



The Impact of COVID on Families and Youth with Intellectual and Developmental Disabilities: Service Implications

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 **AUTISM SOCIETY**

Improving the Lives of All Affected by Autism

Inland Empire

California Stay at Home Order on March 19, 2020

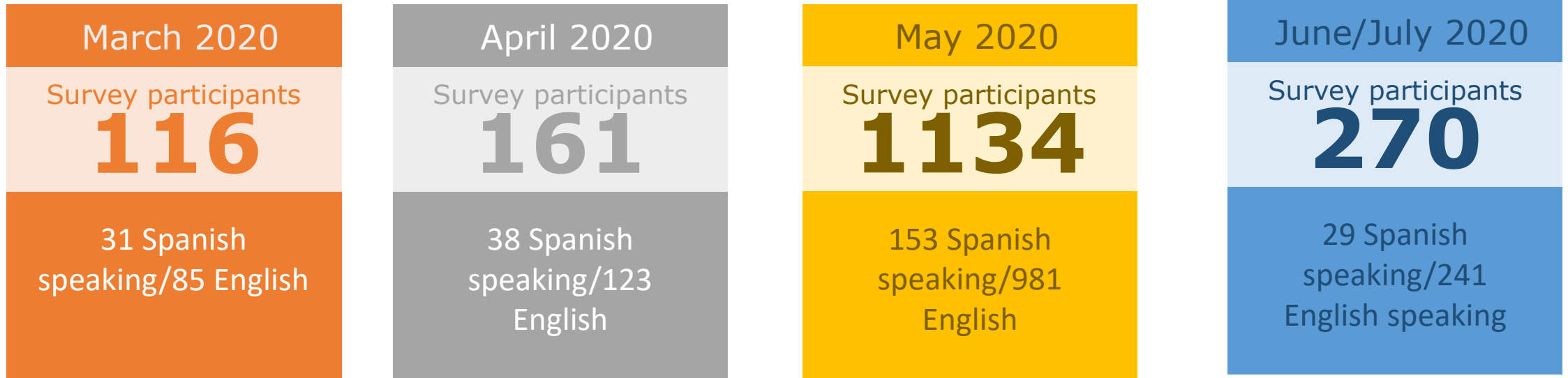


Autism Society COVID Surveys



Electronic Surveys

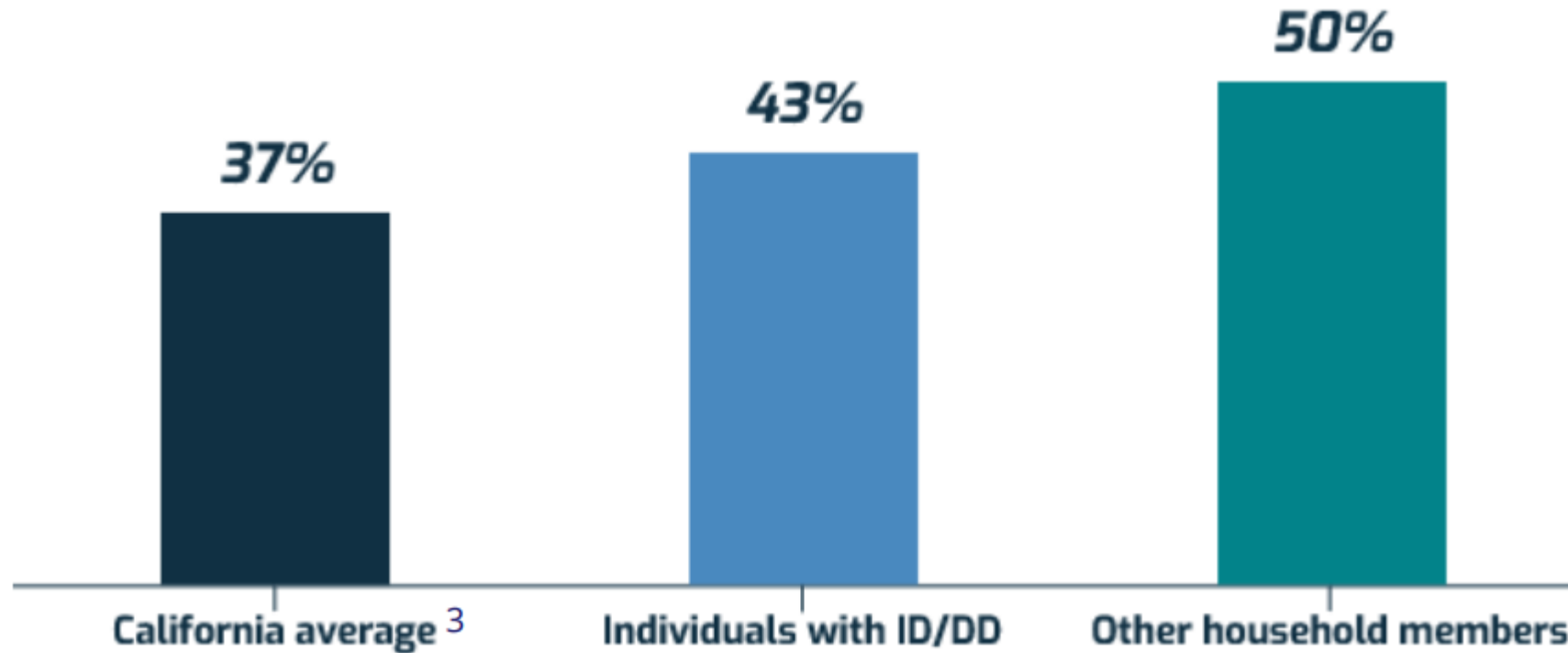
We realize this is not a scientific sample, but it does capture information that can be used to gauge the needs of our community.



