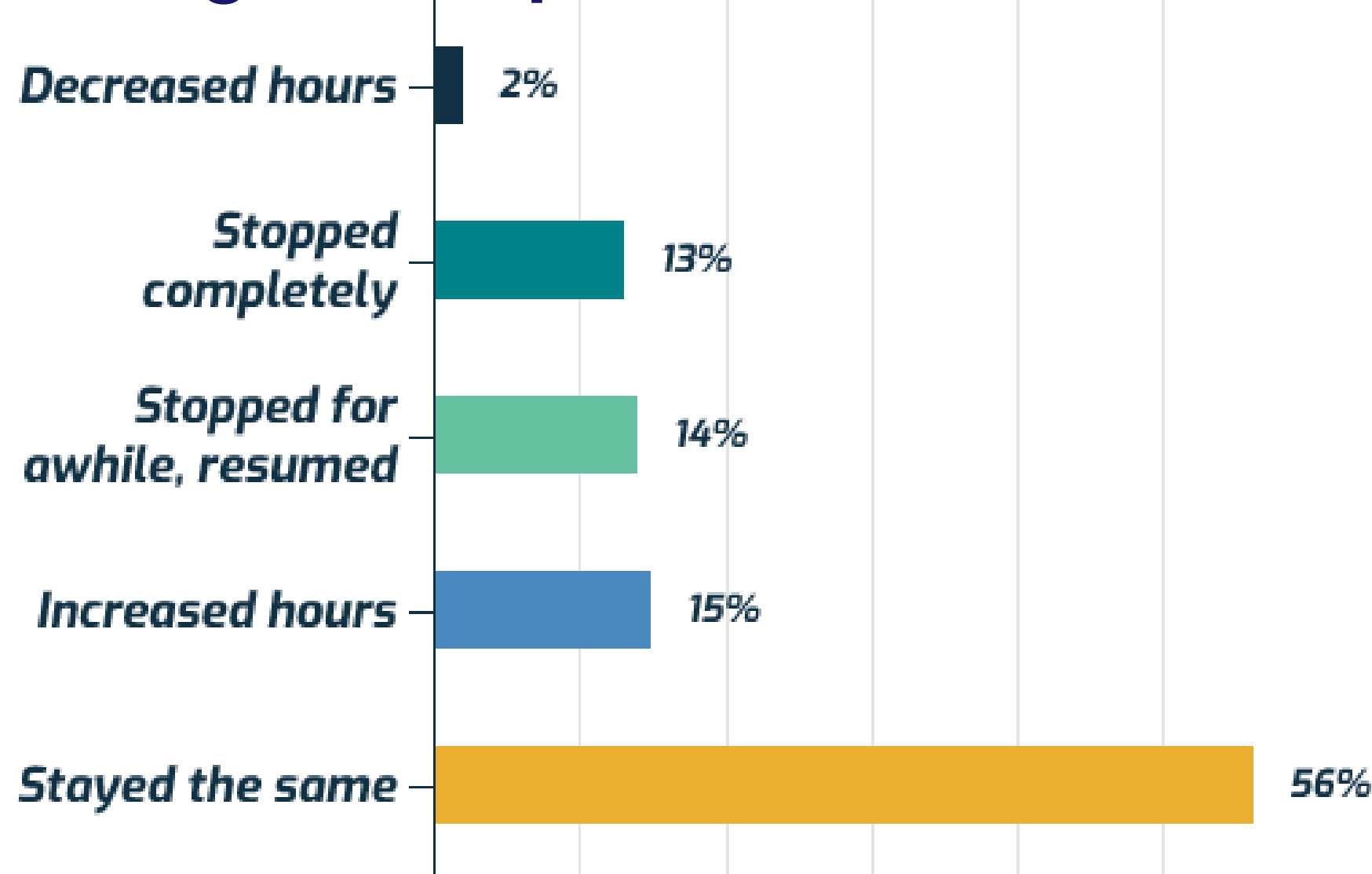
677 SURVEY PARTICIPANTS



# Regional Center Respite Services Rebounded

Only 15% of families had respite services stop completely or decrease hours.

