

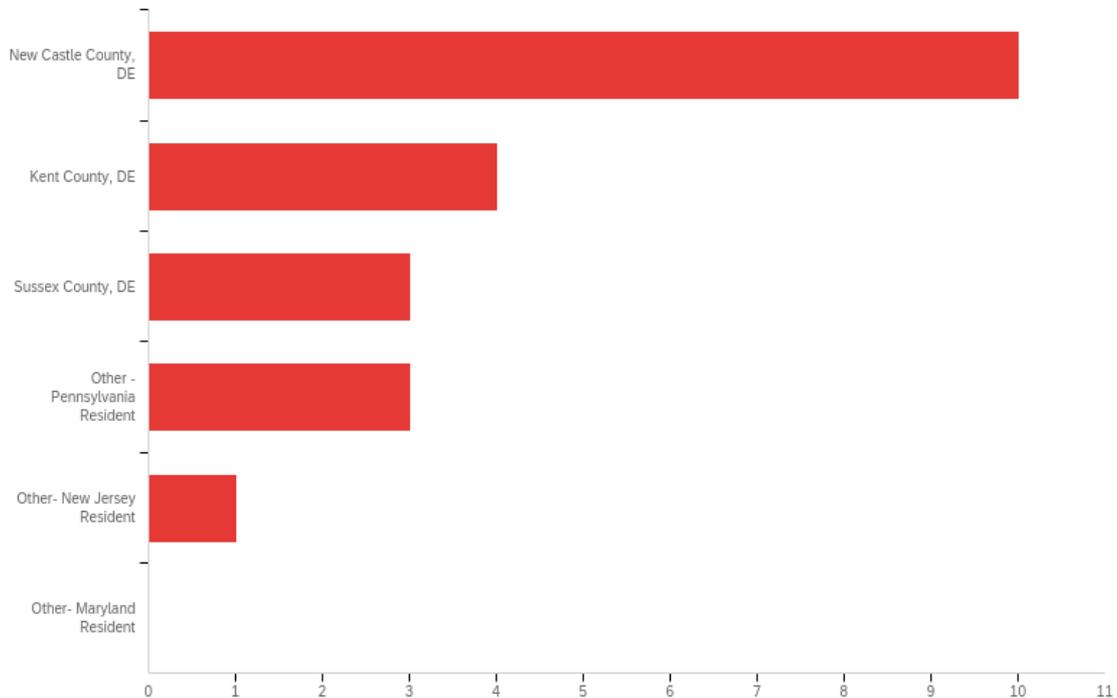
Initial Report

# Coronavirus/COVID-19 Pandemic Needs

Families Know Best - March 2020

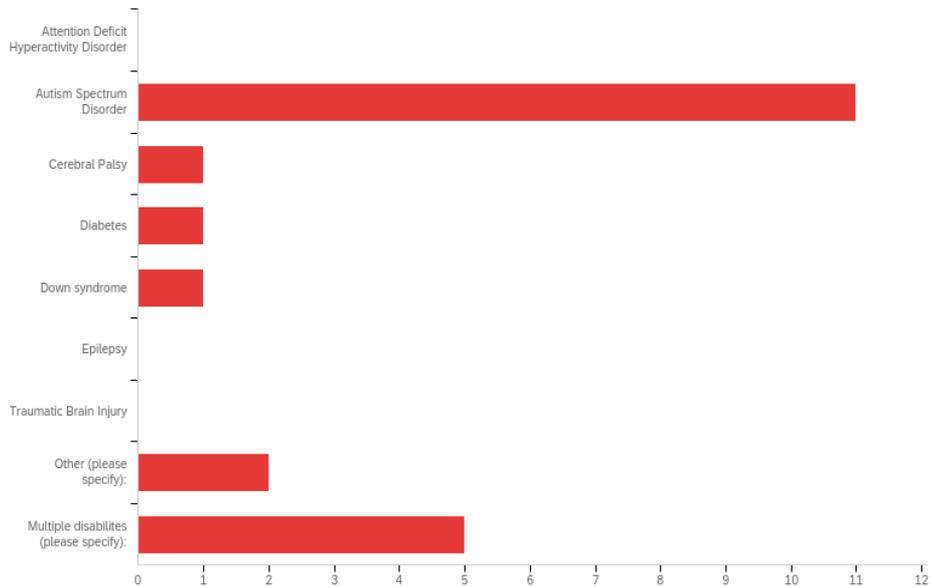
# 1 - What is your place of residence?

Answer	%	Count
New Castle County, DE	47.62%	10
Kent County, DE	19.05%	4
Sussex County, DE	14.29%	3
Other - Pennsylvania Resident	14.29%	3
Other- New Jersey Resident	4.76%	1
Other- Maryland Resident	0.00%	0
Total	100%	21



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

Answer	%	Count
Attention Deficit Hyperactivity Disorder	0.00%	0
Autism Spectrum Disorder	52.38%	11
Cerebral Palsy	4.76%	1
Diabetes	4.76%	1
Down syndrome	4.76%	1
Epilepsy	0.00%	0
Traumatic Brain Injury	0.00%	0
Other (please specify): <i>(see next slide for responses)</i>	9.52%	2
Multiple disabilities (please specify): <i>(see next slide for responses)</i>	23.81%	5
<b>Total</b>	<b>100%</b>	<b>21</b>



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

*(Responses appear as entered by participant.)*

### Other. Please specify:

Cdk13

mild intellectual disability

### Multiple disabilities . Please specify:

CP, epilepsy

genetic dx, cp, seizure disorder, etc.