Most people with developmental or behavioral disorders are not naturally at higher risk for becoming infected with or having severe illness from novel coronavirus (COVID-19). People of any age with certain underlying medical conditions are at increased risk for severe illness from COVID-19:

- Asthma (moderate-to-severe)
- Cancer
- Cerebrovascular disease (affects blood vessels and blood supply to the brain)
- Chronic kidney disease
- COPD (chronic obstructive pulmonary disease)
- Cystic fibrosis
- Hypertension or high blood pressure
- Immunocompromised state (weakened immune system) from blood or bone marrow transplant, immune deficiencies, HIV, use of corticosteroids, or use of other immune weakening medicines
- Immunocompromised state (weakened immune system) from solid organ transplant
- Liver disease
- Neurologic conditions, such as dementia
- Obesity (body mass index [BMI] of 30 or higher)
- Pregnancy
- Pulmonary fibrosis (having damaged or scarred lung tissues)
- Serious heart conditions, such as heart failure, coronary artery disease, or cardiomyopathies
- Sickle cell disease
- Smoking
- Thalassemia (a type of blood disorder)
- Type 1 diabetes mellitus
- Type 2 diabetes mellitus

Autism Society of California Survey: Vulnerable for Serious Illness Due to COVID-19

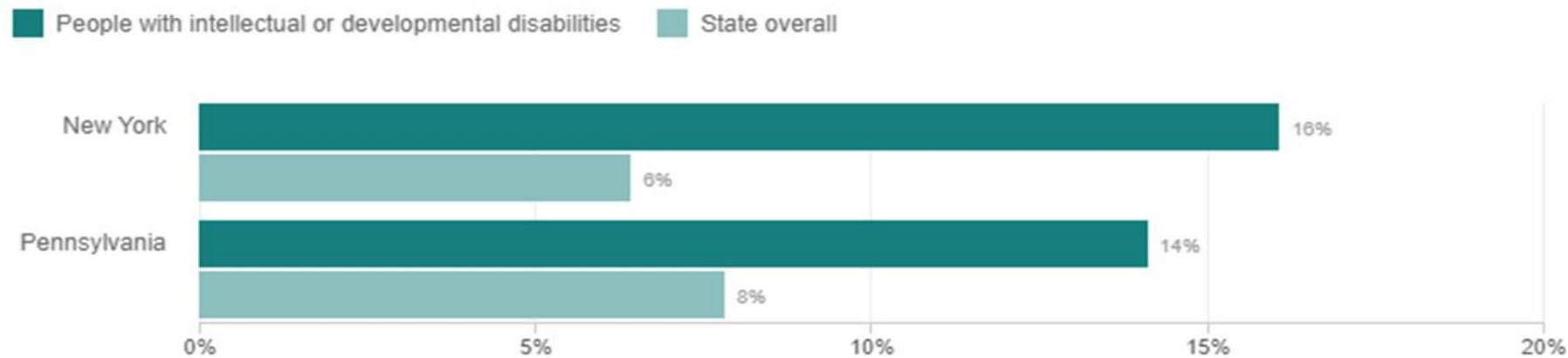


Autism Society of California Survey May 2020
863 survey participants

People with Intellectual Disabilities and Autism Die of COVID-19 at a Higher Rate