## Change in Respite Hours Since COVID-19



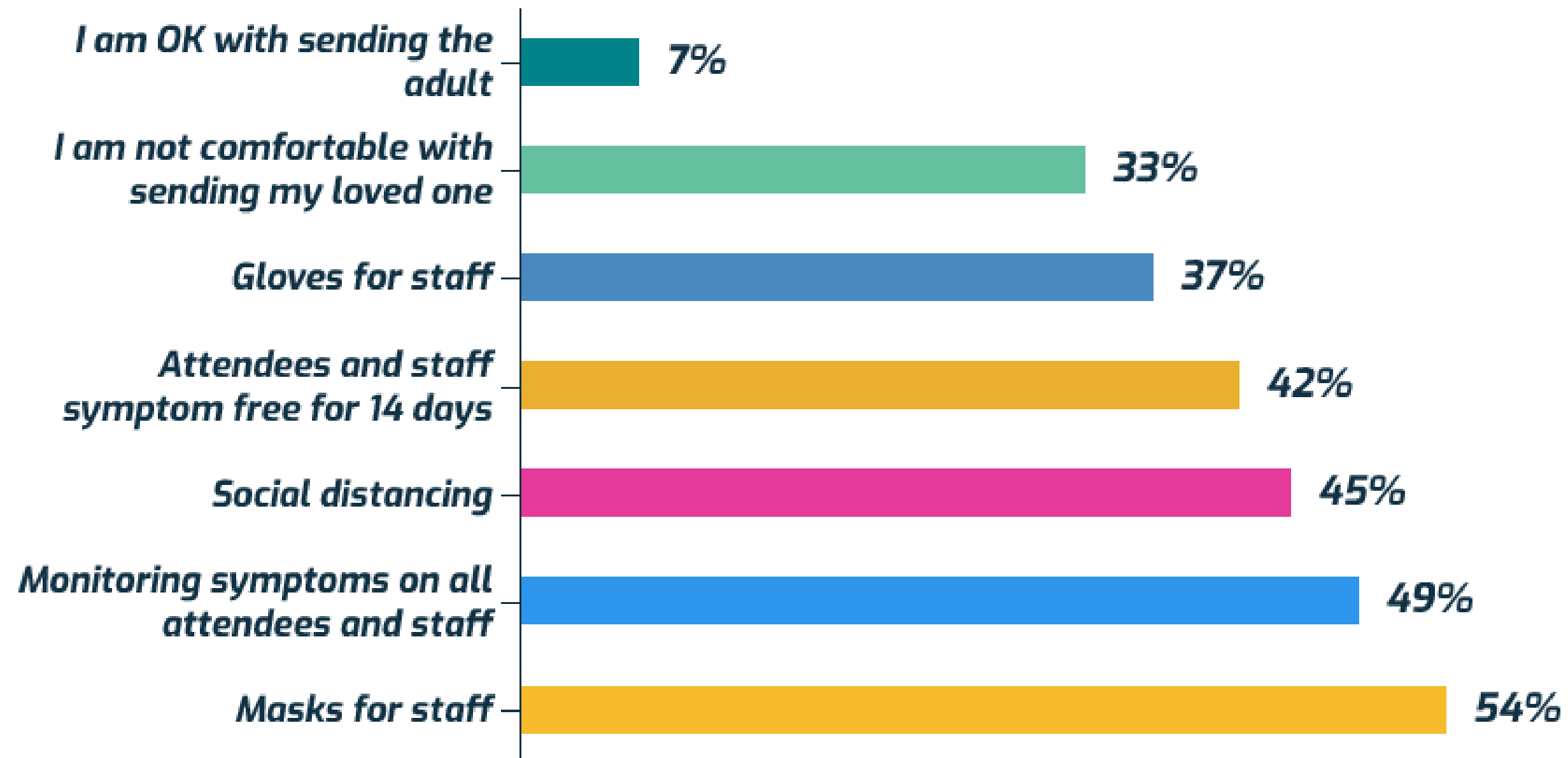
73% of survey respondents indicated they received respite services before the shelter-in-place order.

84% of survey respondents are aware they can refer family/friends to be respite staff.