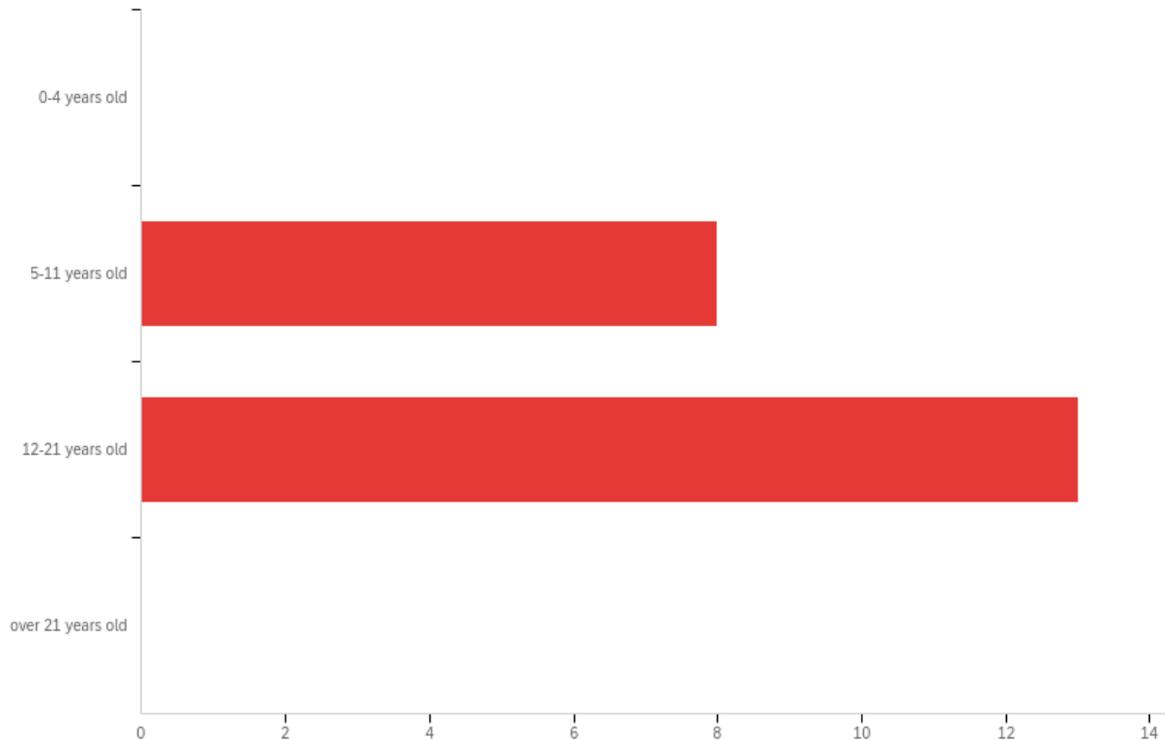
Epilepsy and ADHD

Rett Syndrome

Cerebral palsy , epilepsy, dev delay

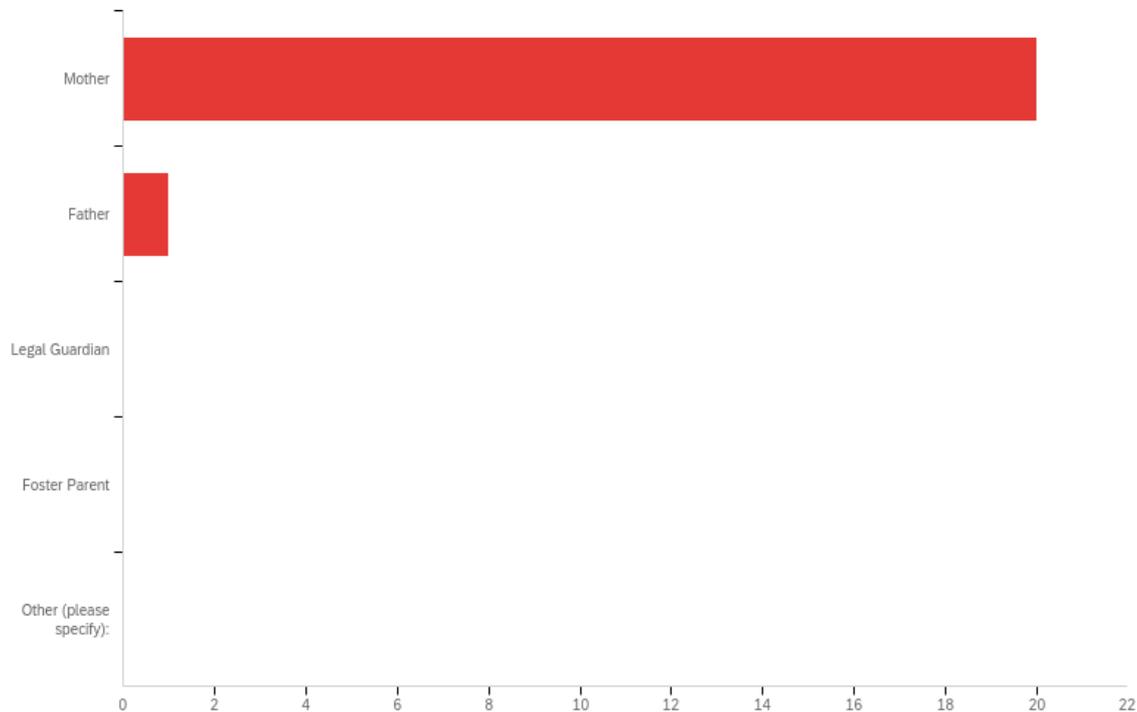
### 3 - What is the age of your child?

Answer	%	Count
0-4 years old	0.00%	0
5-11 years old	38.10%	8
12-21 years old	61.90%	13
over 21 years old	0.00%	0
Total	100%	21



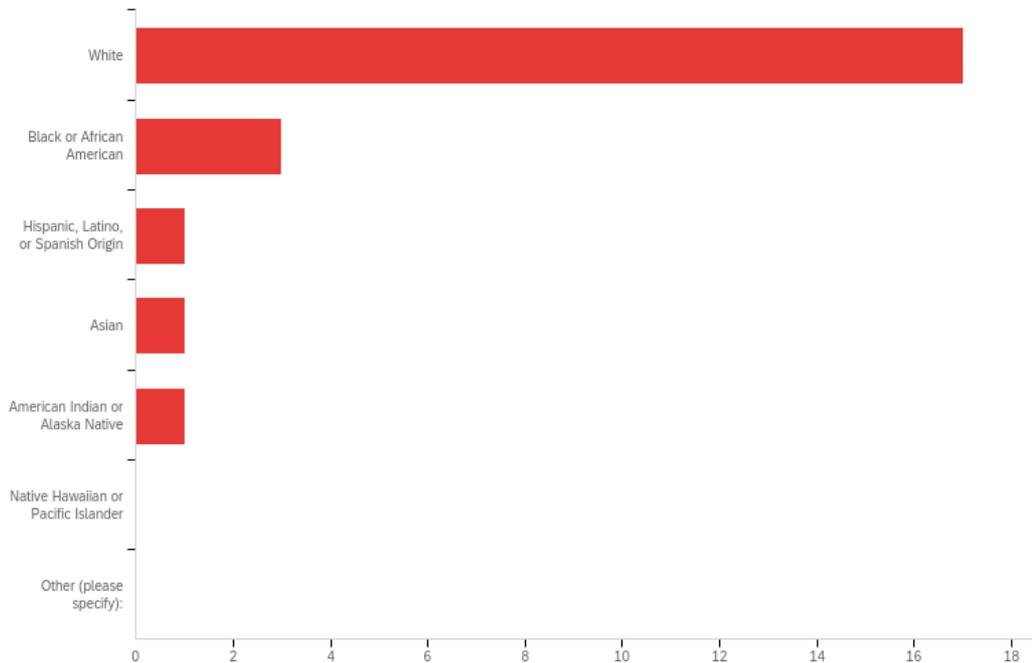
#### 4 - Please identify yourself.

Answer	%	Count
Mother	95.24%	20
Father	4.76%	1
Legal Guardian	0.00%	0
Foster Parent	0.00%	0
Other (please specify):	0.00%	0
Total	100%	21



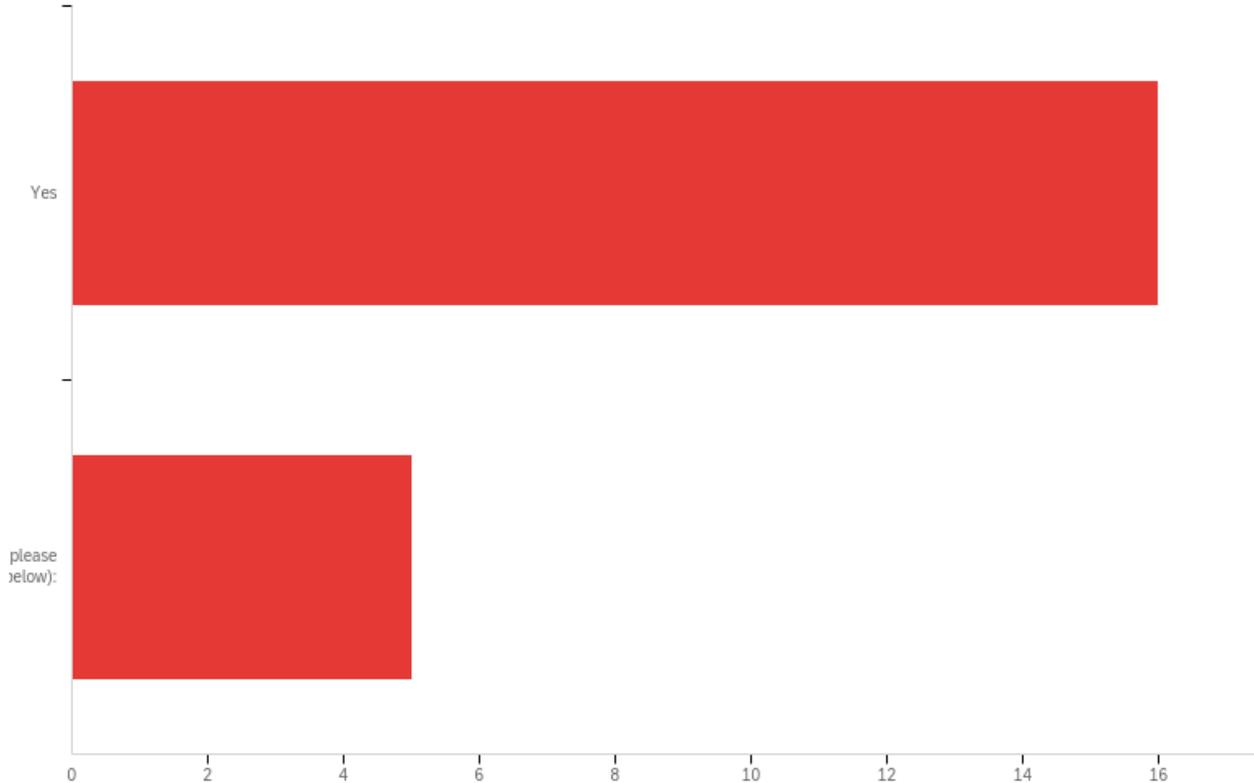
## 5 - What is your race/ethnicity? (Check all that apply)

Answer	%	Count
White	73.91%	17
Black or African American	13.04%	3
Hispanic, Latino, or Spanish Origin	4.35%	1
Asian	4.35%	1
American Indian or Alaska Native	4.35%	1
Native Hawaiian or Pacific Islander	0.00%	0
Other (please specify):	0.00%	0
<b>Total</b>	<b>100%</b>	<b>23</b>



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

Answer	%	Count
Yes	76.19%	16
No (please explain below): <i>(see next slide for responses)</i>	23.81%	5
Total	100%	21



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 below): - Text**

Still struggling to get services covered like home health aid, pharmacy drug coverage for nutrition and supplements, hypotherapy

Primary insurance never covers adequately. Coverage is sufficient only because of Medicaid as her secondary.