People With Intellectual Disabilities And Autism Die Of COVID-19 At A Higher Rate

In New York and Pennsylvania, COVID-19 case-fatality rates for people with intellectual and developmental disabilities are higher than the states' overall rates. (Case-fatality rates are deaths as a percentage of total confirmed cases within the population.)



Notes

Data as of June 3. Numbers for people with intellectual disabilities reflect those who get services from the state.

Source: New York State Department of Health, Pennsylvania Department of Health, Pennsylvania Office for People with Developmental Disabilities, New York Office for People with Developmental Disabilities

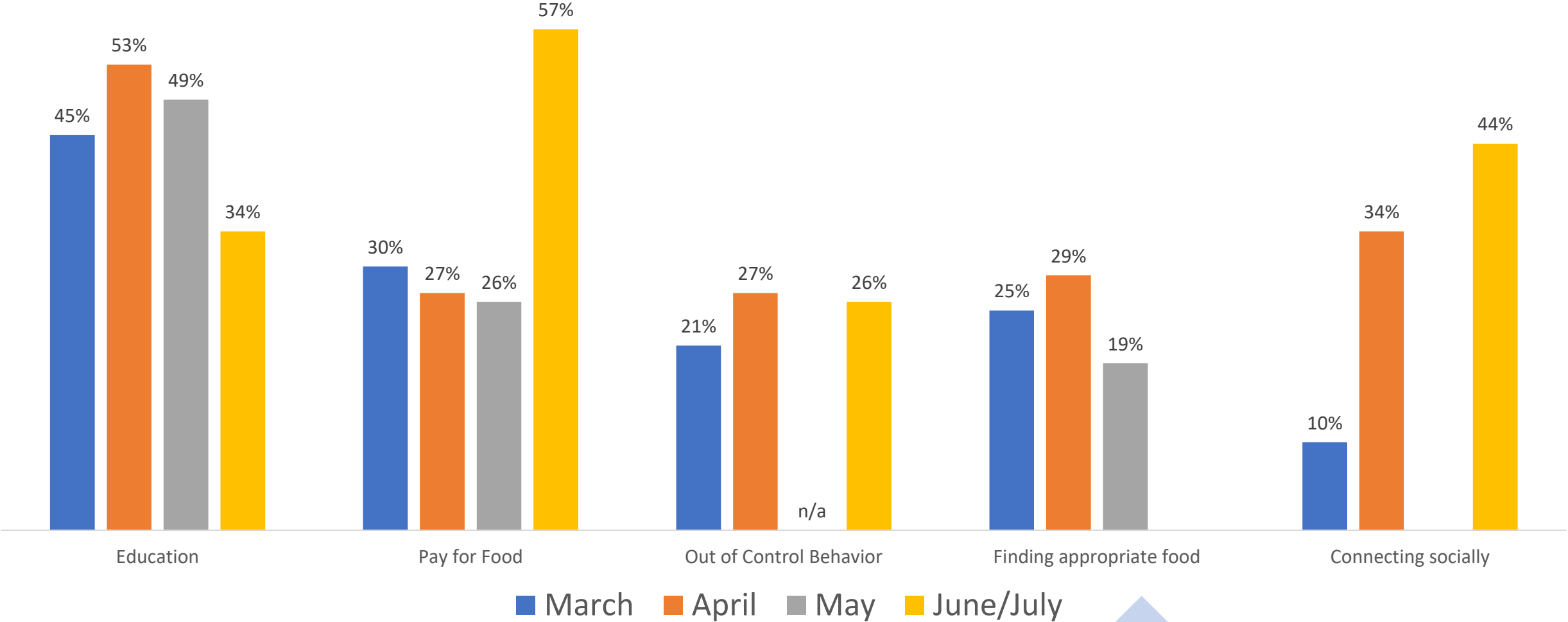
Credit: Stephanie Adeline/NPR

People with developmental disabilities contract COVID-19 4x more and die at a rate 2.5 times the rate of others who contract the virus.