764 SURVEY PARTICIPANTS

# 1 in 3 Families Are Not Comfortable in Participating in Traditional Day Service Model in August

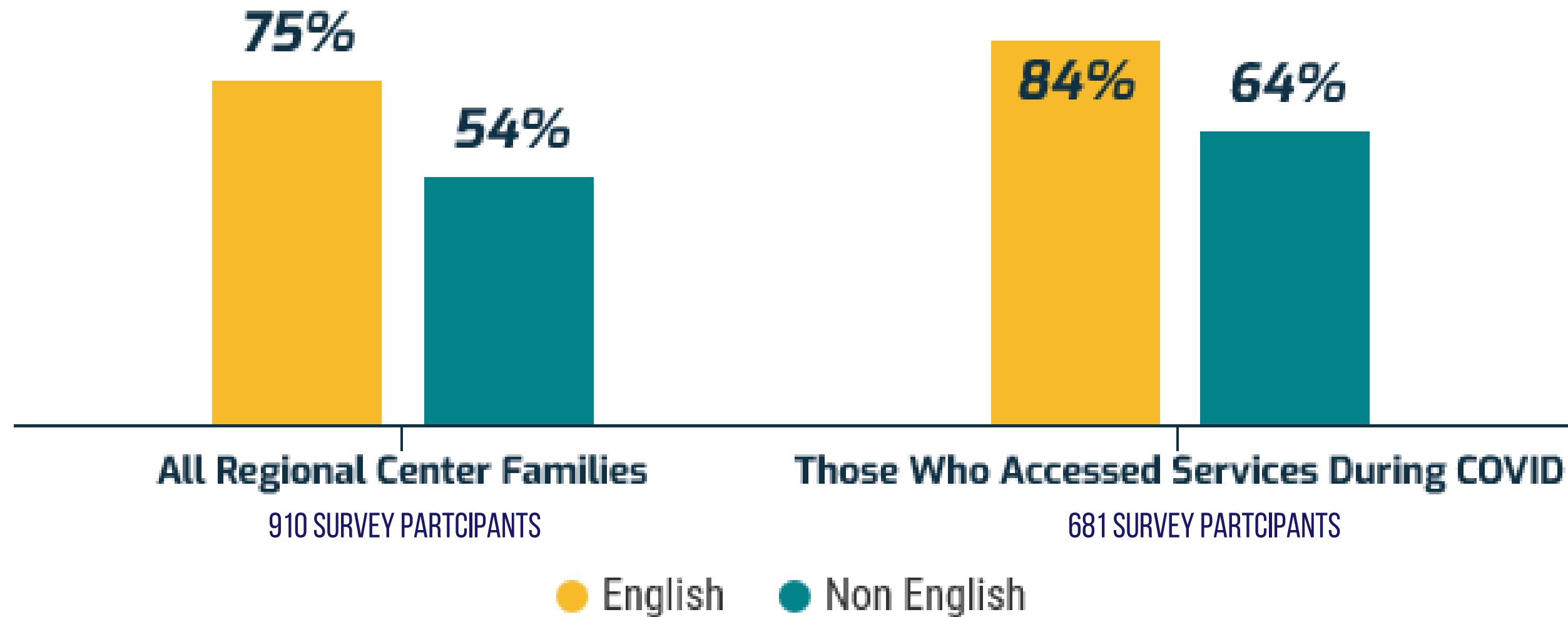
What would it take to make you feel comfortable before you let your loved one attend an adult day service (employment, day program, community program, etc) Multiple answers allowed.





# Most Families Satisfied with Regional Center Support, However, There Continues to be a Disparity Between English and Non-English Speaking Households.

Survey Respondents Who Feel They Have Received Adequate Support from Their Caseworker since COVID-19



