

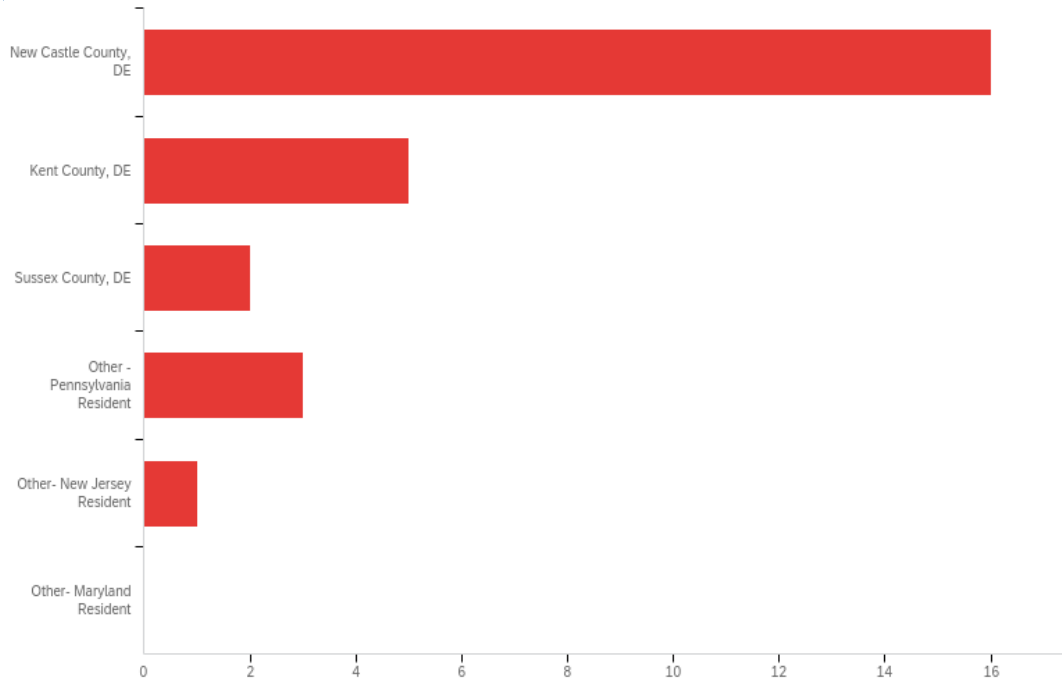
Initial Report

Coronavirus/COVID-19 Pandemic Needs (Follow-up)

Families Know Best Survey - June 2020

1 - What is your place of residence?

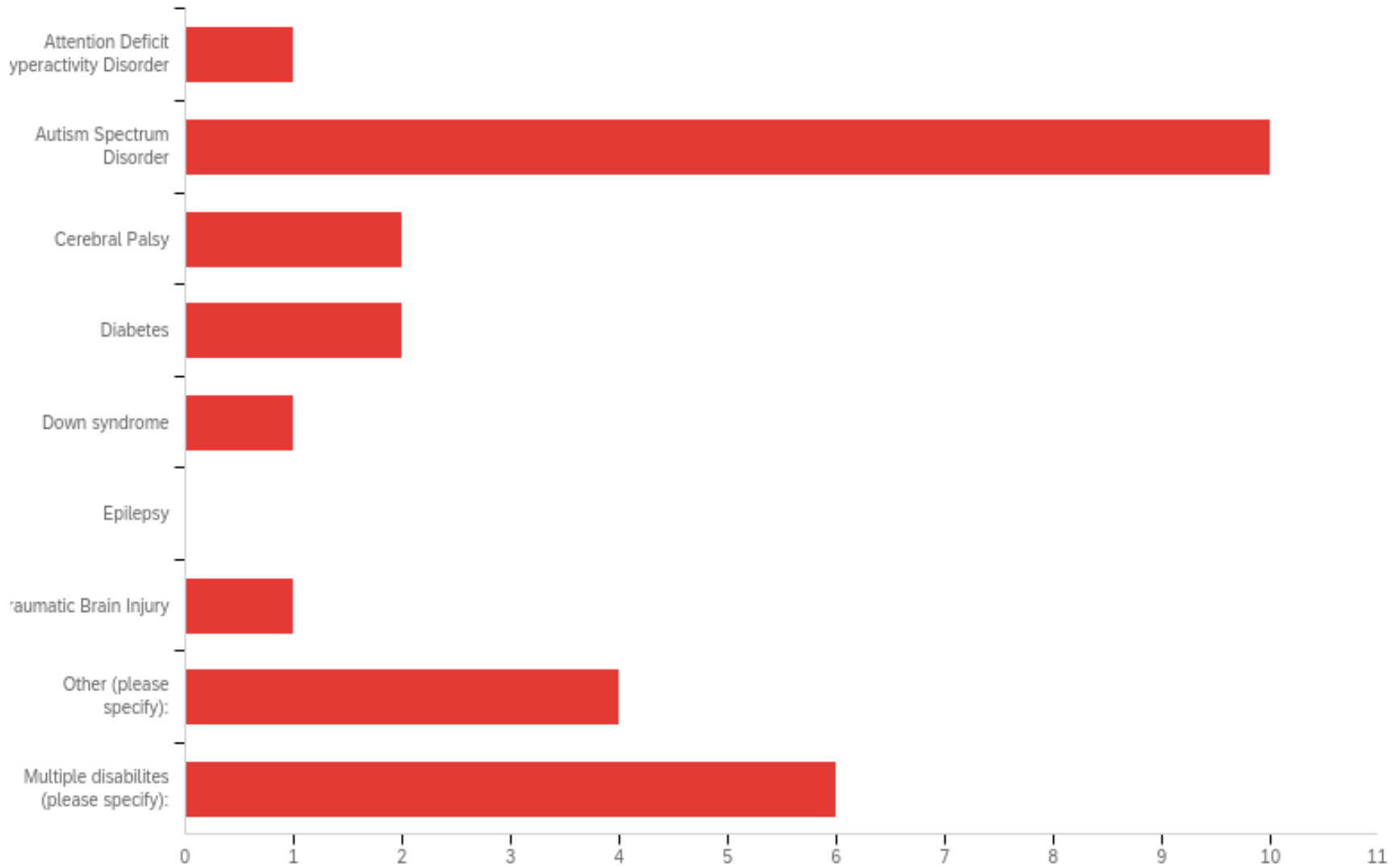
Answer	%	Count
New Castle County, DE	59.26%	16
Kent County, DE	18.52%	5
Sussex County, DE	7.41%	2
Other - Pennsylvania Resident	11.11%	3
Other- New Jersey Resident	3.70%	1
Other- Maryland Resident	0.00%	0
Total	100%	27



2 - What is your child's disability or health condition?

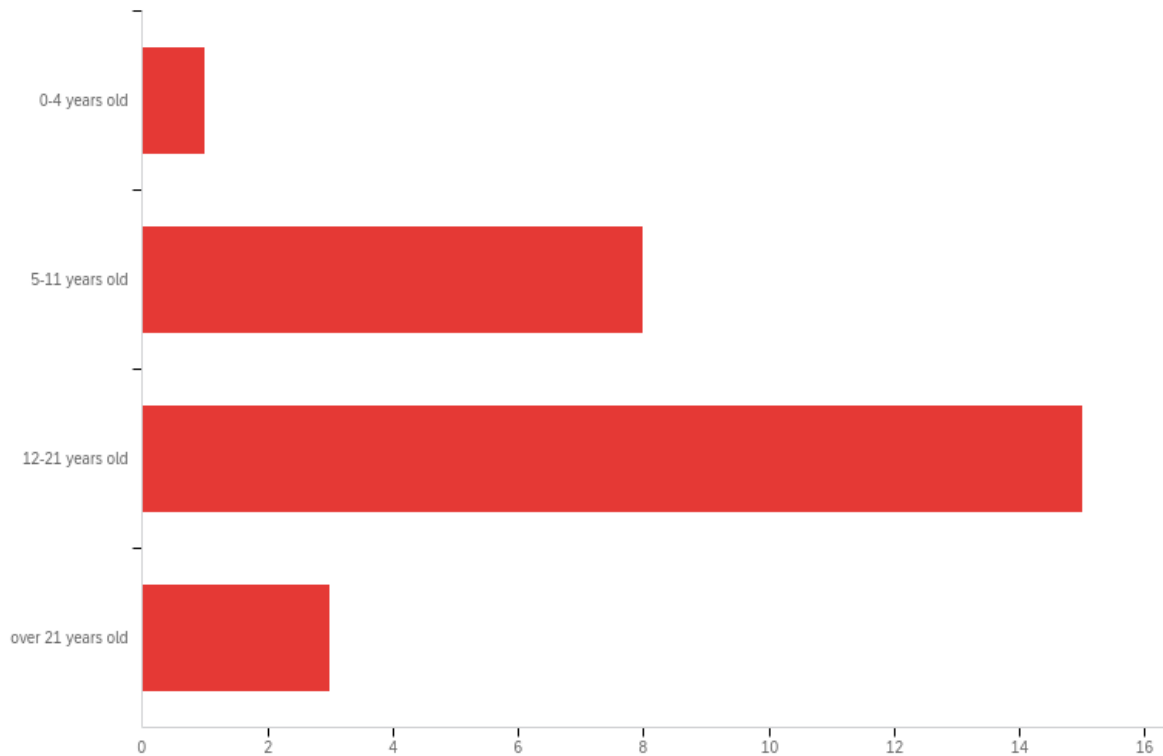
Answer	%	Count
Attention Deficit Hyperactivity Disorder	3.70%	1
Autism Spectrum Disorder	37.04%	10
Cerebral Palsy	7.41%	2
Diabetes	7.41%	2
Down syndrome	3.70%	1
Epilepsy	0.00%	0
Traumatic Brain Injury	3.70%	1
Other (please specify):	14.81%	4
Multiple disabilities (please specify):	22.22%	6
Total	100%	27

2 - What is your child's disability or health condition?



3 - What is the age of your child?

Answer	%	Count
0-4 years old	3.70%	1
5-11 years old	29.63%	8
12-21 years old	55.56%	15
over 21 years old	11.11%	3
Total	100%	27

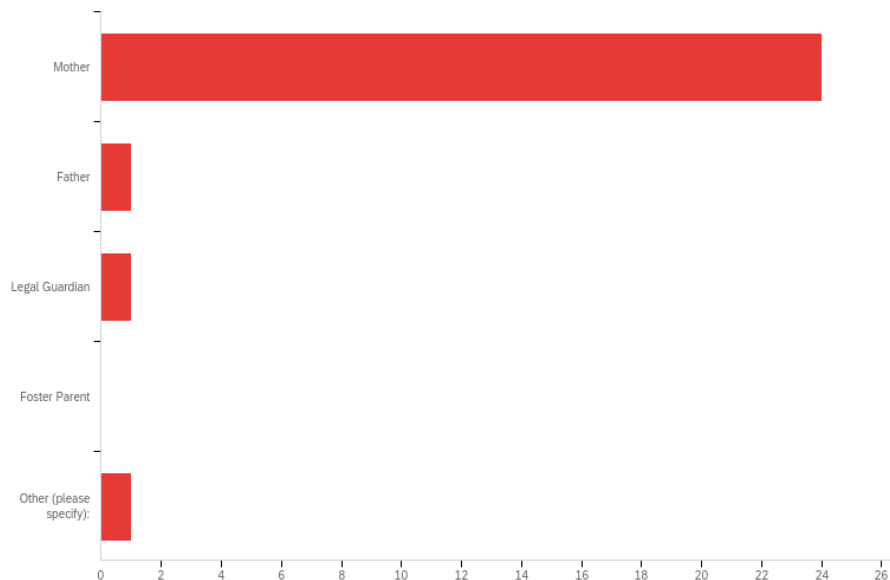


4 - Please identify yourself.