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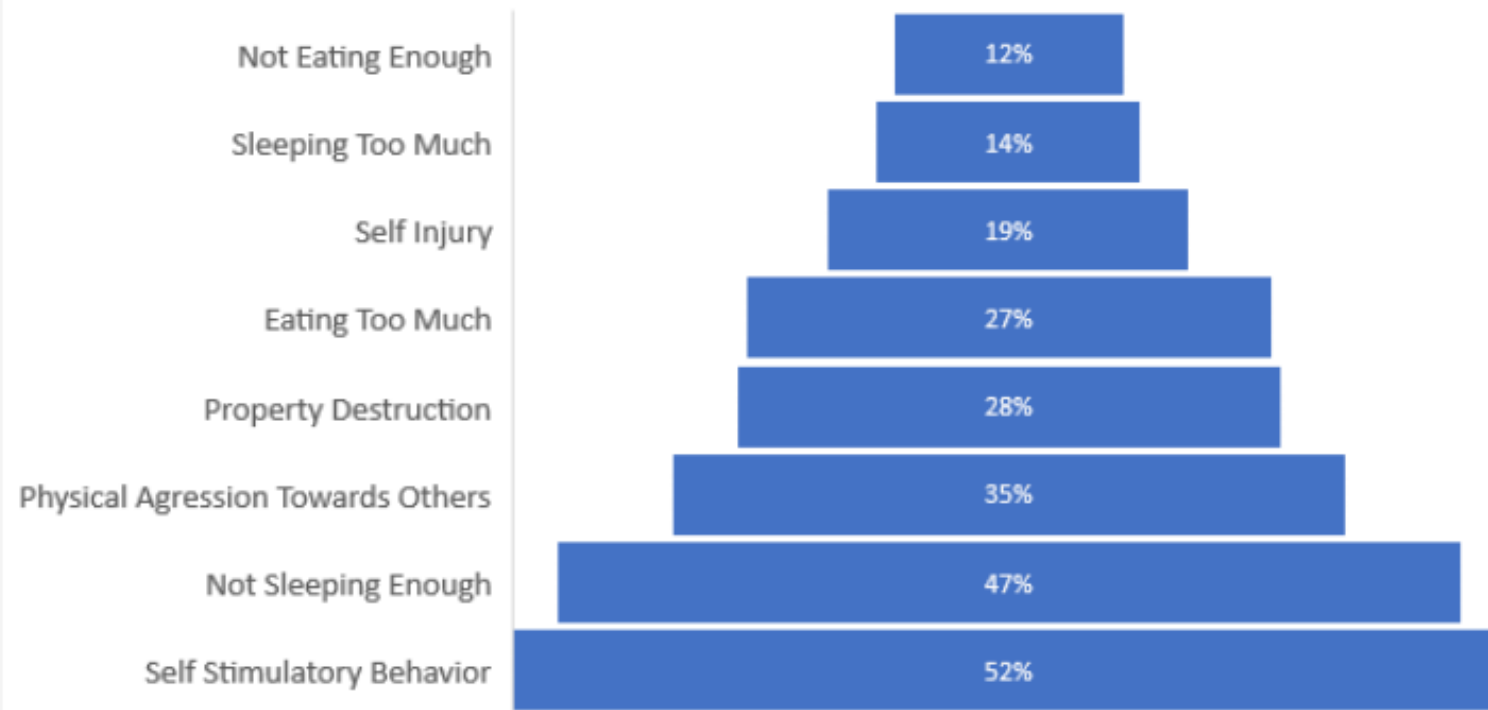
<https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili>

Biggest Issues/Needs Families with Loved Ones with Developmental Disabilities Are Facing During COVID-19



Families report a dramatic increase in behaviors in the household.

Has the Person with ID/DD Had a Change in the Following?