His ins's will not cover residential placement if he needs it

Doesn't cover DME, specialized formula

In network options are not adequate, and not enough in network providers

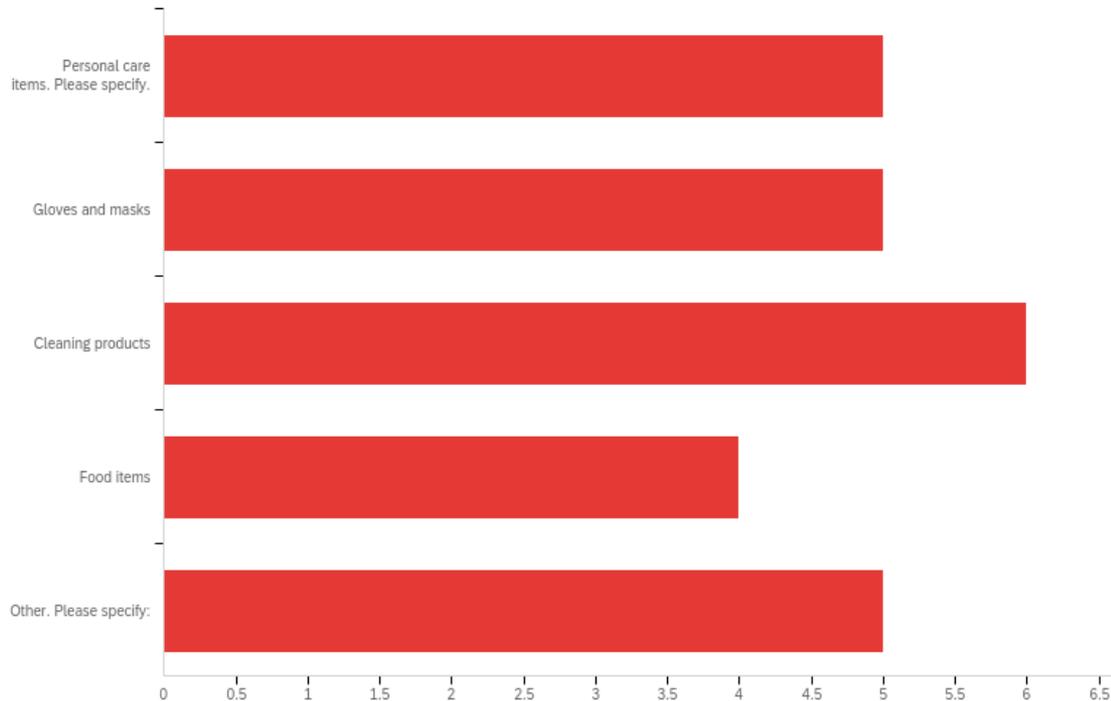
7 - Do you have enough supplies for your child's needs while staying at home for the next 6-8 weeks?

Answer	%	Count
Yes	52.38%	11
No <i>(see next slide for follow-up question)</i>	47.62%	10
Total	100%	21



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>	20.00%	5
Gloves and masks	20.00%	5
Cleaning products	24.00%	6
Food items	16.00%	4
Other. Please specify: <i>(see next slide for responses)</i>	20.00%	5
Total	100%	25



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.**

Pull ups

incontinence supplies

hand sanitizer, medications

have 1 month supply of diapers

Formula

**Other. Please specify:**

prescriptions

Medicines (we don't have gloves but hopefully won't need them, my sister bought us home made masks)

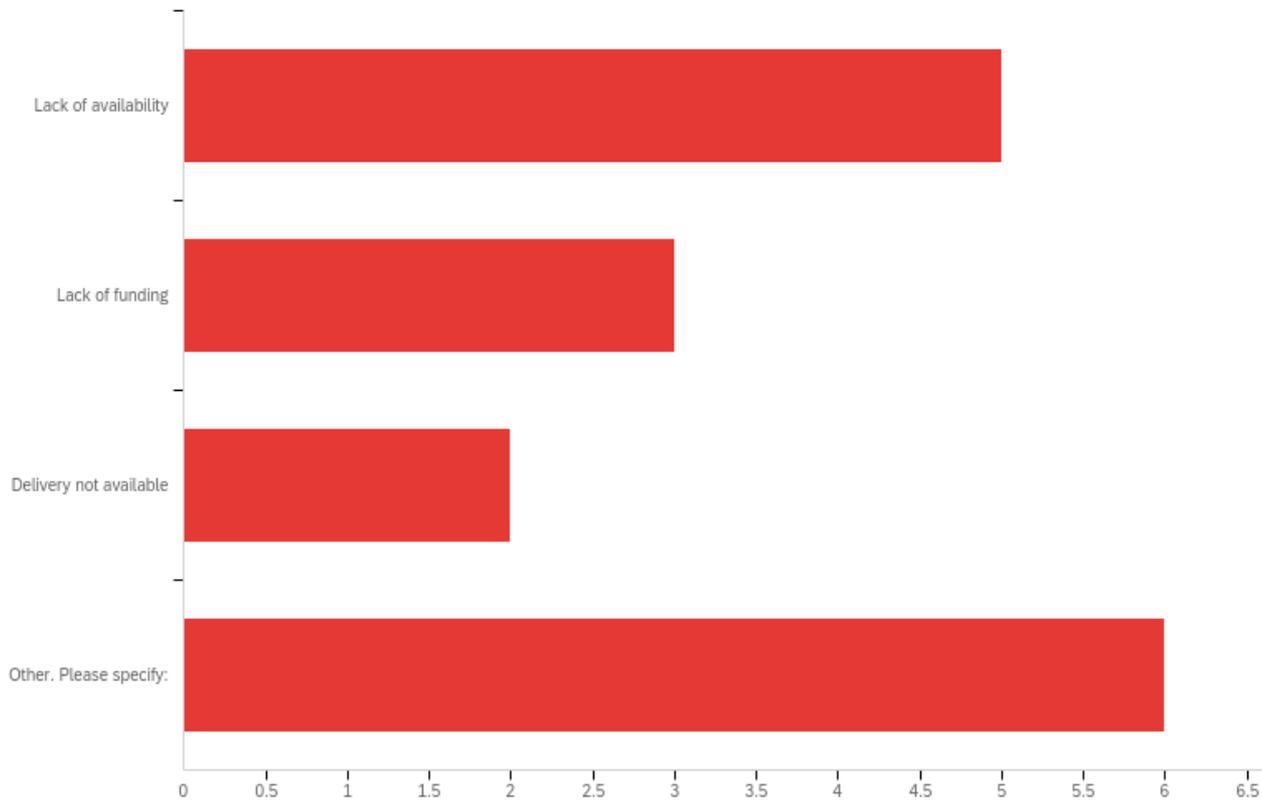
Elecare

Formula, wipes, diapers

Inhalers

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

Answer	%	Count
Lack of availability	31.25%	5
Lack of funding	18.75%	3
Delivery not available	12.50%	2
Other. Please specify: <i>(see next slide for responses)</i>	37.50%	6
Total	100%	16

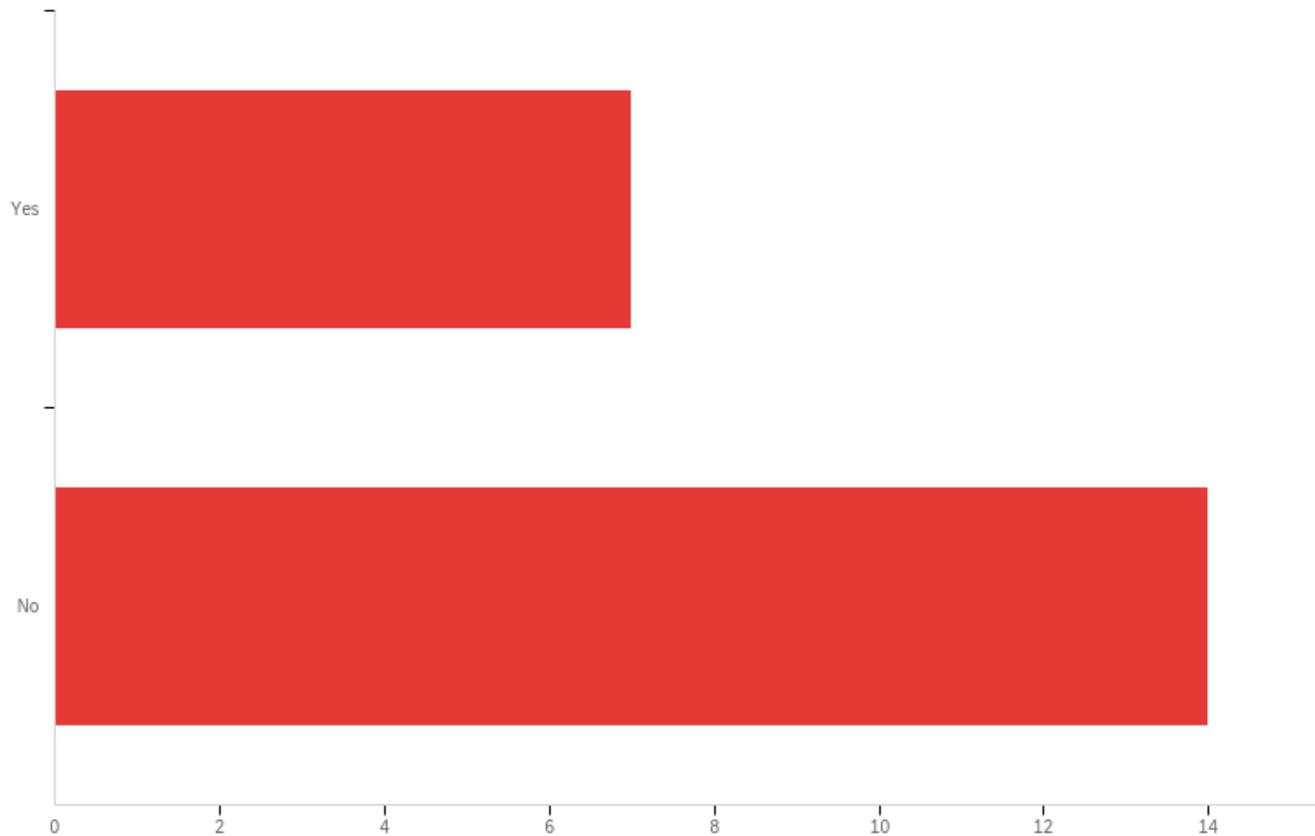


9 - What are the barriers in obtaining needed supplies (check all that apply): Other. Please specify. *(Responses appear as entered by participant.)*