Answer	%	Count
Mother	88.89%	24
Father	3.70%	1
Legal Guardian	3.70%	1
Foster Parent	0.00%	0
Other (please specify): (see response below)	3.70%	1
Total	100%	27

Other (please specify): - Text *(Responses appear as entered by participant.)*

Maternal grandmother, legal guardian



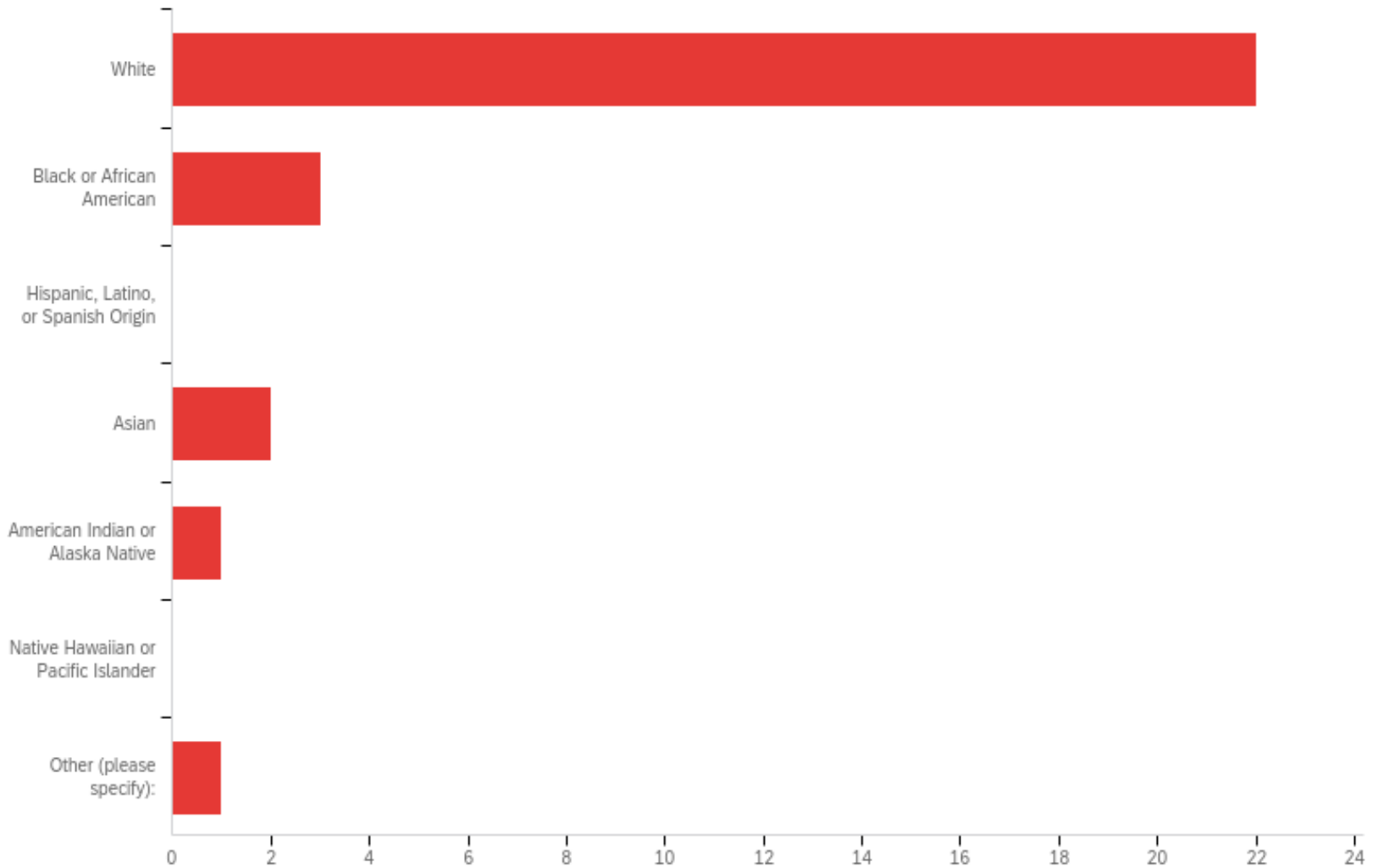
5 - What is your race/ethnicity? (Check all that apply)

Answer	%	Count
White	75.86%	22
Black or African American	10.34%	3
Hispanic, Latino, or Spanish Origin	0.00%	0
Asian	6.90%	2
American Indian or Alaska Native	3.45%	1
Native Hawaiian or Pacific Islander	0.00%	0
Other (please specify):	3.45%	1
Total	100%	29

Other (please specify): - Text *(Responses appear as entered by participant)*

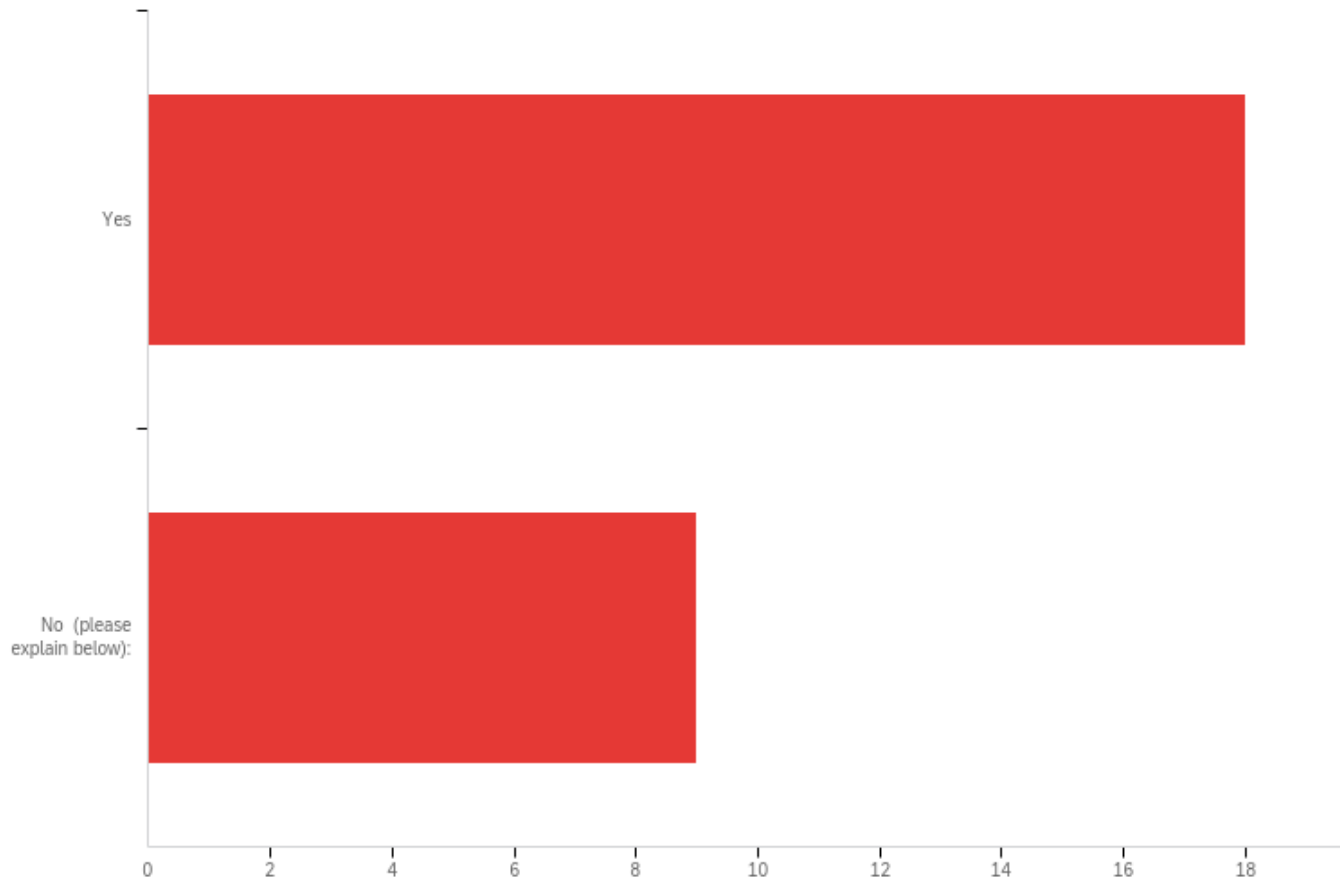
I am white; my child is Asian

5 - What is your race/ethnicity? (Check all that apply)



6 - Do you consider your child's health insurance coverage to be adequate to meet your child's needs?

Answer	%	Count
Yes	66.67%	18
No (please explain): <i>(see next slide for responses)</i>	33.33%	9
Total	100%	27



6 - Do you consider your child's health insurance coverage to be adequate to meet your child's needs? *(Responses appear as entered by participant.)*

No (please explain): - Text

I have difficulty getting the services and supplies covered. Co-pays add up

some are not met

It does not allow for treatment at Kennedy Krieger. Nemours simply isn't equipped to treat or help families with moderate- severe autism

Almost, but it doesn't pay for an extra dental cleaning each year (his Fine motor doesn't allow him to brush well) and it doesn't pay for specialize fitness instruction. It is difficult to get ABA covered and paid for.

No participating specialist providers , prior approval needed for every DME and pcp is unable or I willing to do prior auth

We are not getting nursing care home support for his tube feeding

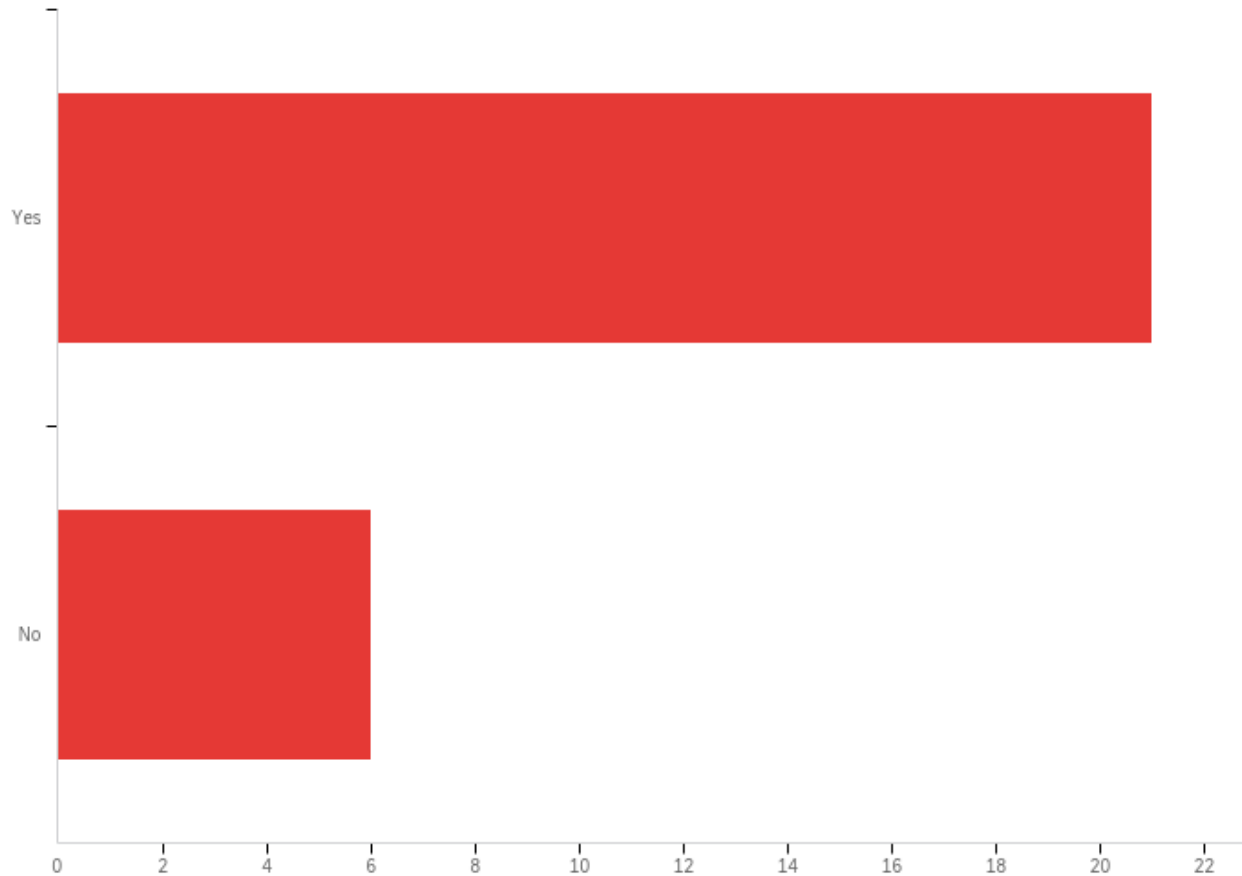
Primary insurance denies necessities which then have to be covered by Medicaid.

In-home and at-school needs are either not covered or require red tape / paperwork / proof battles

My son needs support to get his teeth cleaned. Consequently, he goes to Practice Without Pressure. His insurance pays for the actual dental cleaning But not for the support services. As a result I am still paying far more for a dental cleaning than I would if he were neurotypical. (Other than that, I am fortunate enough to have very good insurance.)