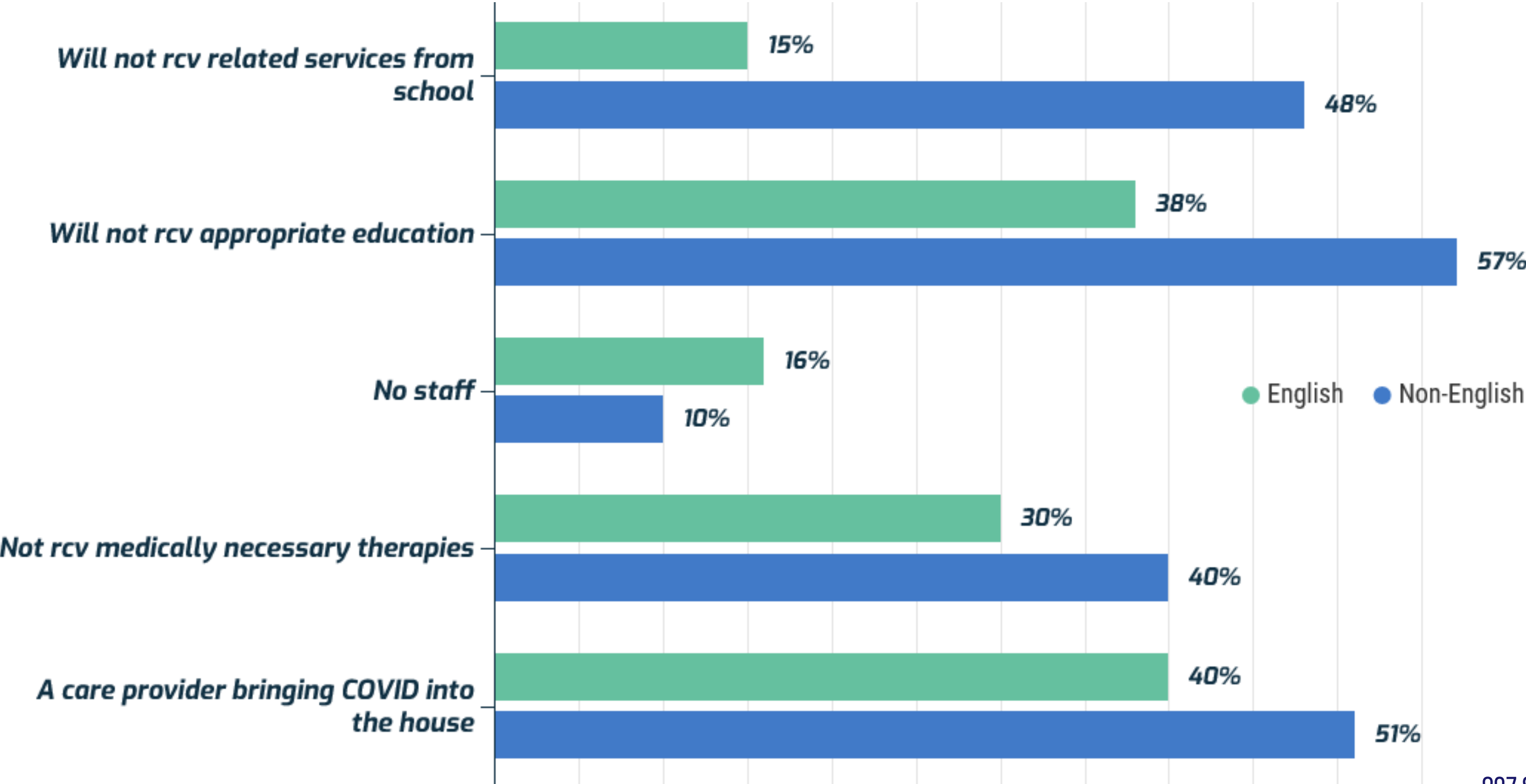


# Needs of the Community & Disparity

# Non English Households Are More Concerned About Not Receiving Services Than English Speaking Households.



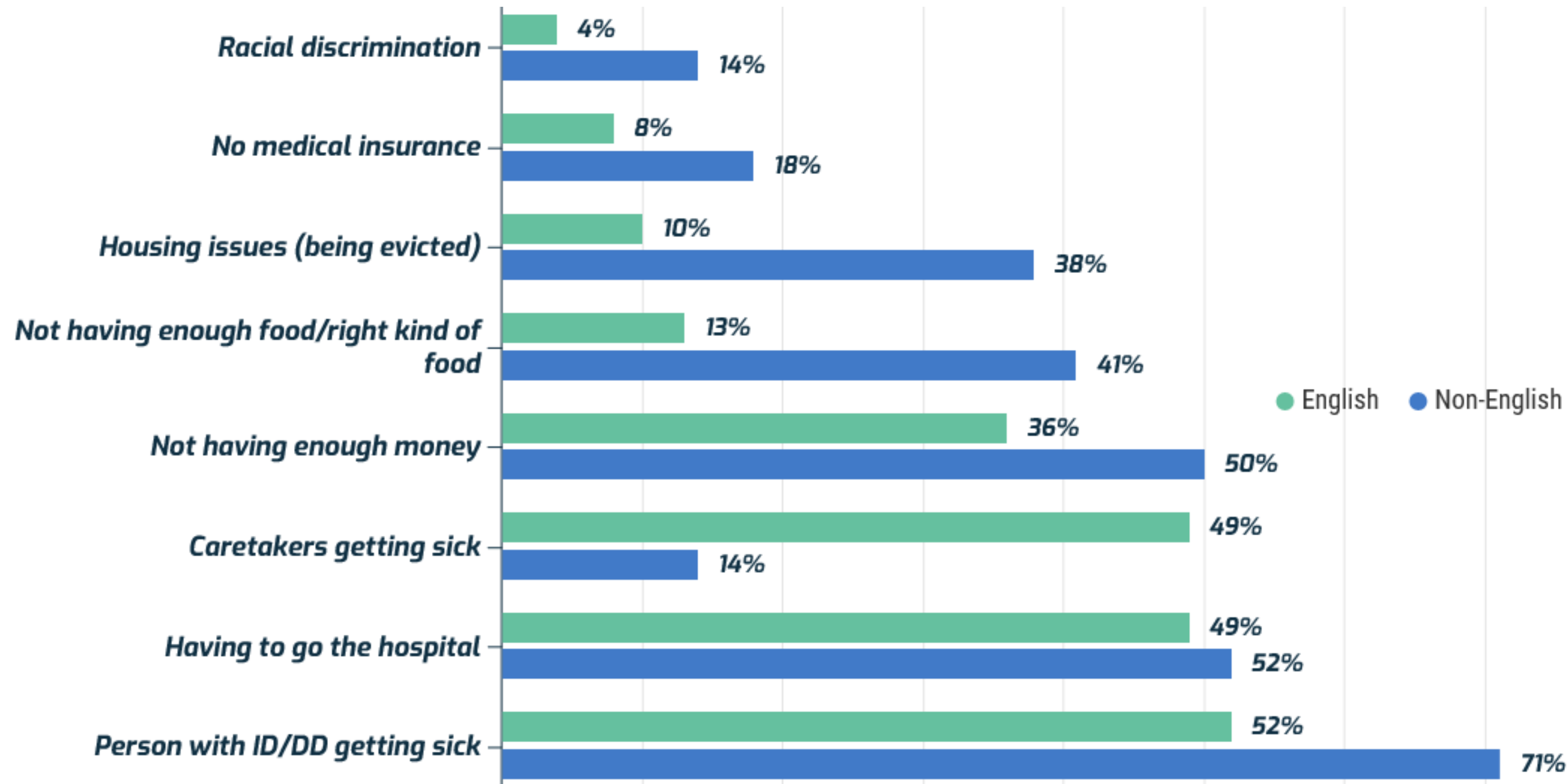
## Biggest Concerns Regarding Services: English Speaking Households Compared to Non English Households





# Non English Households Have More Anxiety Around Basic Needs and Person with ID/DD Becoming Ill

## Biggest Fears English Speaking Households Compared to Non English Households



# Autism Society of California Policy Recommendations

as of June 19, 2020

All of the following recommendations are made based on the knowledge that we are all living under the veil of the COVID-19 pandemic where there currently is no cure.

This report is being released based on the Autism Society of California's May 2020 Survey. This survey focused on how COVID-19 was affecting the population we serve. Currently the number of people with COVID 19 is on the rise. Due to this pandemic, California is potentially facing a \$54 billion shortfall to the state budget unless the State receives assistance from the Federal government. If federal assistance does not happen, California's health and human services and education systems will be facing catastrophic cuts. This would decimate service delivery for the intellectual and developmental disabilities (ID/DD) population at a time when there is a need for service flexibility and creativity as well as putting into place additional safety measures such as PPE and hazard pay.

COVID-19 brought tremendous stress and anxiety for Californians in general including the loss of income, frustration with schooling at home, and the fear of getting sick. However, survey participants indicate that individuals and families with loved ones with ID/DD frequently have additional stressors in the household. These include an increase of significant behaviors, the inability to follow safety protocols, the closing of medically necessary therapies and the decrease in crucial in-home support services such as IHSS, supported living services and those services that require direct support assistance. Additionally, individuals with ID/DD are at a higher risk of serious illness due to COVID-19 compared to the average Californian. This caused 1/3 of our survey participants to respond that they do not plan on allowing outside staff into their homes nor will they return to schools, medical clinics, or traditional center/community-based services by August 2020.