Other. Please specify:
Insurance 30 day supply
delivery available once monthly
insurance snags
Can get to grocery once a week, prescriptions are for one month, have had trouble finding TP, masks, sanitizer (was out of town during the hoarding)
Insurance will only cover 30 day supplies. When child is home 24/7 more materials are used.....Can only get 30 day supplies
Meds can only be filled every 30 days

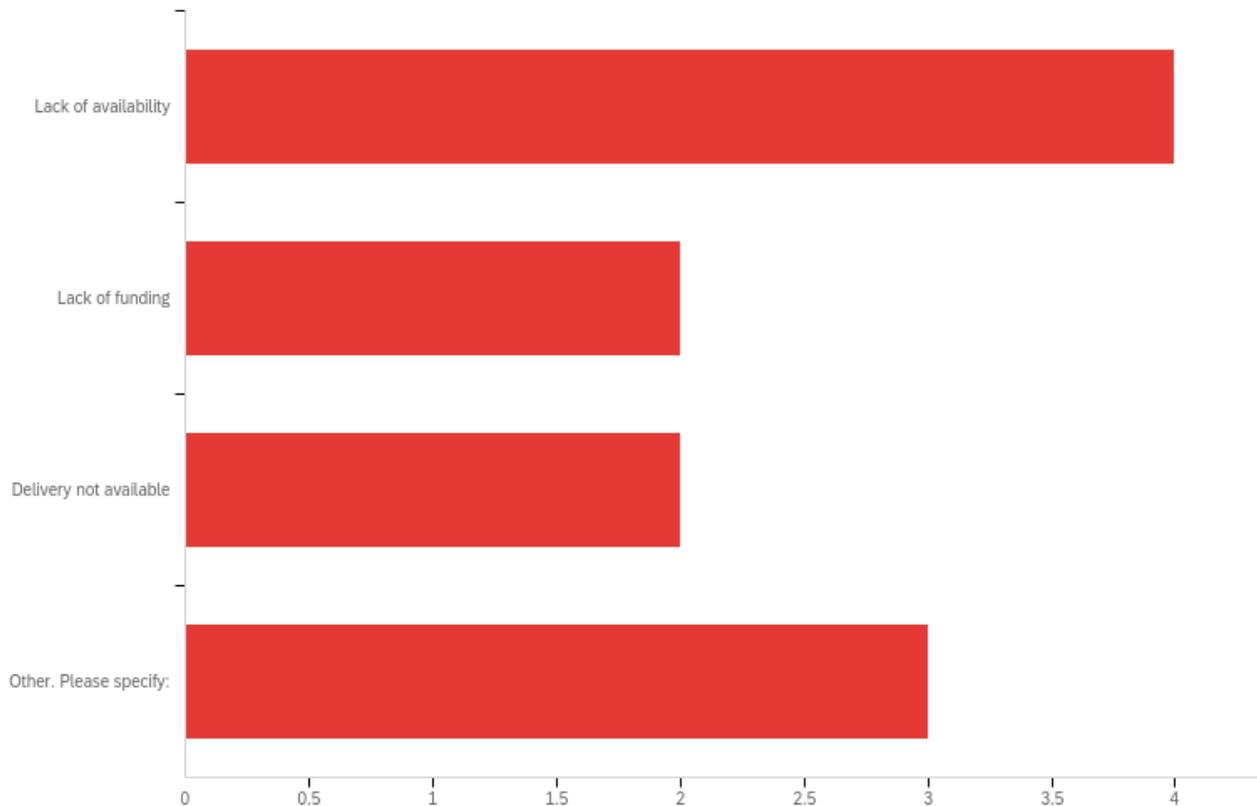
## 10 - Do you have any concerns with obtaining medications while Delaware is under a stay-at-home order?

Answer	%	Count
Yes <i>(see next slide for follow-up question)</i>	33.33%	7
No	66.67%	14
Total	100%	21



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

Answer	%	Count
Lack of availability	36.36%	4
Lack of funding	18.18%	2
Delivery not available	18.18%	2
Other. Please specify: <i>(see next slide for responses)</i>	27.27%	3
Total	100%	11



11 - Which of the following are your concerns with obtaining medications (check all that apply): Other. Please specify. *(Responses appear as entered by participant.)*

Other. Please specify:

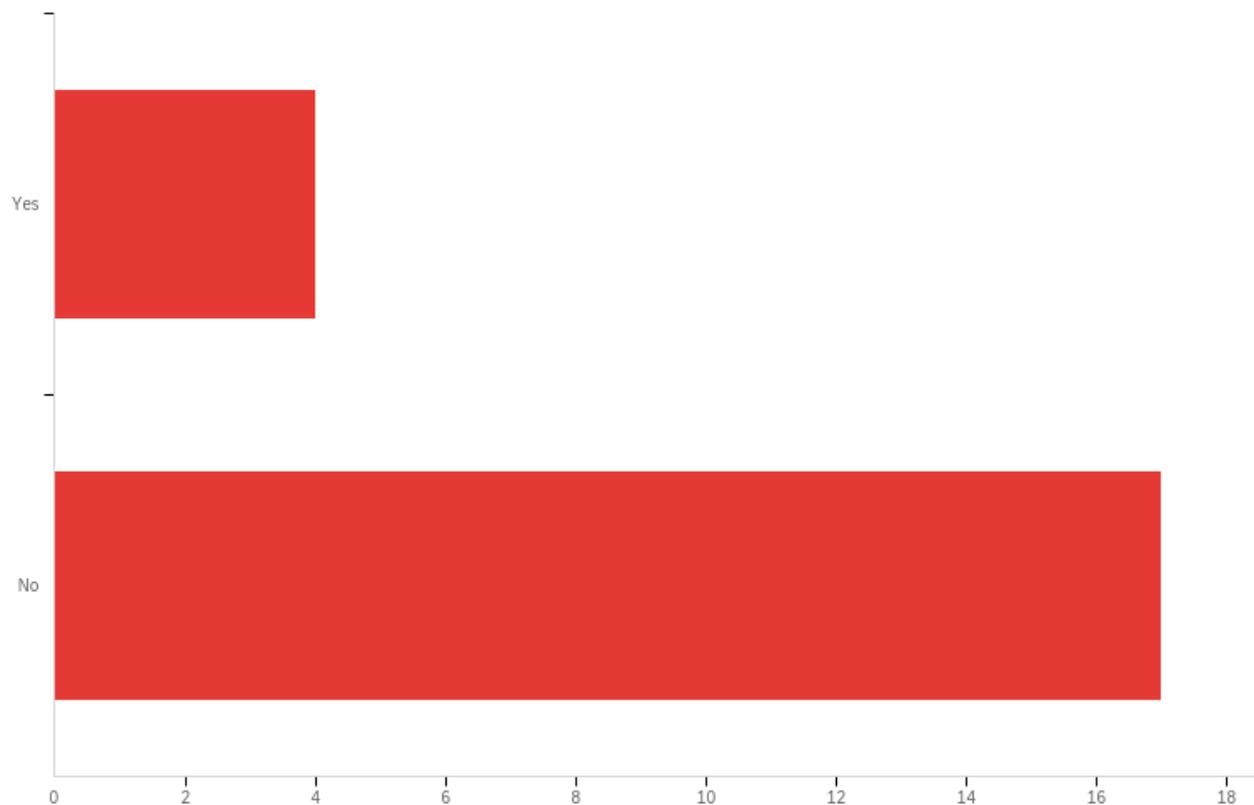
My son's doctor is not in Delaware - transportation

One script is controlled and one script we need to see doctor but appt was cancelled