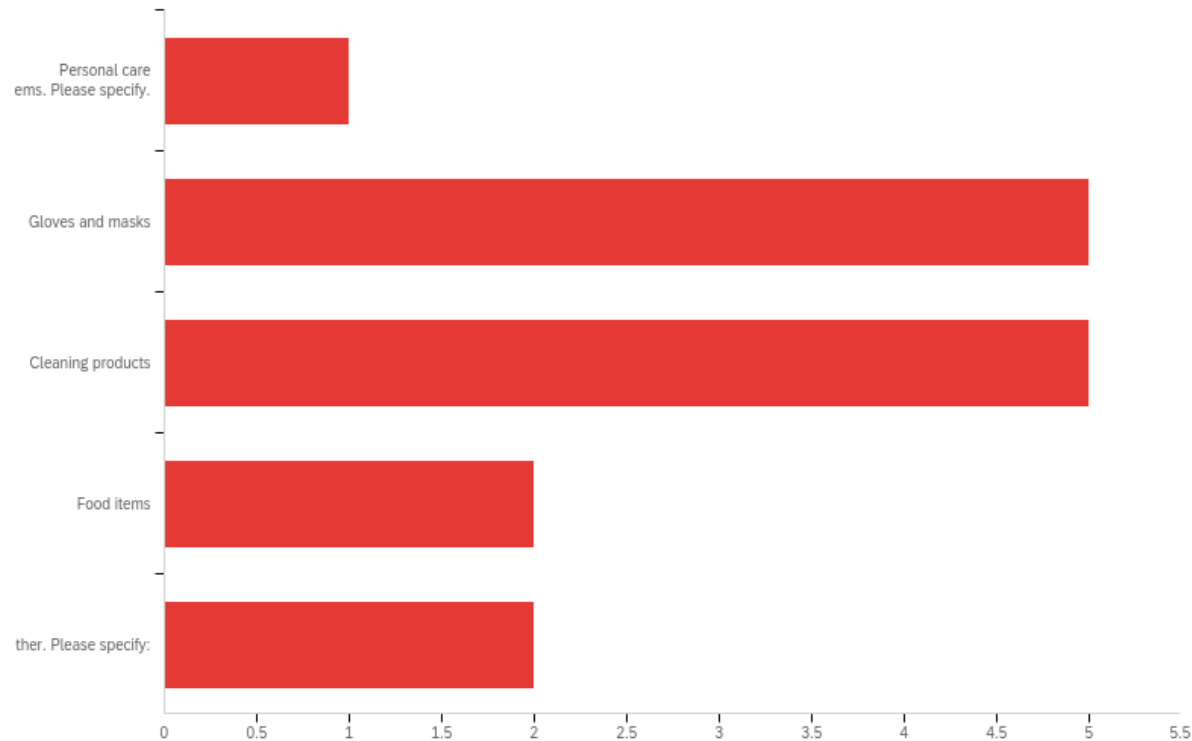
7 - Do you have enough supplies for your child's needs while Delaware phases out from stay at home orders?

Answer	%	Count
Yes	77.78%	21
No <i>(see next slide for follow-up question)</i>	22.22%	6
Total	100%	27



8 - Which of the following supplies are you in need of (check all that apply):

Answer	%	Count
Personal care items. Please specify. <i>(see next slide for responses)</i>	6.67%	1
Gloves and masks	33.33%	5
Cleaning products	33.33%	5
Food items	13.33%	2
Other. Please specify: <i>(see next slide for responses)</i>	13.33%	2
Total	100%	15



8 - Which of the following supplies are you in need of (check all that apply):

(Responses appear as entered by participant.)

Personal care items. Please specify.

- Text

incontinence supplies

Other. Please specify:

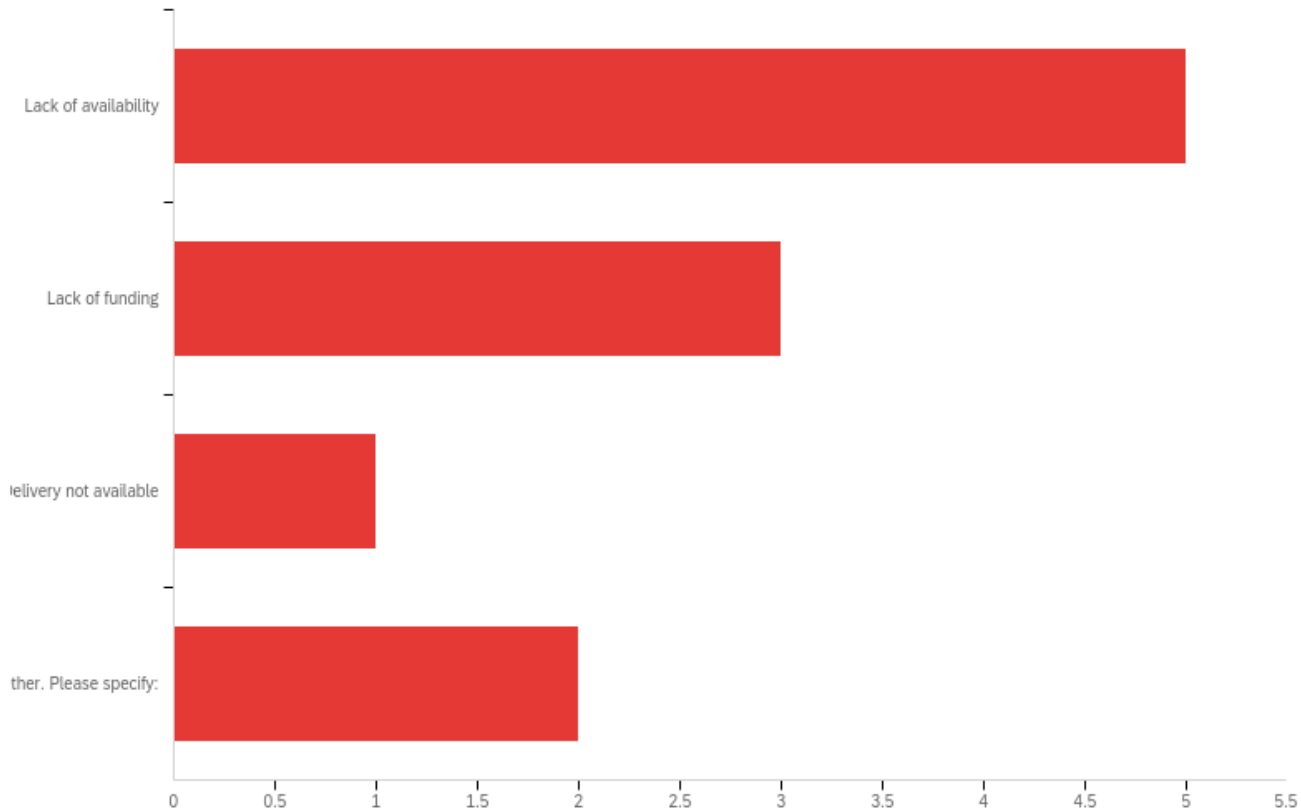
- Text

Specialty elemental formula

Learning supplies

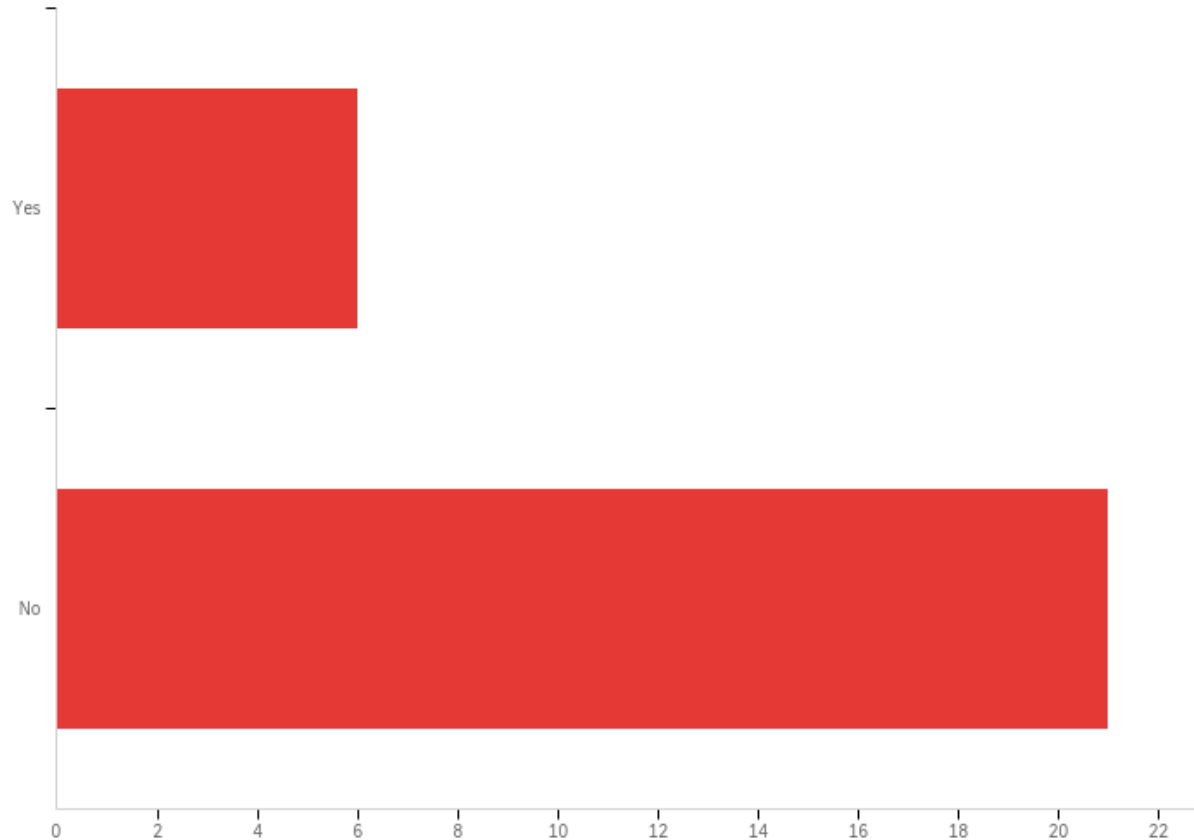
9 - What are the barriers in obtaining needed supplies (check all that apply):

Answer	%	Count
Lack of availability	45.45%	5
Lack of funding	27.27%	3
Delivery not available	9.09%	1
Other. Please specify:	18.18%	2
Total	100%	11



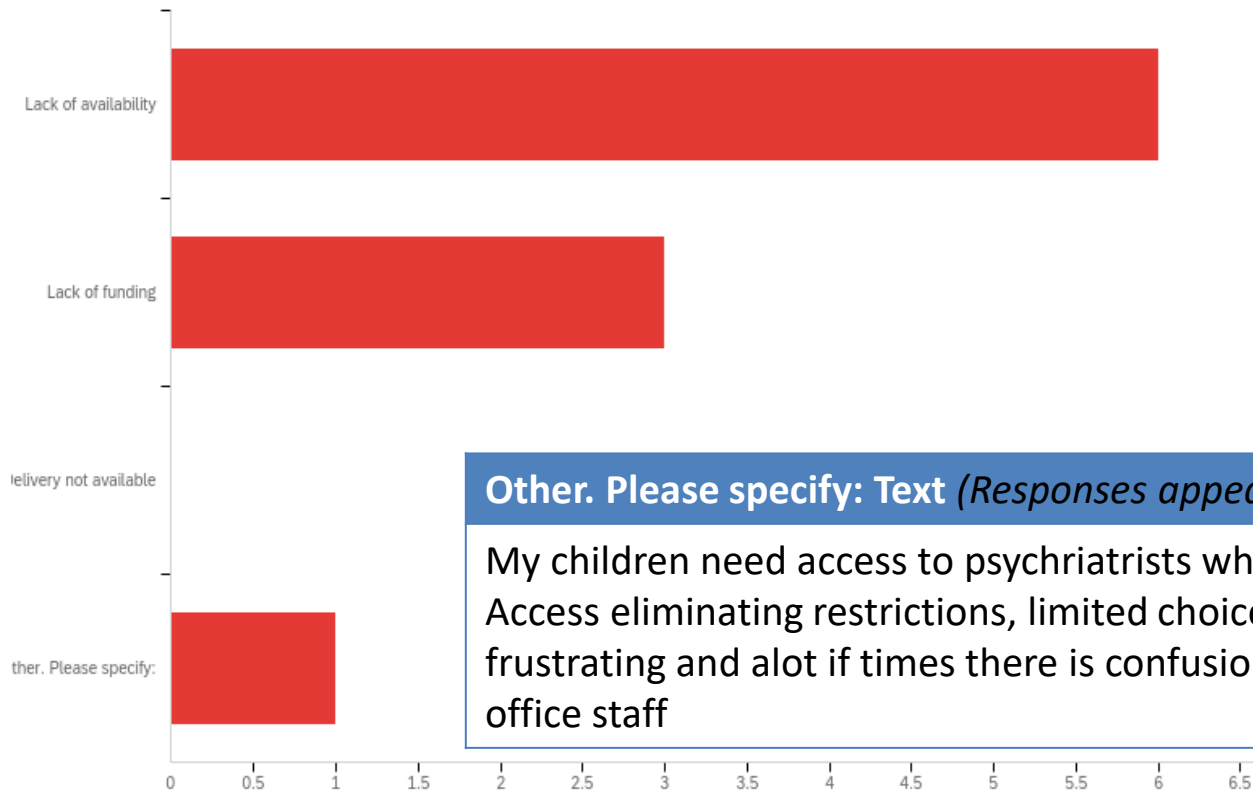
10 - Do you have concerns about obtaining medications for your child with a special healthcare need as Delaware phases out from stay at home orders?