820 SURVEY PARTICIPANTS



**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

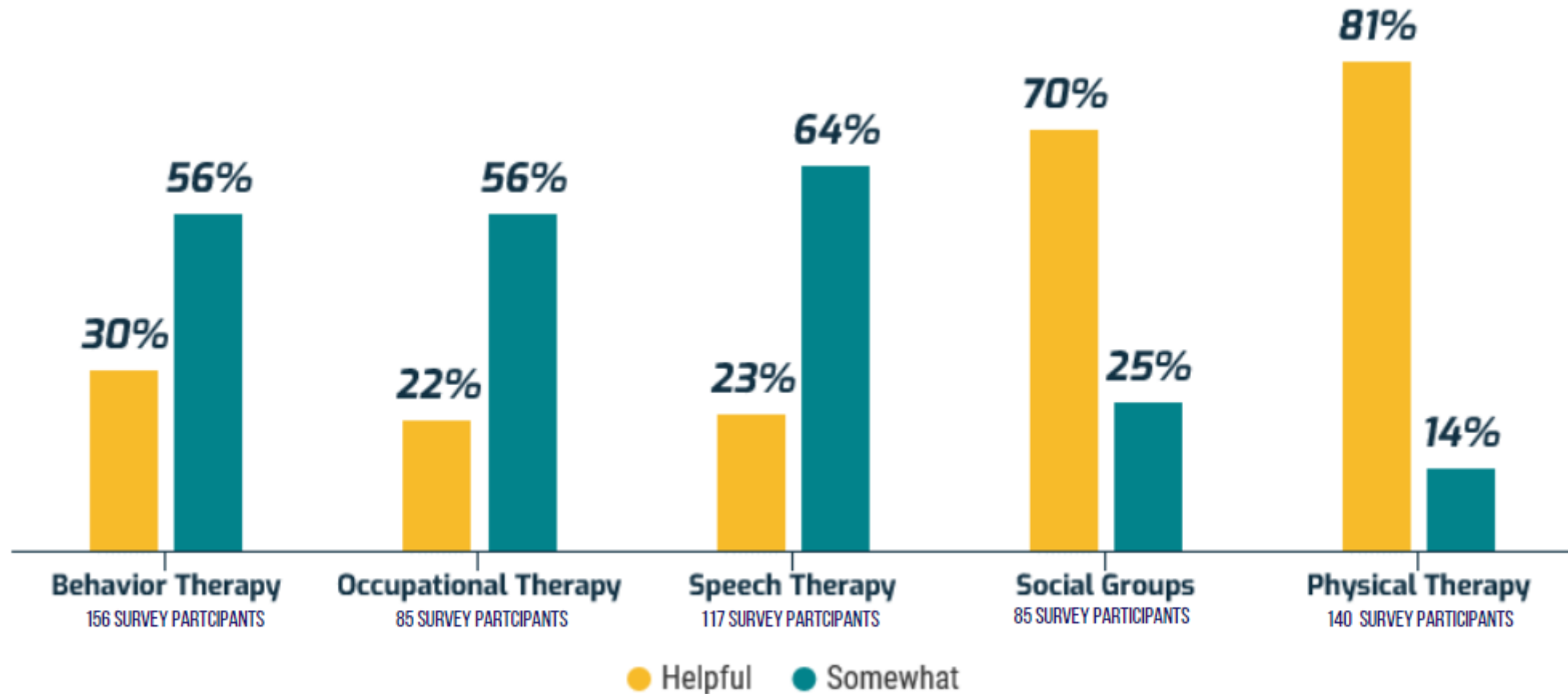
Individuals with ID/DD (ages 6 years and older) can not practice social distancing.

1 in 4

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

Telehealth Was An Effective Option for Many

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



25%

Of families reported the child/adult with ID/DD **does not** have access to a computer or laptop with a camera they could use for 3 hours a day
(July Survey: 165 participants)