The Autism Society of California recommends:

## **1. Even in this extraordinary time we can not allow devastating funding cuts to the health and human service system. We must ensure funding is tied to person-centered, outcome-based services and supports.**

The most pressing issue to our community today is the potential for catastrophic funding cuts to multiple health and human services including In Home Supportive Services (IHSS), Regional Center services/supports, Medi-Cal, and Supplemental Security Income/State Supplementary Payment (SSI/SSP). The front-line workers including IHSS workers, supported living providers, independent living providers, personal assistants, in-home respite workers, residential care providers, and medical treatment providers were and continue to be the necessary lifelines in the ID/DD community. Many of them risked their own health in order to provide critical support and keep the pandemic from ravaging our ID/DD community.

- a) In order to live a **self-determined life** services should not be tied to service codes. **Flexible billing and funding** should support multiple pathways to access person-centered services and supports. These options should include in-home, virtual, and hybrid services.
- b) There must be a **sufficient network of providers** who can offer creative service solutions to meet individual needs. Agencies who have current contracts with Regional Centers should be permitted to alter their program designs which may include new services to meet the current service delivery crisis. New providers should be able to quickly and expeditiously fill service delivery gaps. This can be made possible by establishing an **expedited vendor process**.
- c) **Pilot a data collection systems on person-centered quantitative and qualitative outcomes.** For the DDS system, we suggest the LifeCourse Framework developed and adapted by the University of Missouri Kansas City Institute for Human Development [www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/](http://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/)
- d) There must be **continued transparency and stakeholder involvement** in decisions being made around safety plans and services and supports options for the ID/DD community.

# Autism Society of California Policy Recommendations

as of June 19, 2020

## 2. The safety of participants, families and employees should be the top priority while maintaining the maximum flexibility possible in providing services and supports.

- a. The **development of site and service re-entry plans should include individual and family member input.** In the event of positive COVID-19 exposure, plans should include whether services would stop completely, transition to a virtual model or some other option. Plans should also include procedures if a staff person and/or client tests positive as well as information about accessing services if the business must physically close.
- b. **Re-entry plans should be shared with employees, individuals, and families prior to the re-opening.** After reviewing the plan individuals and families can decide if they are comfortable with the safety measures outlined. If not, flexibility should be provided for alternative ways to access services through the current provider or another provider.
- c. **Define who is responsible for paying for and providing masks, hand sanitizer, face shields or other PPE for staff and participants.**
- d. **If a participant is unable to comply with the safety precautions listed in the re-entry plan, they must be given the option to receive services by alternate means.**

## 3. Develop and disseminate teleservice access and best practices for medical treatment, day, employment, social and educational services.

While teleservice was beneficial for many families, approximately 15% of the survey respondents did not receive any value from this delivery method. Therefore, a range of service delivery options must continue to be made available so that individuals and families can access the services they need.

- a) **Hold monthly Community of Practice meetings** to share emerging and best practices with families and professionals so all stakeholders have equal access to the knowledge.
- b) **Technology Lending libraries or mini-grant programs for technology should be funded and made available** for acquiring technology/internet access for families and to train families on using new technology.

## 4. Continued focus on eliminating cultural and socioeconomic disparity issues.

The COVID-19 pandemic has magnified existing disparity issues. Non-English-speaking households have a greater need for food, housing and medical insurance. Non-profits are currently trying to meet the needs of this community with little or no funding.

- a) Since this population is more vulnerable, **caseworkers should be contacting these individuals and families more frequently** in order to assess their current needs around not only Regional Center services but also to offer support in accessing basic needs. This should include helping them overcome the barriers they face in accessing those services. Further, case managers should take this opportunity to assess how individuals and families are feeling about returning to their previous services/supports and discuss other options that may be available for them to access.
- b) **Critical information must always be disseminated in a culturally responsive way in a timely manner.**
- c) There needs to be a **continued investment in staff training of Regional Center caseworkers, educators, medical therapy service providers and direct support professionals on the dynamics that result from cultural differences**, the expansion of cultural knowledge, and how to adapt services to meet culturally unique needs.