Answer	%	Count
Yes <i>(see next slide for follow-up question)</i>	22.22%	6
No	77.78%	21
Total	100%	27



11 - Which of the following are your concerns with obtaining medications (check all that apply):

Answer	%	Count
Lack of availability	60.00%	6
Lack of funding	30.00%	3
Delivery not available	0.00%	0
Other. Please specify: <i>(see information below)</i>	10.00%	1
Total	100%	10

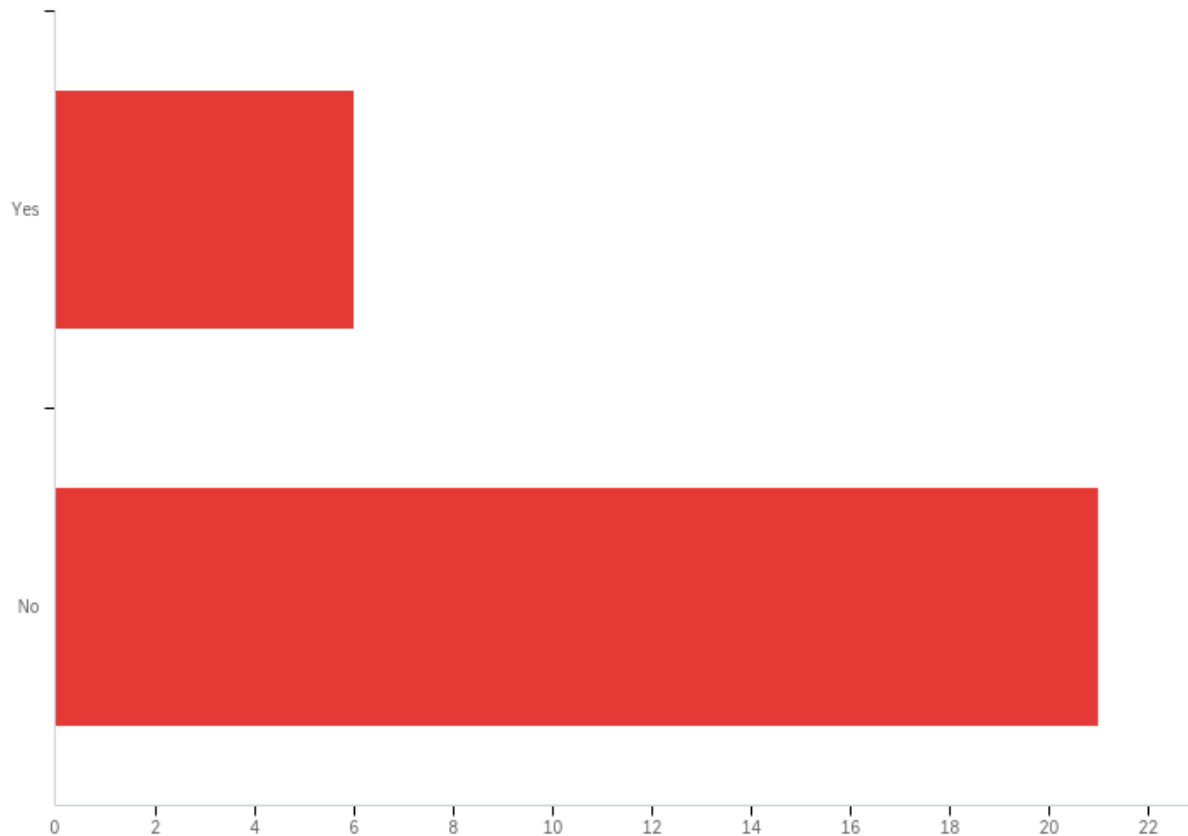


Other. Please specify: Text *(Responses appear as entered by participant.)*

My children need access to psychiatrists who can provide medications. Access eliminating restrictions, limited choice of, and wait lists are frustrating and alot if times there is confusion or no patient follow up from office staff

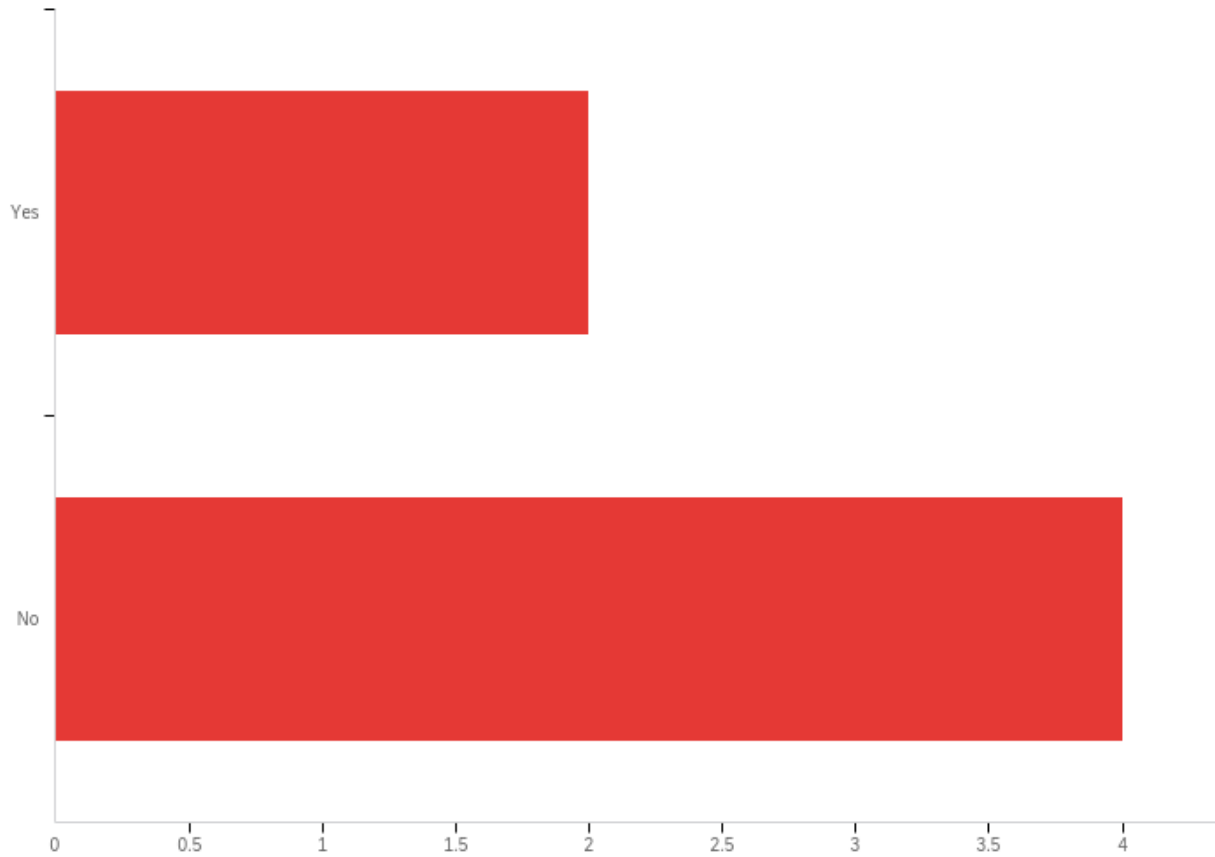
12 - Do you have concerns about ordering/repairing durable medical equipment as Delaware phases out from stay at home orders?

Answer	%	Count
Yes <i>(see next 2 slides for follow-up questions)</i>	22.22%	6
No	77.78%	21
Total	100%	27



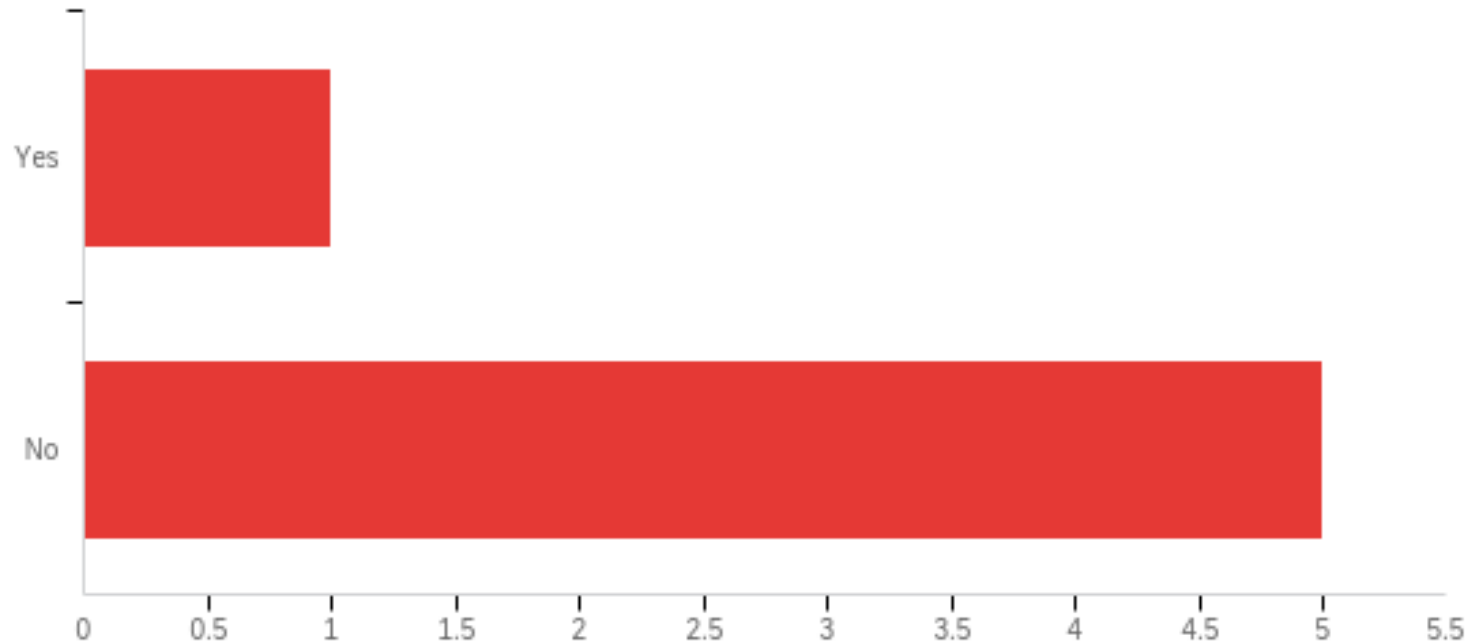
13 - If a durable medical equipment company is having trouble getting you supplies, do you have alternative options in dealing with low supplies?

Answer	%	Count
Yes	33.33%	2
No	66.67%	4
Total	100%	6



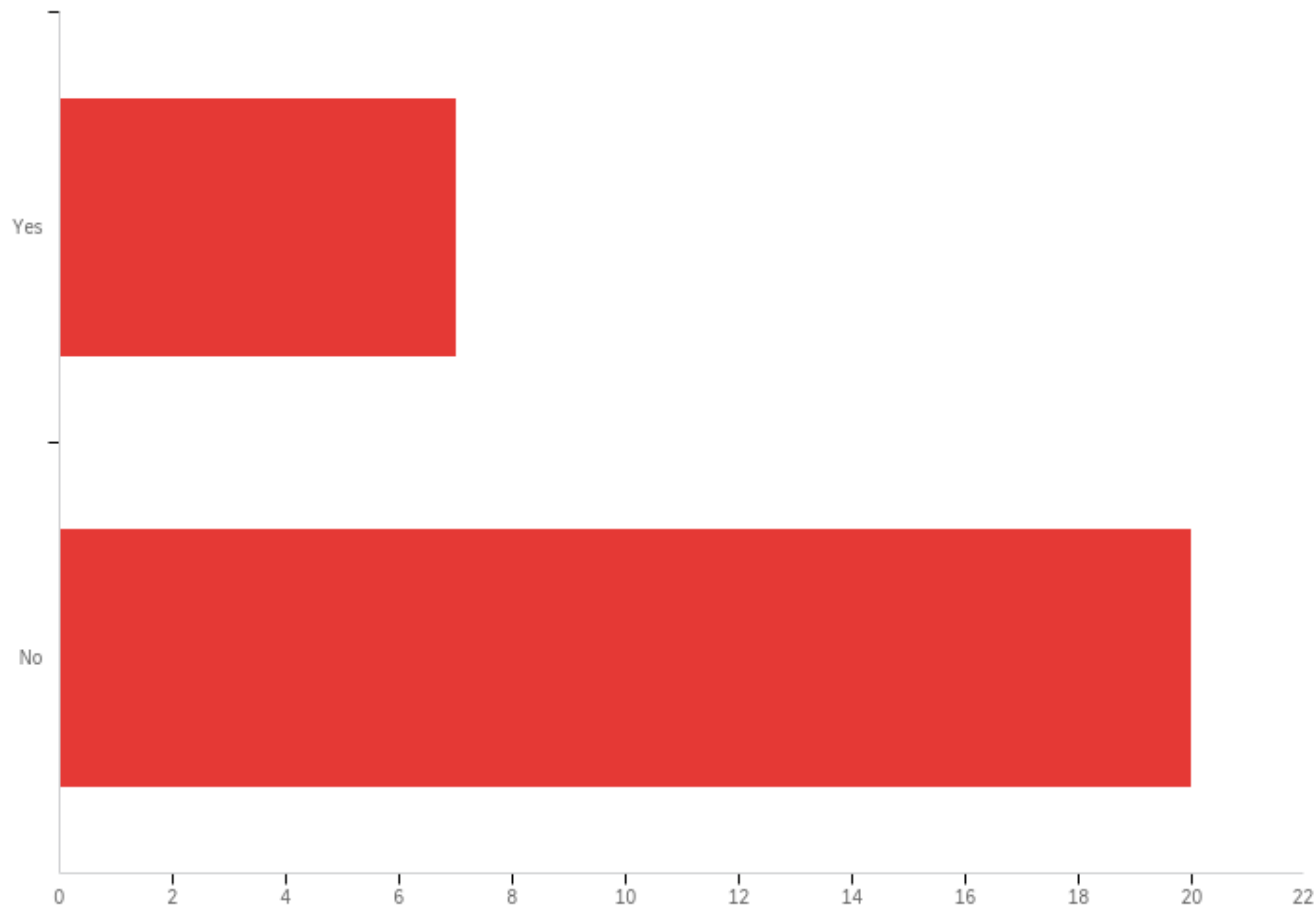
14 - If a durable medical equipment company is having trouble providing repair services, do you have alternative options?