Problems with the pharmacist/pharmacy

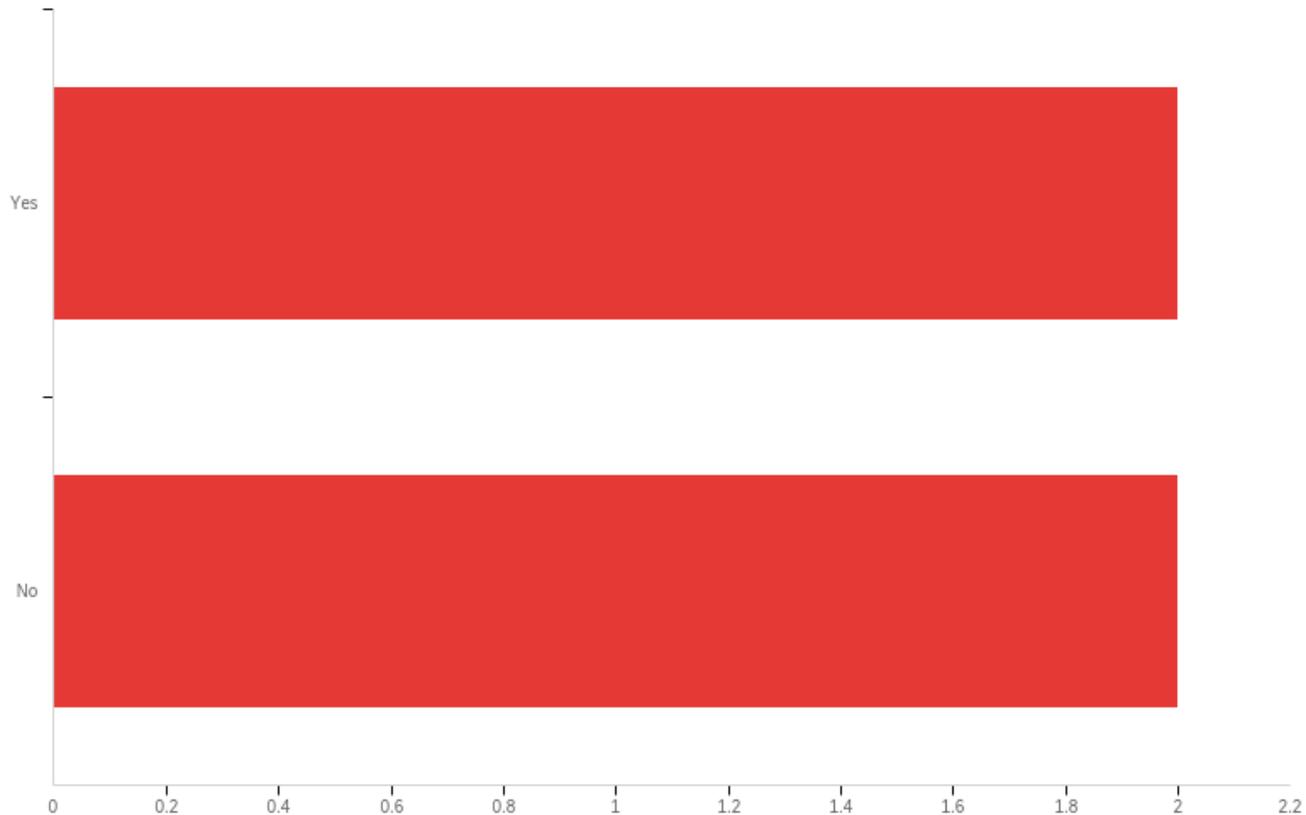
## 12 - Do you have concerns about ordering/repairing durable medical equipment?

Answer	%	Count
Yes <i>(see next slide for follow-up question)</i>	19.05%	4
No	80.95%	17
Total	100%	21



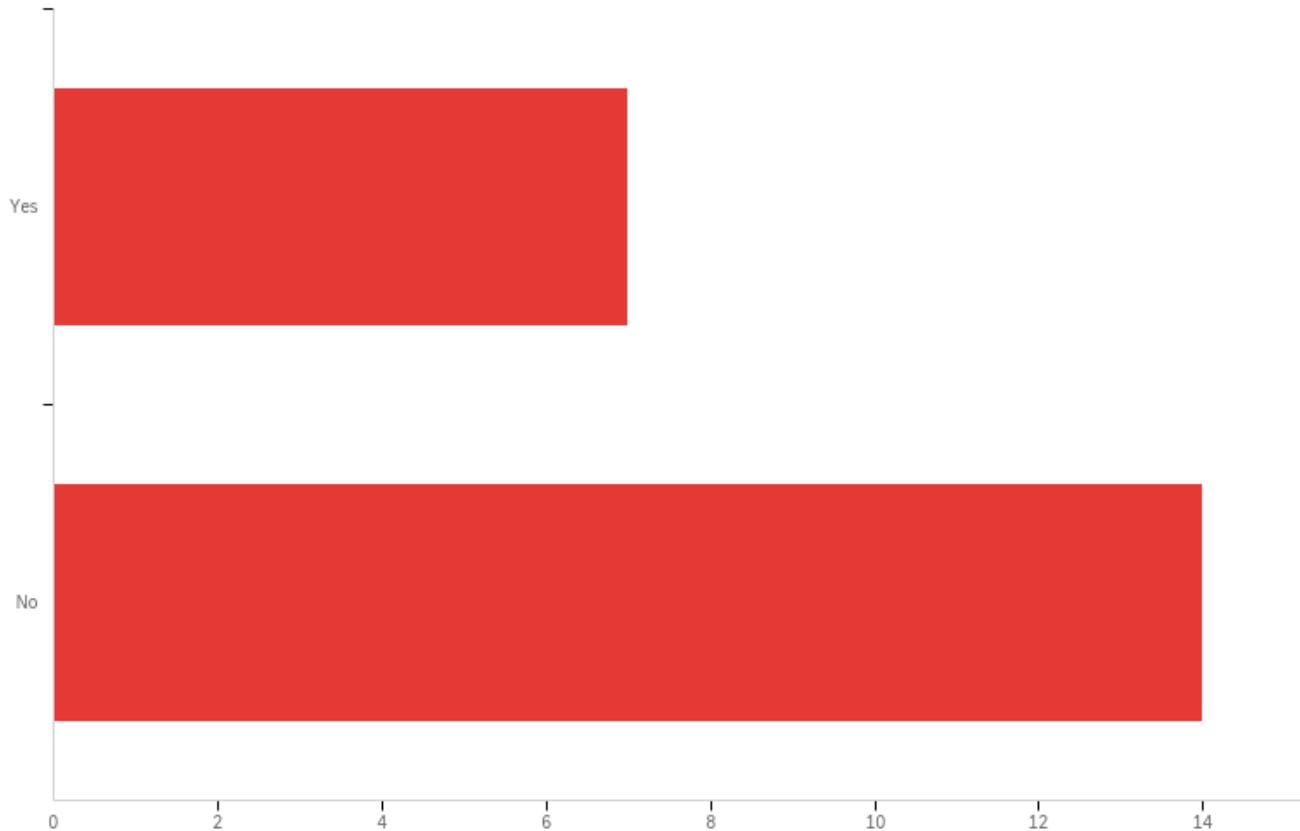
13 - If a durable medical equipment company is having trouble getting you supplies, do you have alternative options in dealing with low supplies?

Answer	%	Count
Yes	50.00%	2
No	50.00%	2
Total	100%	4



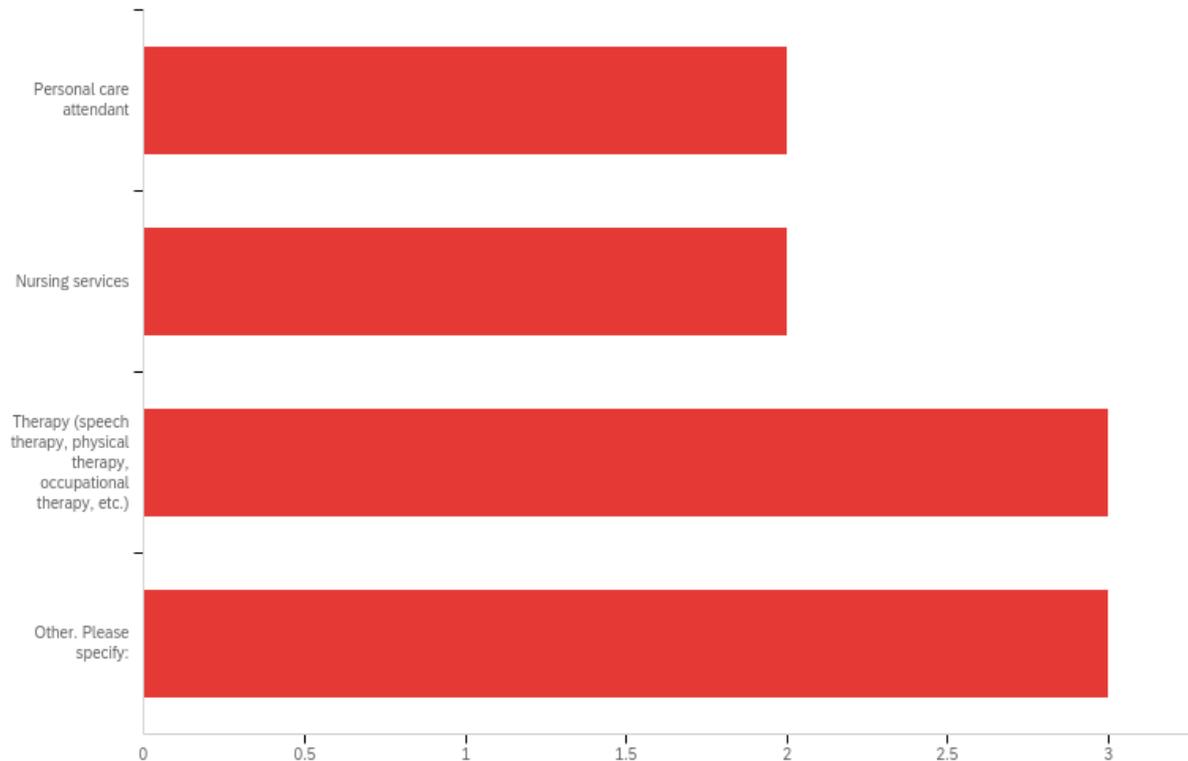
15 - Are you allowing home health services to continue, such as therapies or skilled services?

Answer	%	Count
Yes <i>(see next slide for follow-up question)</i>	33.33%	7
No <i>(see question 18 on slide #24 for follow-up question)</i>	66.67%	14
Total	100%	21



## 16 - Which services have you retained (check all that apply)?

Answer	%	Count
Personal care attendant	20.00%	2
Nursing services	20.00%	2
Therapy (speech therapy, physical therapy, occupational therapy, etc.)	30.00%	3
Other. Please specify: <i>(see next slide for responses)</i>	30.00%	3
Total	100%	10



16 - Which services have you retained (check all that apply)? Other. Please specify.