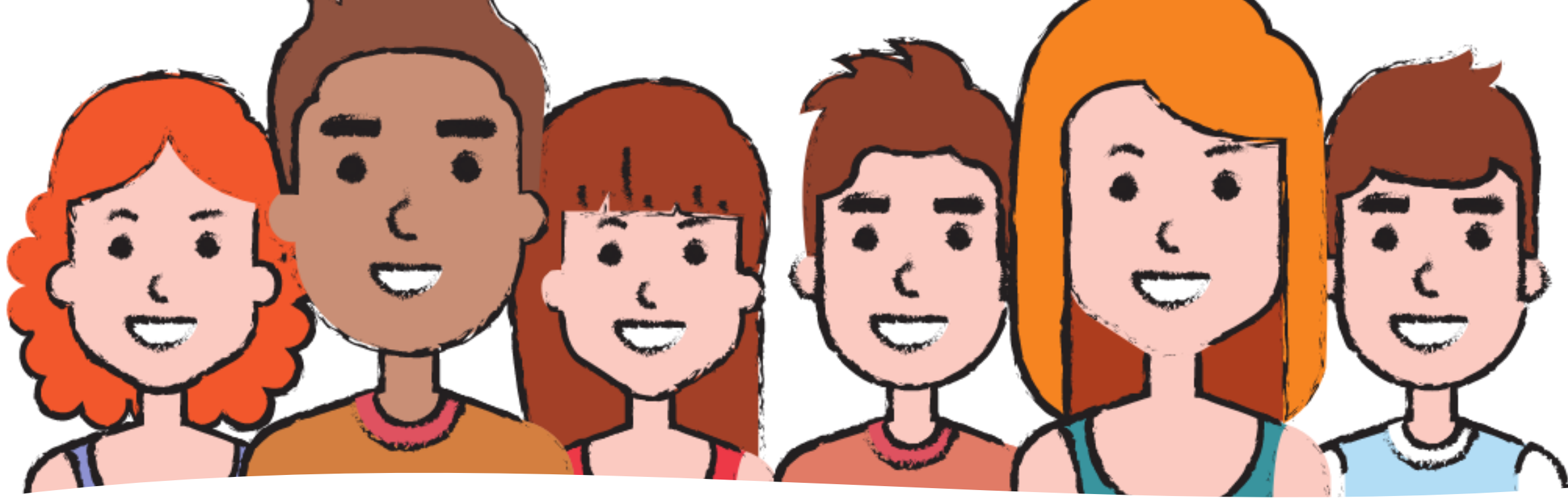
Would having someone you could call to walk you through the technology the	YES
the school is using be helpful to you?	33%
medical provider is using be helpful to you?	25%
Adult programs is using?	19%



Re-entry: School

- 33% of families reported they would not be comfortable letting their loved one go back to school in person school. (May 2020 California Survey: 927 participants)
- 31% of families reported they would not have their student attend in person school. (July Autism Society Inland Empire Survey: 196 participants)





Service Implication: Adult Services

- 33% of families with adults reported they would not be comfortable letting their loved one go back to Adult Day Services in person; 7% wanted in person services. (May 2020 California Survey: 128 participants)
- 28% of families reported they want online services for their adults; 27% want in person and 45% are unsure. (July Autism Society Inland Empire Survey: 62 participants)

Using the Data to Tell the Story of Our Community

More Vulnerable: People with developmental disabilities contract COVID-19 4x more and die at a rate 2.5 times the rate of others who contract the virus.

- Underlying medical conditions
- Service providers
- Live in congregate settings
- 1 in 6 can not follow safety protocol



Using the Data to Tell the Story of Our Community

Families in Crisis Above What the Typical Family Has to Face

- 25% – 30% Need help with food
- 25% Behavioral crisis
- 20-30% Restricted food



Using the Data to Tell the Story of Our Community

Need Service Delivery Options:

- 25% need access to technology and help to access
- Telehealth is not effective for 13-22% of our population
- 1/3 of families will not send child to in-person school or adult to in-person day program



Data Driven Person-Centered, Outcome Based Decisions



- Autism Society Inland Empire Food Program
- Distributing Masks
- Online educational webinars, fun events and support groups
- Advocating state and local levels for meaningful safe in person and online options
 - Special Education
 - Regional Center services
- Collaborating with other groups around access to technology, childcare, lack of housing and the re-opening of the counties
- Sharing resources newsletter, website and our Resource Specialists



AUTISM SOCIETY INLAND EMPIRE

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IMPROVING THE LIVES OF ALL AFFECTED BY AUTISM



BASIC NEEDS



CONFERENCES & TRAINING



PARENT SUPPORT



RESOURCES



SAFETY & DISASTER PREPAREDNESS



SOCIAL RECREATION

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