Answer	%	Count
Yes	16.67%	1
No	83.33%	5
Total	100%	6



15 - Are you currently utilizing home health services, such as therapies or skilled services?

Answer	%	Count
Yes <i>(see follow-up questions #17-19)</i>	25.93%	7
No <i>(see next 2 slides for follow-up question)</i>	74.07%	20
Total	100%	27



16 - What are the barriers in currently obtaining home health services for your child? *(Responses appear as entered by participant.)*

What are the barriers in currently obtaining home health services for your child?

Risks of catching the disease.

Not applicable; my son currently lives at a residential school.

None

No barriers. Very satisfied

Not comfortable allowing providers in my home due to virus

Don't want others in our home during pandemic although we could really use our home health aide hours!!!!

Coverage and available providers

this does not apply to my son

NA

We are not currently pursuing any speech/sound therapies for my son, but COVID would have made that impossible since close contact would be needed, as my son is profoundly deaf and severely deaf even with his hearing aids.

Receiving in home respite care. She will not wear a mask.

Availability of ABA therapists in Delaware

We are doing tele-health

16 - What are the barriers in currently obtaining home health services for your child? (continued) *(Responses appear as entered by participant.)*

What are the barriers in currently obtaining home health services for your child?

Her therapies through summer school will be via zoom for PT and OT - no in person therapy due to covid

None

I'm afraid of contracting, lack of funding, etc

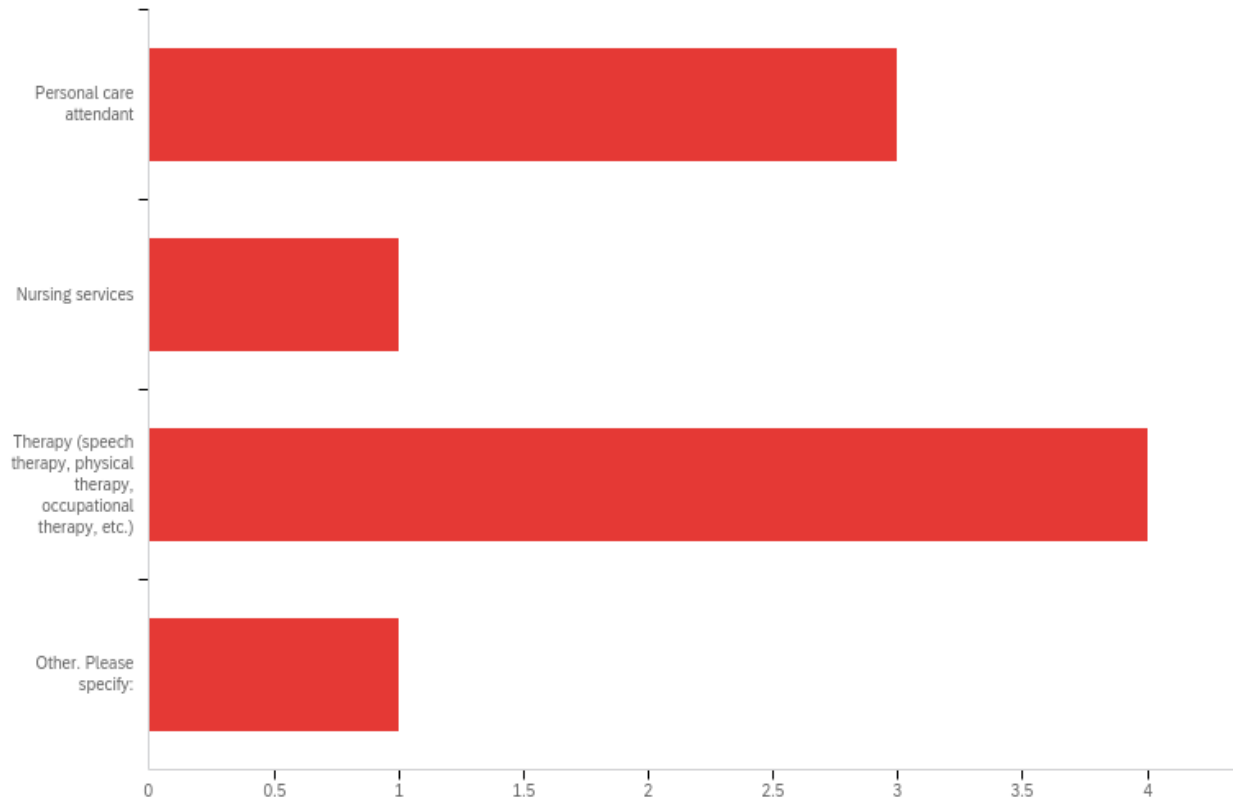
We don't currently have home health services ordered/prescribed for my son

not needed at this time

N/A

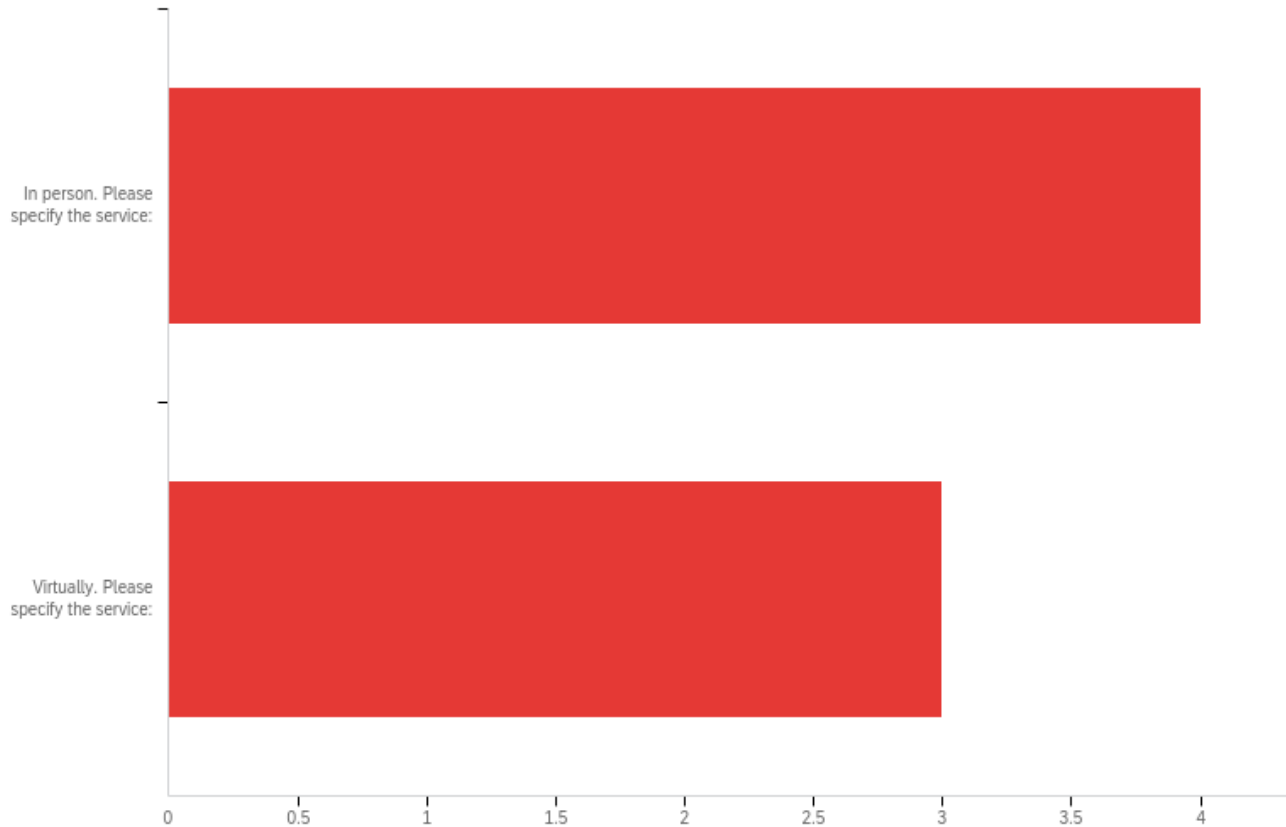
17 - Which services are you currently utilizing (check all that apply)?

Answer	%	Count
Personal care attendant	33.33%	3
Nursing services	11.11%	1
Therapy (speech therapy, physical therapy, occupational therapy, etc.)	44.44%	4
Other. Please specify:	11.11%	1
Total	100%	9



18 - How are you currently utilizing these services (check all that apply)?

Answer	%	Count
In person. Please specify the service: <i>(see next slide for responses)</i>	57.14%	4
Virtually. Please specify the service: <i>(see next slide for responses)</i>	42.86%	3
Total	100%	7



18 - How are you currently utilizing these services (check all that apply)?
(continued) *(Responses appear as entered by participant.)*

In person. Please specify the service:

OT, HHA

Nursing

home health aide

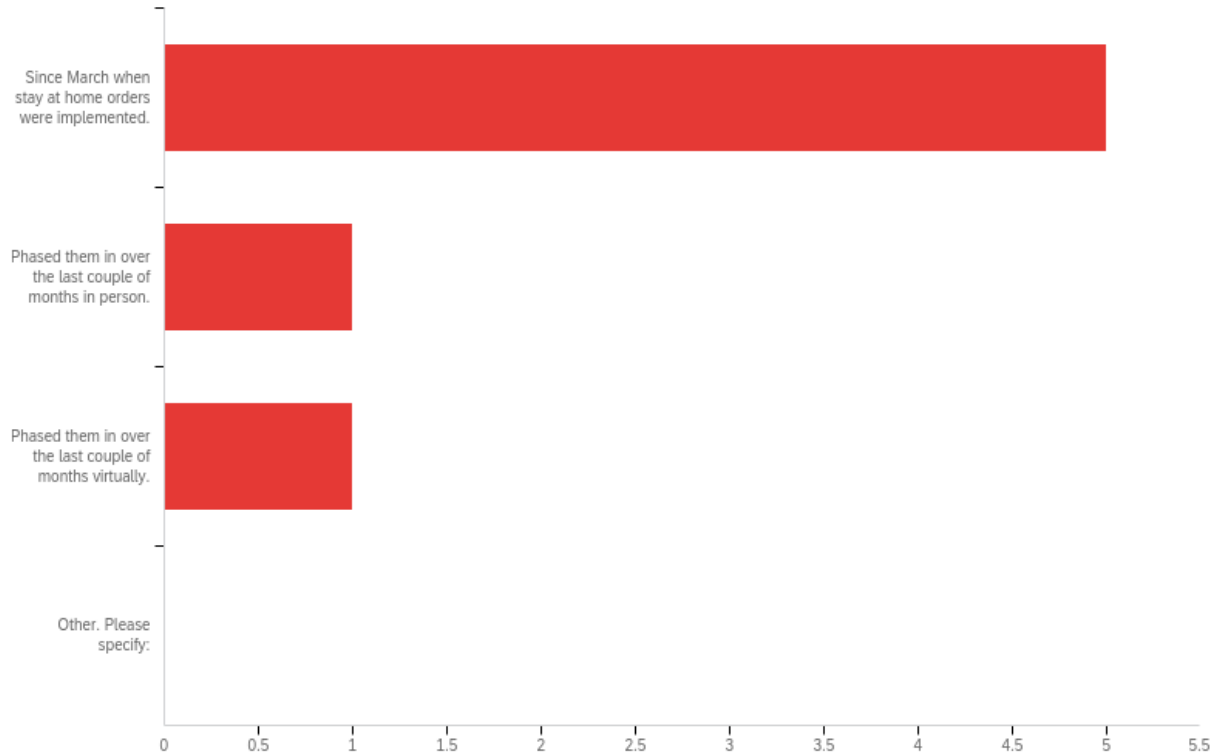
Virtually. Please specify the service:

Zoom

Speech and OT

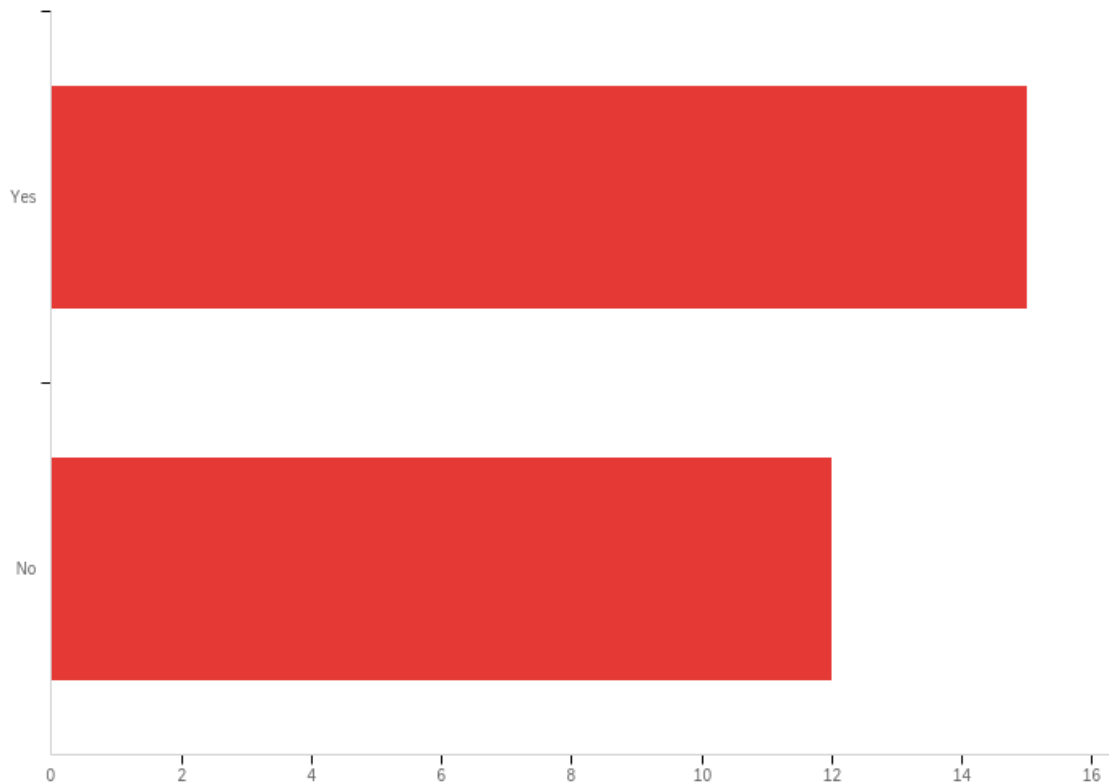
19 - How long have you been utilizing these services?

Answer	%	Count
Since March when stay at home orders were implemented.	71.43%	5
Phased them in over the last couple of months in person.	14.29%	1
Phased them in over the last couple of months virtually.	14.29%	1
Other. Please specify:	0.00%	0
Total	100%	7



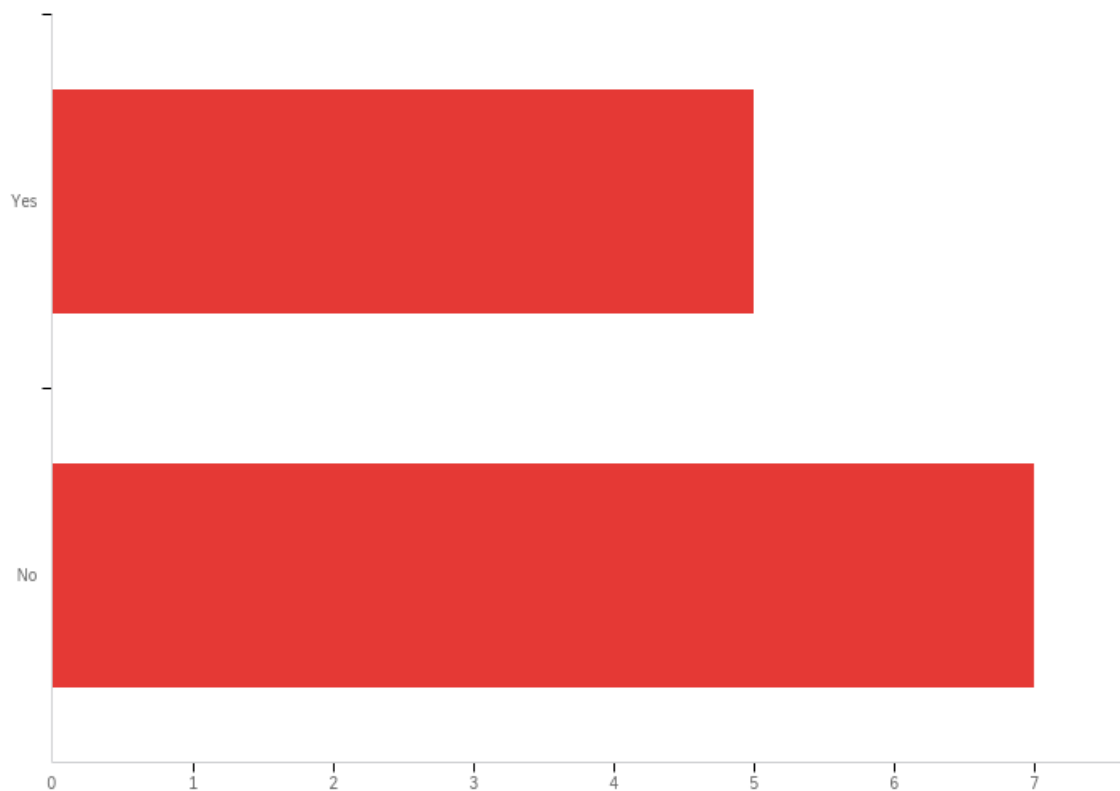
20 - Has your medical provider made contact with you to field any concerns you may have?

Answer	%	Count
Yes	55.56%	15
No <i>(see next slide for follow-up question)</i>	44.44%	12
Total	100%	27



21 - Would you like to hear from your medical provider?

Answer	%	Count
Yes	41.67%	5
No	58.33%	7
Total	100%	12



22 - What services/supports are you, as a caregiver, utilizing to take care of yourself?

(Responses appear as entered by participant.)

What services/supports are you, as a caregiver, utilizing to take care of yourself?

Trying to remain calm and meditate as needed

helping with school work

My sons respite, his grandmother and uncle have been able to take him overnight for a few/couple nights so We can Both go and have alone time and decompress/de stress from each other.

I also have started individual therapy for myself teleheaph wise

None unfortunately

telemedicine urgent care & primary care services

Wearing Masks

Reading online articles regarding strategies for coping

Consulting professionals

Family support

none.
even though my child is getting home health aide services, it is beyond the scope of services he needs. my child exhibits aggressive and disruptive behaviors, and it is taking a toll on everyone. you have no way to go for help with those.

None

In home respite care to work and occasional break.

22 - What services/supports are you, as a caregiver, utilizing to take care of yourself? (continued)

(Responses appear as entered by participant.)

What services/supports are you, as a caregiver, utilizing to take care of yourself?

Nursing for my child helps with that

None

Frequent outdoor activities while social distancing, and accepting my limitations regarding what I could do during remote/online learning since I am not fluent in ASL.

None are offered... are grants being given to help?

personal time, family support

i am maintaining my preventive and specialist visits via telehealth or in person

None

not getting time

Family, school (HMS School for Cerebral Palsy)

None

Family and individual counseling and some medical attention

None. Very happy content.

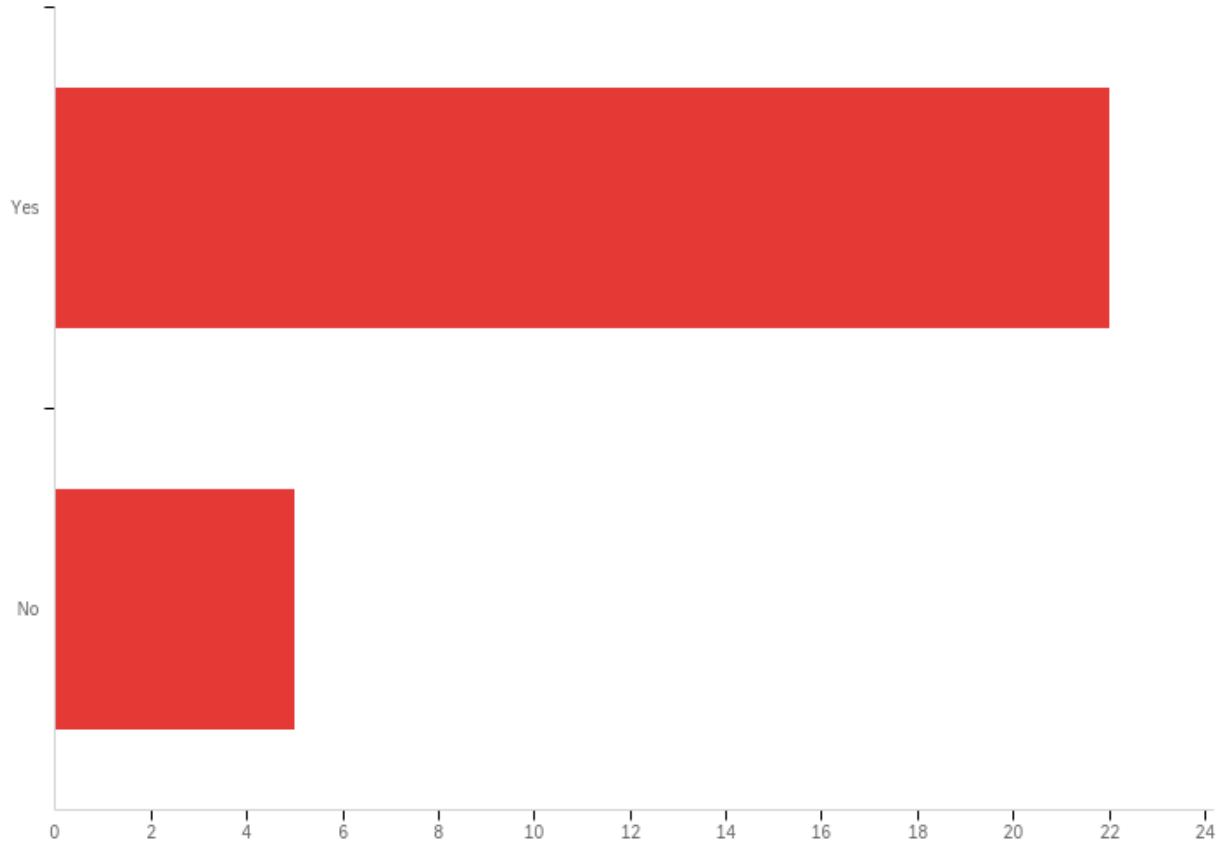
None

I am avoiding all unnecessary In-person services, and using Telemedicine where possible.

Most things.

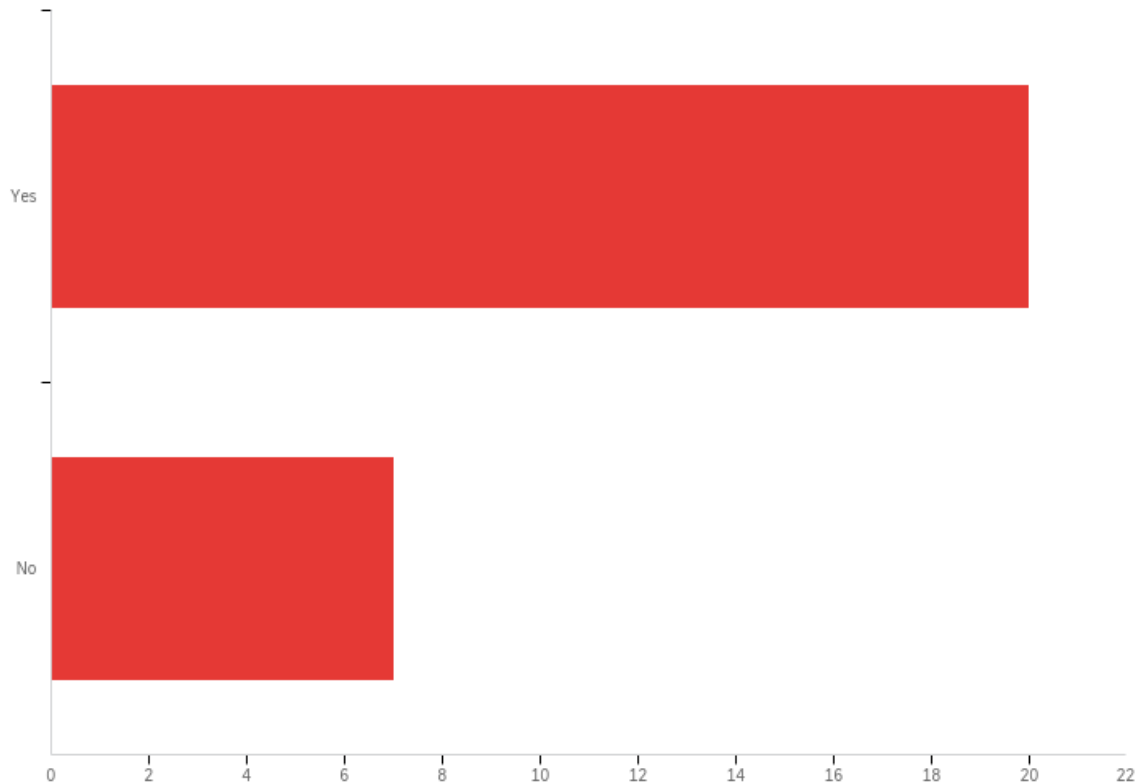
23 - Has your child been happy at home while under stay at home orders?