*(Responses appear as entered by participant.)*

**Other. Please specify:**

ABA, feeding behavioral therapy

None

Teletherapy

17 - What precautions are in place to protect your family?

*(Responses appear as entered by participant.)*

**Answer**

Hand washing and sanitation processes in place

Standard precautions

Wash your hands frequently. Avoid contact with too many people,

Telehealth

I make hyphen remove shoes and coat, and wash hands as soon as they enter our home. We are only allowing those we have worked with before into our home - no new people or fill ins

What the White House Task Force has put in place and listen to them.

Keeping social distancing

## 18 - What are your concerns about allowing home health services to continue?

*(Responses appear as entered by participant.)*

### Answer

it is not available to us. we have been on a wait list for over 4 years now.

6 feet distant room - can't have home health services in the house

We are self-quarantining since our son (and grandmother who lives with us) are high risk and do not want to have any other people come and go from the house

N/a

Risks of catching the disease.

The ABA therapist does not Donn PPE.

My child is immunocompromised

We do not use them

We don't have home health services anymore

He could really use the in home 1 on 1 therapies he used to have

Exposure to virus

Because it's clear we cannot identify all people who have the virus because we don't have enough tests. So if someone came in to my house, they could be positive and not even know it or have symptoms. Then we are just spreading it around. Further, even if each worker only kept 1 client, that worker goes home to their family, and may have a spouse who is also going out working, so this spread is wider than people realize.

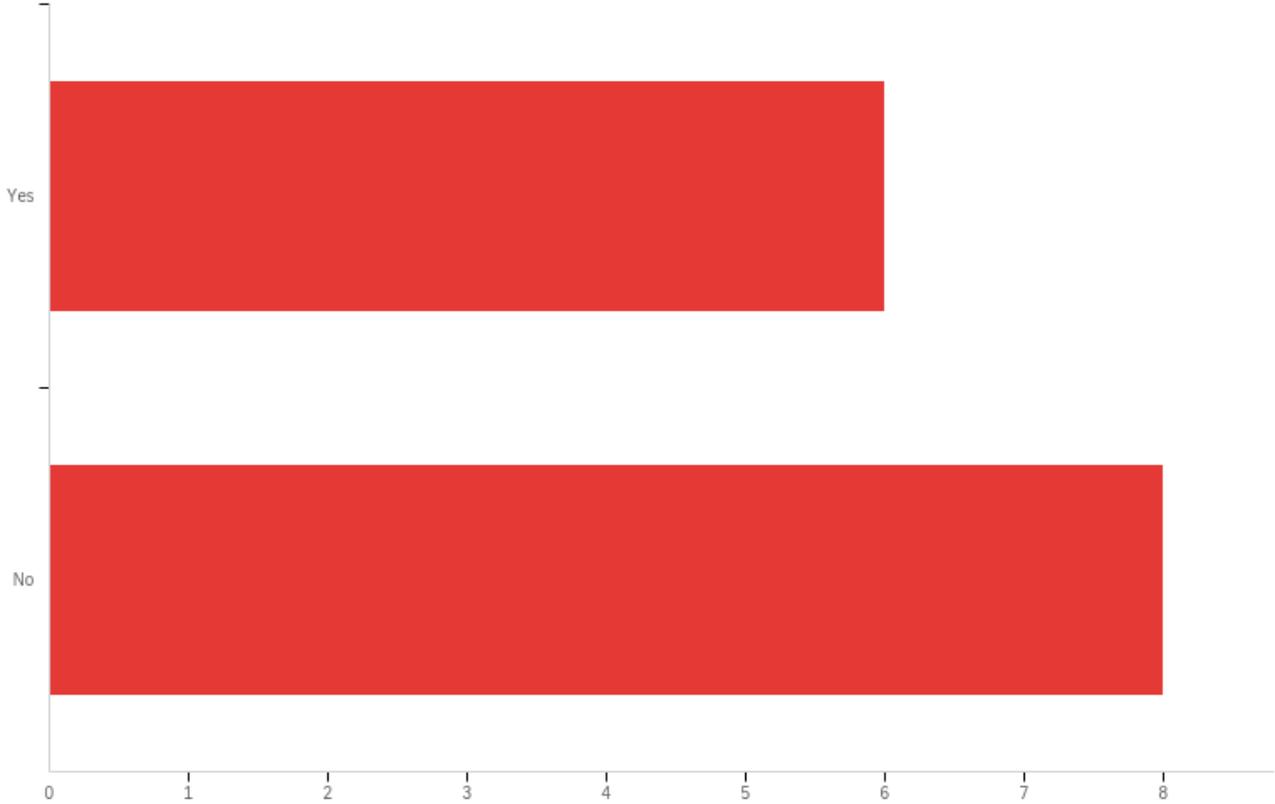
Spreading the virus

We don't usually receive home health services other than brace adjustments which we are allowing for now.

none at this time

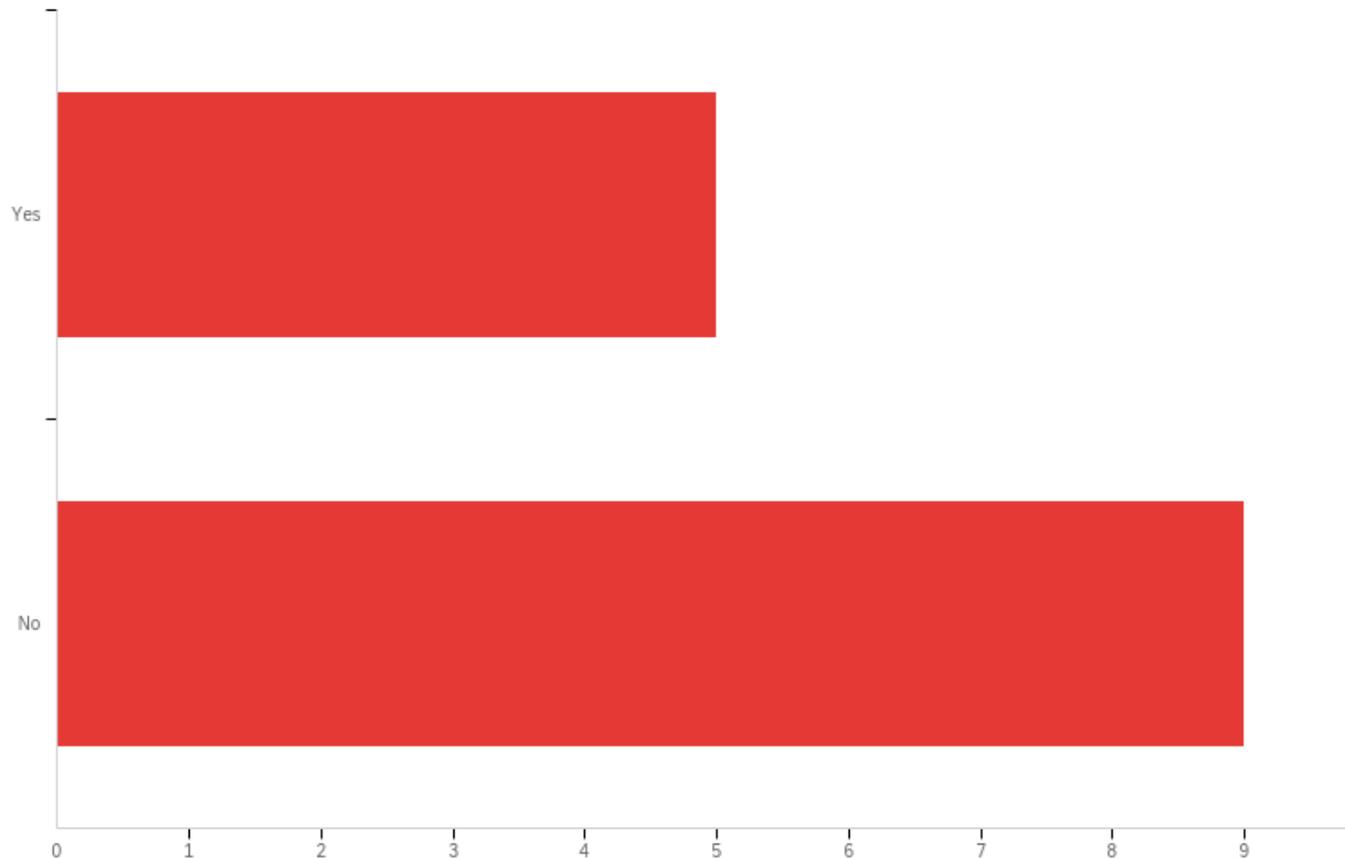
# 19 - Are you concerned about your child not receiving home health services during this pandemic?

Answer	%	Count
Yes	42.86%	6
No	57.14%	8
Total	100%	14



20 - Are virtual alternatives available to be coached over the phone, or webcast, to work on your child's therapy at home?

Answer	%	Count
Yes	35.71%	5
No	64.29%	9
Total	100%	14



21 - What could help in this situation? *(Responses appear as entered by participant.)*

**Answer**

my child is non verbal with behavior problems.

We have to wait for virus to end

We are receiving therapies through school virtually, but that requires an adult to actually do the therapy and participate the whole time, as well as take care of all activities of daily living, while also trying to work from home.

N/a

Virtual doctor visits.