Answer	%	Count
Yes	81.48%	22
No	18.52%	5
Total	100%	27



24 - Do you notice any stressors that have come up for you and/or your child with special healthcare needs while staying at home?

Answer	%	Count
Yes <i>(see next 2 slides for follow-up question)</i>	74.07%	20
No	25.93%	7
Total	100%	27



25 - Please describe the stressors you have noticed for you and/or your child.

(Responses appear as entered by participant.)

Please describe the stressors you have noticed for you and/or your child.

See other people out without facemasks and not social distancing

He misses his teachers and other adults to talk to.

Lack of socialization, fear of infection

bored, worried, afraid, etc

Increased attention problems

Unable to see friends, go to usual places to play or exercise

Physical rehabilitation training

extreme aggression and disruption coupled with sleeplessness.

My son now has a low growl...when he is disappointed.

more anxiety about not being able to go anywhere. not stop repeating. Becomes agitated at times when she can't have her way.

Boredom and lack of stimulation

25 - Please describe the stressors you have noticed for you and/or your child. (continued)

(Responses appear as entered by participant.)

Please describe the stressors you have noticed for you and/or your child.

A lack of interaction with Deaf peers/mentors who use ASL. Zoom is great, but doesn't meet that need sufficiently, and again, I'm not fluent in ASL (although I'm learning more and more every day).

Not being able to leave our property bc he can't tolerate masks, or understand social distancing. He also mouths everything and has pica— So is at risk

since he has ASD, he is really enjoying the decrease in social demands, and he also gets into a habit really quickly so I'm afraid he will never want to leave the house again now. We worked on that for other reasons when he was younger, and got it to a good place, But now he's been home for 3 months straight already.

Regression, social skills

not having time for self-care, lot of roles playing at the same time

He seems bored and since he is not verbal, I can't tell if some of his verbalizations or physical or emotional. My stressors is needing to be his therapist and teacher and keeping him occupied while trying to work., along with his sisters.

Difficulty finding enough to keep my child entertained and engaged at home. Delays and cancellations of medical appointments.

Bored, sibling rivalry

Alone time. Eating more than usual. Not always paying attention to bolus or not.

26 - Have you accessed any of the following services/supports to relieve some of the stressors (check all that apply)?

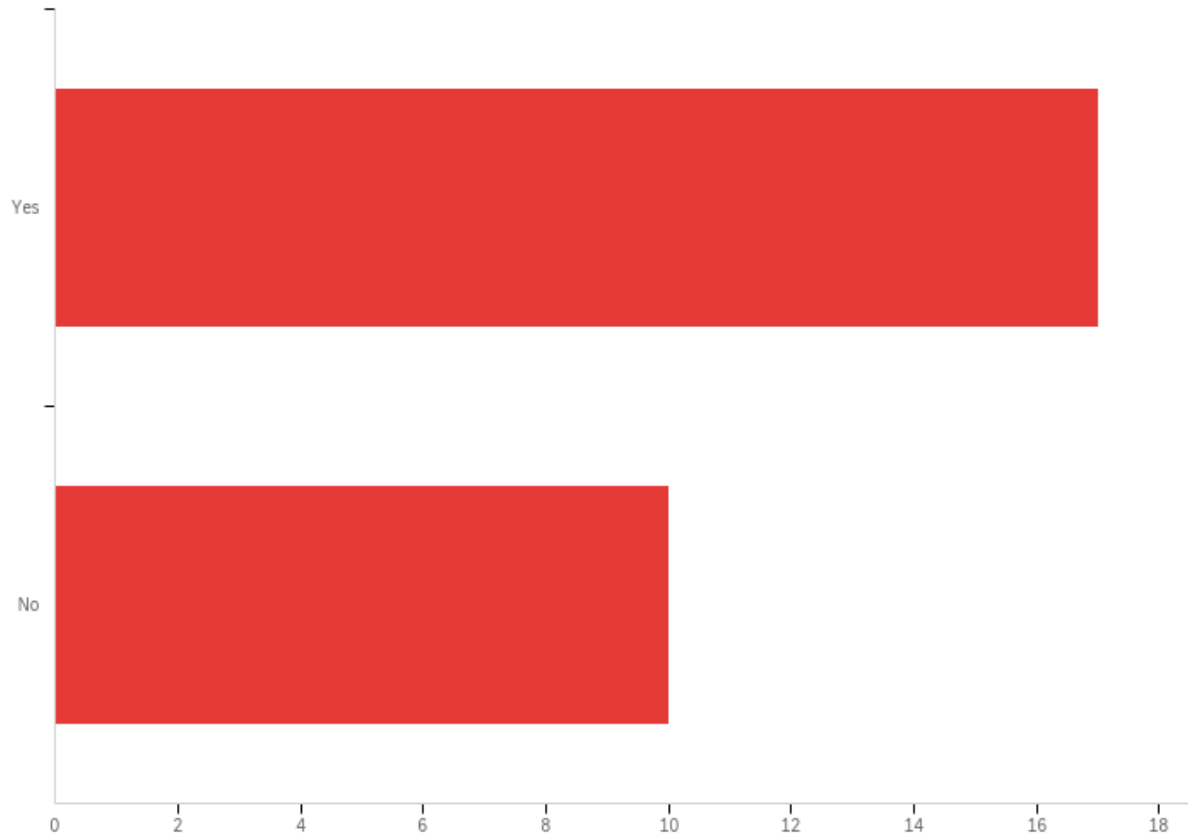
Answer	%	Count
State agency services/supports. Please specify: <i>(see below)</i>	16.67%	3
Non-profit organization services/supports. Please specify:	0%	0
Healthcare organization services/supports. Please specify:	0%	0
Other. Please specify: <i>(see below)</i>	11.11%	2
Have not accessed any services to help with stressors.	72.22%	13
Total	100%	18

State agency services/supports. Please specify:
Respite care
respite
delcode.delaware.gov

Other. Please specify:
Family counseling
ABA Analyst

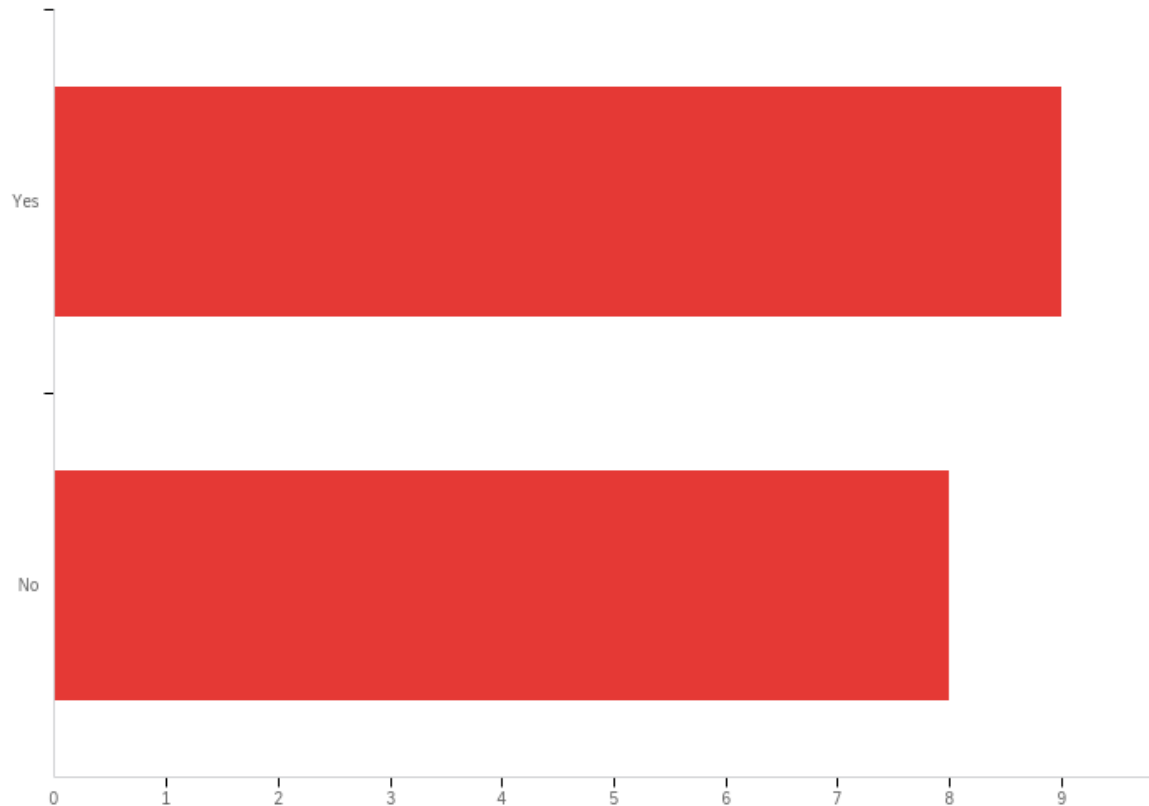
27 - Are you continuing to work from home as Delaware phases out from stay at home orders ?

Answer	%	Count
Yes <i>(see follow-up questions #28-30)</i>	62.96%	17
No	37.04%	10
Total	100%	27



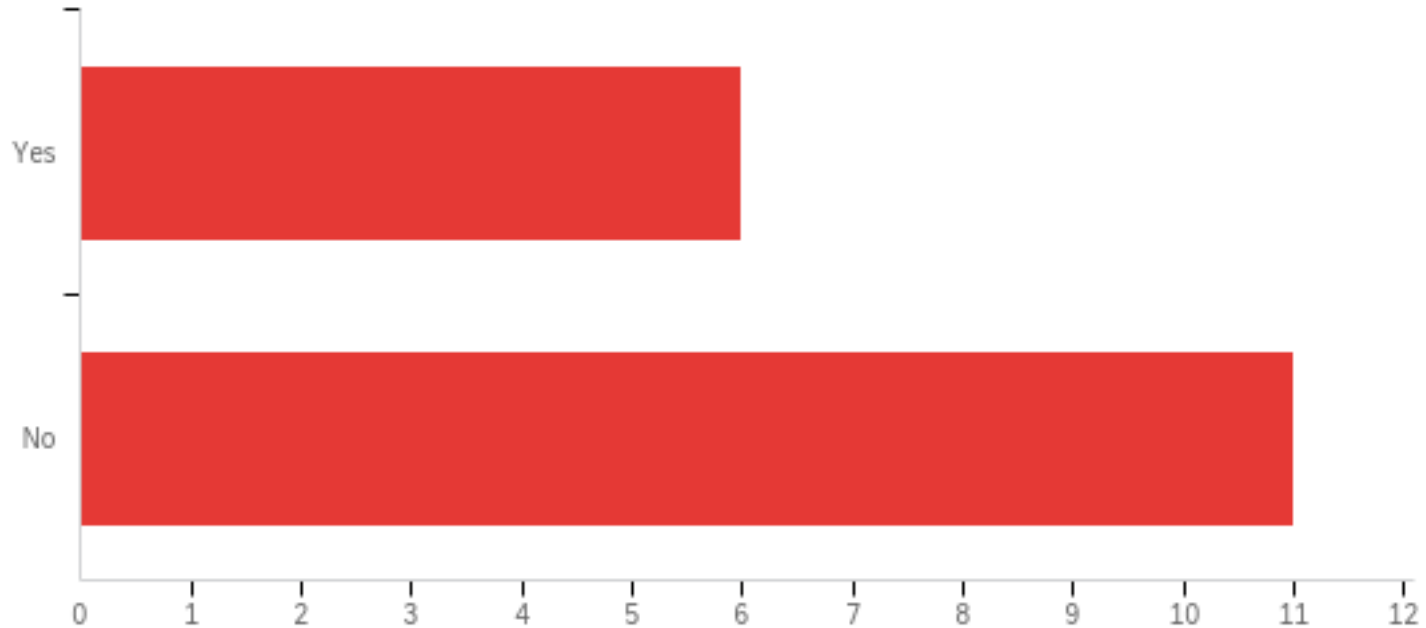
28 - Do you currently need additional support while you work from home?

Answer	%	Count
Yes	52.94%	9
No	47.06%	8
Total	100%	17



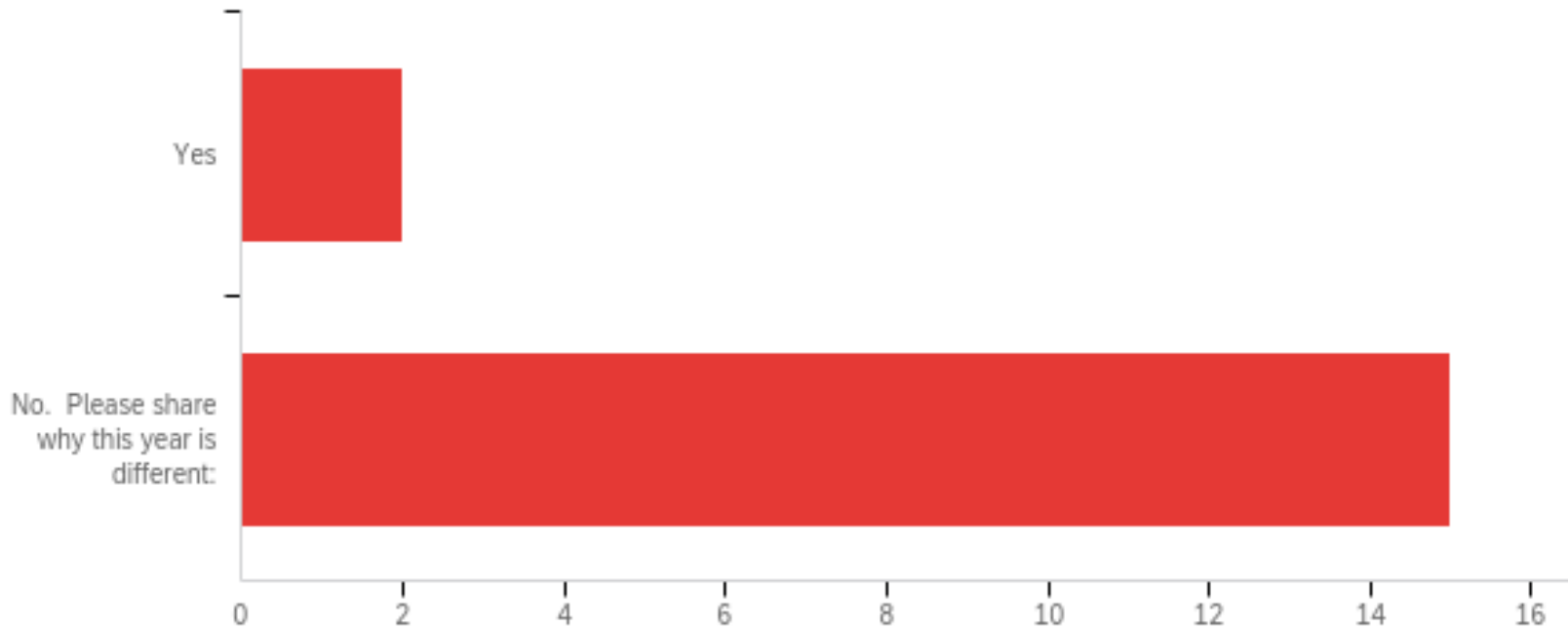
29 - In a typical summer, would your child participate in a summer camp?

Answer	%	Count
Yes	35.29%	6
No	64.71%	11
Total	100%	17



30 - Have you signed your child up for any virtual camps?

Answer	%	Count
Yes	11.76%	2
No. Please share why this year is different: <i>(see next slide for responses)</i>	88.24%	15
Total	100%	17



30 - Have you signed your child up for any virtual camps?

(Responses appear as entered by participant.)

No. Please specify: Text

Unaware of such

My child is attending virtual ESY

His ESY is very comprehensive.

aac summer camp

not really one that would work right now

No camps will accept a child who isn't toilet trained. He normally is in school during the summer

He does not need it.

She would not participate in virtual anything.

my child is non verbal and very hyperactive. not a candidate for virtual instruction.

Too much screen time

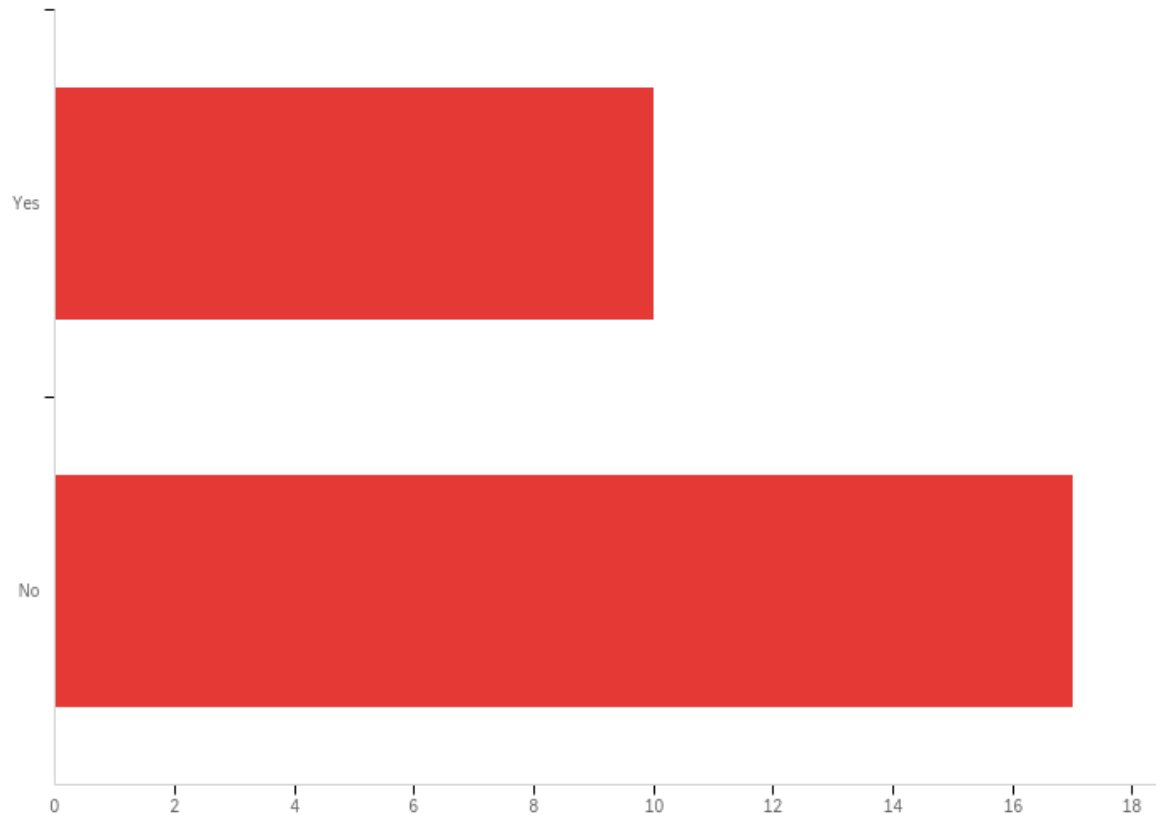
N/A

My child does not attend camp

N/A

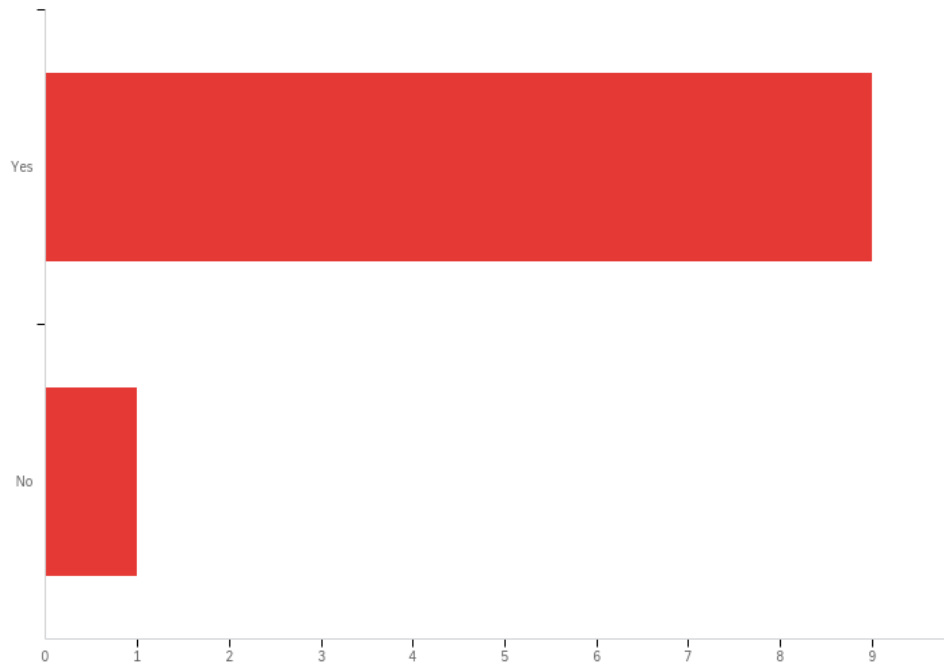
31 - Did your child require medical attention during stay at home orders?

Answer	%	Count
Yes	37.04%	10
No	62.96%	17
Total	100%	27



32 - Did you choose to access needed services?

Answer	%	Count
Yes	90.00%	9
No <i>(see response to follow-up question below)</i>	10.00%	1
Total	100%	10



33 - What concerns did you have about accessing services?

(Responses appear as entered by participant.)

What concerns did you have about accessing services?

Exposing my child to COVID and docs not seeing patients or returning calls.

34 - What concerns you the most as Delaware phases out from stay at home orders and begins to re-open? *(Responses appear as entered by participant.)*

What concerns you the most as Delaware phases out from stay at home orders and begins to re-open?

That it is happening too quickly and people are not wearing masks and social distancing

staying healthy

Catching the virus

That we will reopen too quickly and myself or my child will become infected

the coming of the second wave

Increased chance of infection

We are in new jersey

COVID-19

That we are re opening too soon.

looking forward for my son to get some services that he requires.

Educating my son to keep a mask on, social distancing, and sanitizing with hand sanitizer on a regular basis.

My daughters safety in coming in contact with others and not understanding the hazardous conditions when interacting with people she doesn't live with. Just her total lack of cognitive ability to understand the pandemic.

School reopening
Keeping her safe

34 - What concerns you the most as Delaware phases out from stay at home orders and begins to re-open? (continued) *(Responses appear as entered by participant.)*

What concerns you the most as Delaware phases out from stay at home orders and begins to re-open?

None

I think the state is handling the reopening in a safe and reasonable manner; my primary concern is what will happen in the fall with school since my son requires very specific instruction in ASL that I can't provide. I think my son's school basically did the best it could given the unexpected situation in March, but much more consideration is needed for all kids if typical instruction can't be offered in the fall, and especially for students like my son who have a very specific IEP.

No cleaning or dose decking protocols are being required. No plan for keeping our persons with developmental disabilities are in place.

is my child with several special needs safe out there???

Employers having enough PPE and enforcing safe practices: social distancing, cleaning the facilities, mask wearing, etc.

Surge of infection, contracting covid

safety and spread of virus

Increased numbers of infections

People becoming less vigilant with face mask and social distancing recommendations putting us at risk for a relapse of the virus

Increased Covid19 cases

Him being exposed we are still limiting our expose to people places.

34 - What concerns you the most as Delaware phases out from stay at home orders and begins to re-open? (continued) *(Responses appear as entered by participant.)*

What concerns you the most as Delaware phases out from stay at home orders and begins to re-open?

None

First, a couple of clarifications of previous answers: Since I am retired, the working-from-home question was irrelevant to me. Second, I based my answers on my son's adjustments to arrangements in the COVID era upon both the reports I have heard of how he is doing and on what I have observed during our weekly Zoom meetings.

My primary concern is that premature opening of the state will result in a huge increase in the number of COVID cases.

My family's health.

35 - Is there anything else you would like to share about your/your family's experiences during the pandemic? *(Responses appear as entered by participant.)*

Is there anything else you would like to share about your/your family's experiences during the pandemic?

We have adapted quite well to going nowhere but the grocery store every other week.

not at this time

Nope not at this time

No

No, Thanks

children with autism are finding it difficult to cope with online classes

Telehealth was frustrating because It is hard to treat some of her issues without being seen in person

No

No

it's been isolating, dealing with the aggression and disruption constantly

None

As a family we have tried to be safe as possible and not expose our daughter to unnecessary risks.

No

No

Nothing medical, just the limitations with school and remote/online instruction as noted above.

35 - Is there anything else you would like to share about your/your family's experiences during the pandemic? (continued) *(Responses appear as entered by participant.)*

Is there anything else you would like to share about your/your family's experiences during the pandemic?

It's been awful and we are terrified of school in the fall. The work group is not considering our most vulnerable populations. Students with severe disabilities are getting short changed and not supported and no one cares

Its so hard for everyone....for so many reasons!

not at this time

Schools should have provided computers etc, so kids wouldn't fall behind

it was fearful at the beginning but slowly we got our rhythm to deal with everyday struggles

Just tough to have the whole family at home and take care of everyone's needs. Nemours has been fabulous.

No

Was a little hard to access school work for 4 children on a "1 per household device"

No

No

I think the survey has covered everything.

Everything has been covered in this survey.