Teachers have sent an email out stating it will start next Monday.

The availability of telemedicine and insurance approval of additional supplies/ tools to help

N/A

If there was...

I'm going to reach out to his therapist (but we have NO connection with her, she's new this year and we miss our old therapists horribly!)

Being allowed to order medications ahead of schedule. For example, not being constrained by insurance to have to wait until the normal time to refill prescriptions, but rather be allowed a 6 month supply.

Yes. Some therapies are late to offer this and some not offering it at all but it is a much better solution

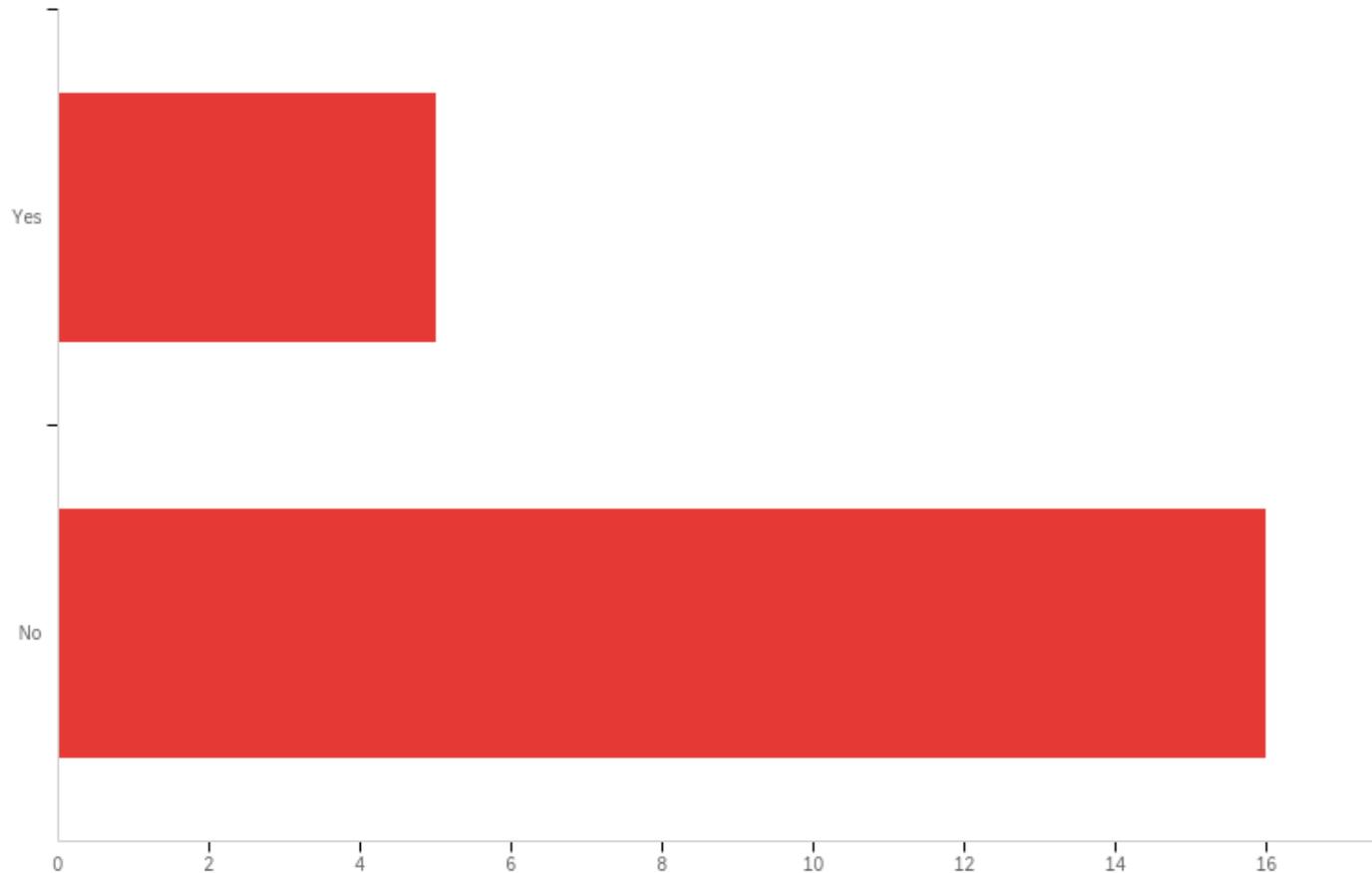
More phone calls

We are in NJ school system - PT, OT and ST are reachable by email - PT can also do FaceTime

not needed

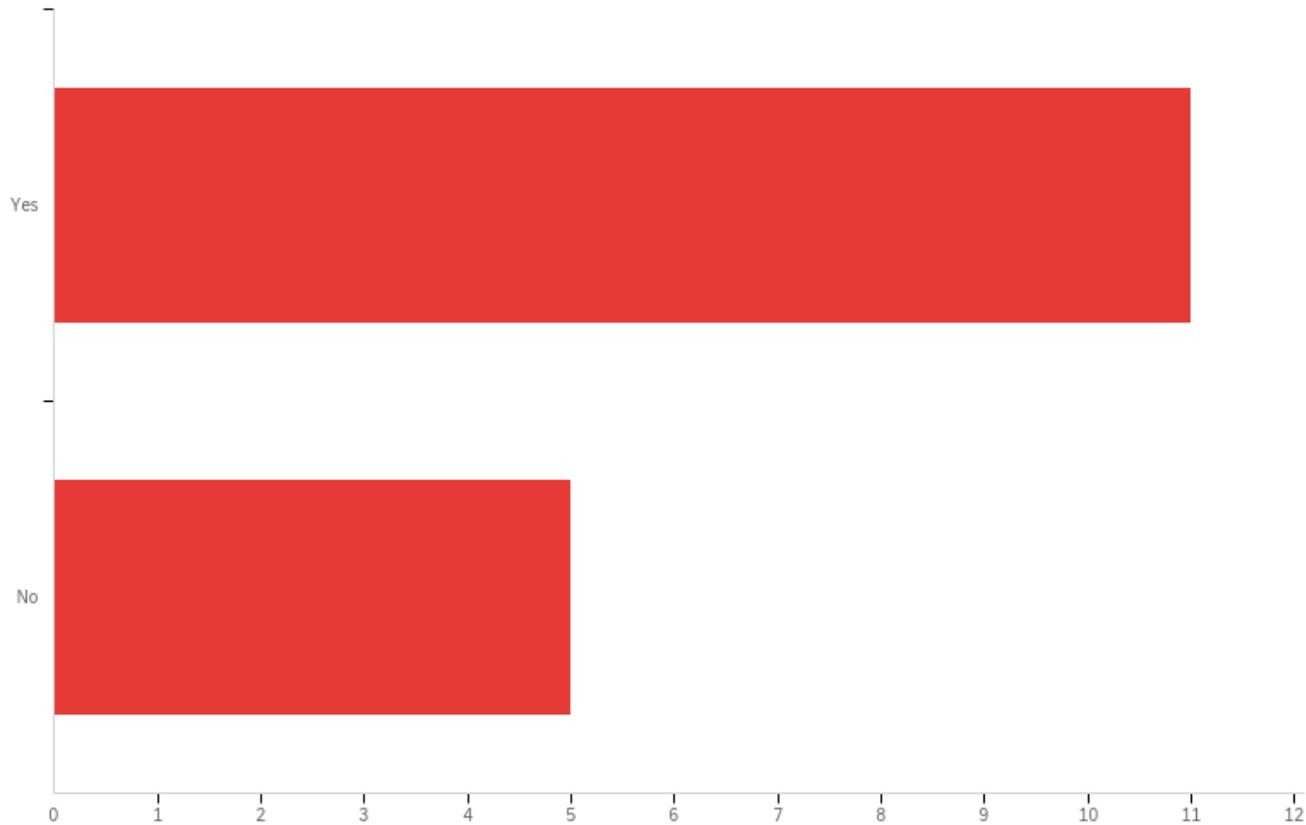
22 - Has your medical provider made contact with you to field any concerns you may have?

Answer	%	Count
Yes	23.81%	5
No <i>(see next slide for follow-up question)</i>	76.19%	16
Total	100%	21



## 23 - Would this be of interest to you?

Answer	%	Count
Yes	68.75%	11
No	31.25%	5
Total	100%	16



24 - 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?**

n/a

Keeping informed but not watching too much on tv because it worries my daughter. Using strategies my mental health provider gave me for anxiety.

Food bank of delaware

Gloves

Masks

virtual support groups, video calling family, taking a long bath, going out in my yard whenever it's nice out

Not getting rest and struggling to get things done for myself

None

None - my son is 19 years old and is very high functioning.

None and it's getting hard! I have a close

Loved one who is acting as tho this is no big deal and the world is over reacting!

Nothing

Nothing, not sleeping,

*Responses continued on next slide.*

24 - 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?**

I am a healthcare worker with PPE for my family.

None. We don't have any

Will follow up with doctor about scripts, will use delivery for food if necessary

Protect against infection

N/A

Nothing

school therapies and our at-home, quarantined family

None

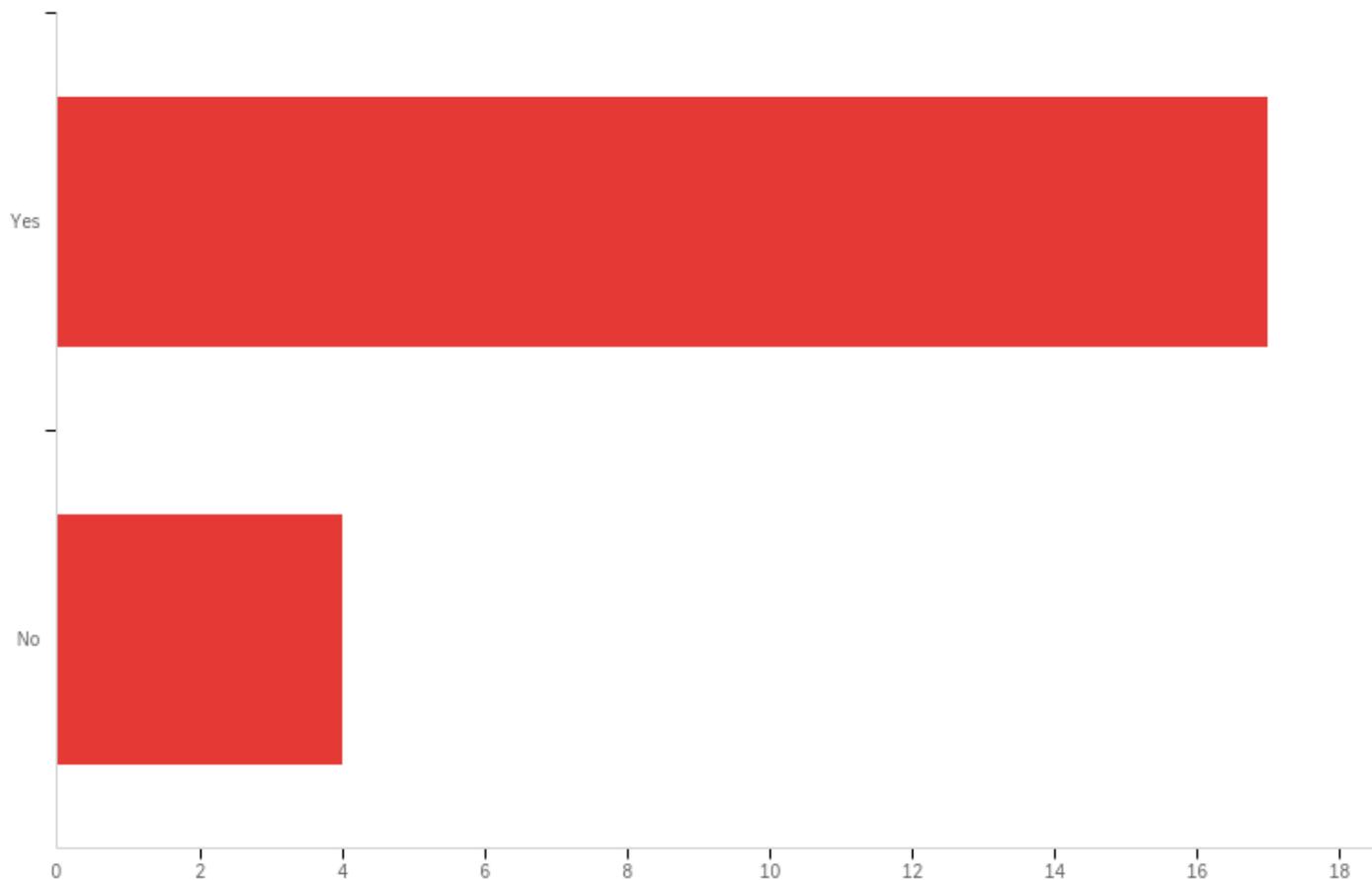
None

Rest, vitamins, frequent cleaning

Hand washing and other sanitized measures

## 25 - Has your child been involved in functional activities while at home?

Answer	%	Count
Yes <i>(see next slide for follow-up question)</i>	80.95%	17
No	19.05%	4
Total	100%	21



26 - Please list the functional activities your child has enjoyed while at home.

*(Responses appear as entered by participant.)*

**Please list the functional activities your child has enjoyed while at home.**

doing school work being active by riding our bikes and going to the park.

Helping me around the house with cooking , laundry , yard work.

Playing, coloring, being outside

ADLs. Hygiene routines, cooking, leisure activities

Cleaning, independent bathing, like ch and dinner together as fmaily

Online schooling. Conferences with PT, OT, Speech

Laptop

Cleaning and going to learn how to help cook

Walks, play outside

Life skills, free writing

Typing, cooking, sorting, stacking and organizing, shredding, copying, painting, basketball, dog walks, bike rides

Remote school, exercise bike, walking neighborhood

Fitness exercise

Worksheets.

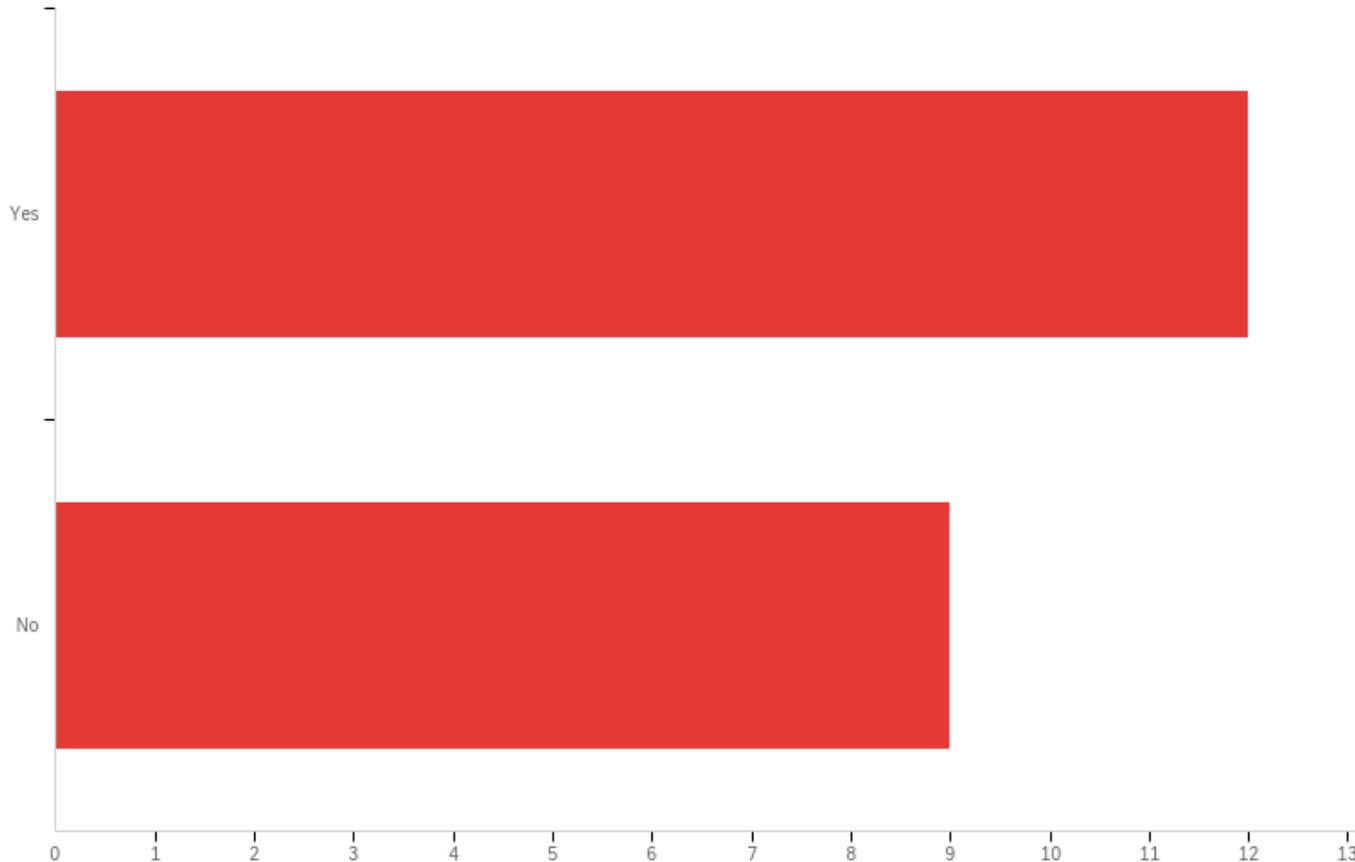
I homeschool him

Zoom sessions with school, walks with his sisters and family outside, we are searching the house now to see if we have any OT-type tools in the house.

Riding bike , playing board games, coloring, using electronics

## 27 - Has your child been involved in sensory activities while at home?

Answer	%	Count
Yes <i>(see next slide for follow-up question)</i>	57.14%	12
No	42.86%	9
Total	100%	21



28 - Please list the sensory activities your child has enjoyed while at home.

*(Responses appear as entered by participant.)*

**Please list the sensory activities your child has enjoyed while at home.**

We are doing her ot and PT exercises at home - also her workouts for gym class - taking walks and playing outside when weather is nice

art projects

Swing, rocking chair, ball, trampoline

arts & crafts, baking/cooking, etc.

Crafts, yoga

Swinging, trampoline, obstacle courses, cloud pillows, sensory beans and sand, ear phones.

Jumping, spinning, vocal stimming

Music, puzzles

Intelligence game, Family physical exercise

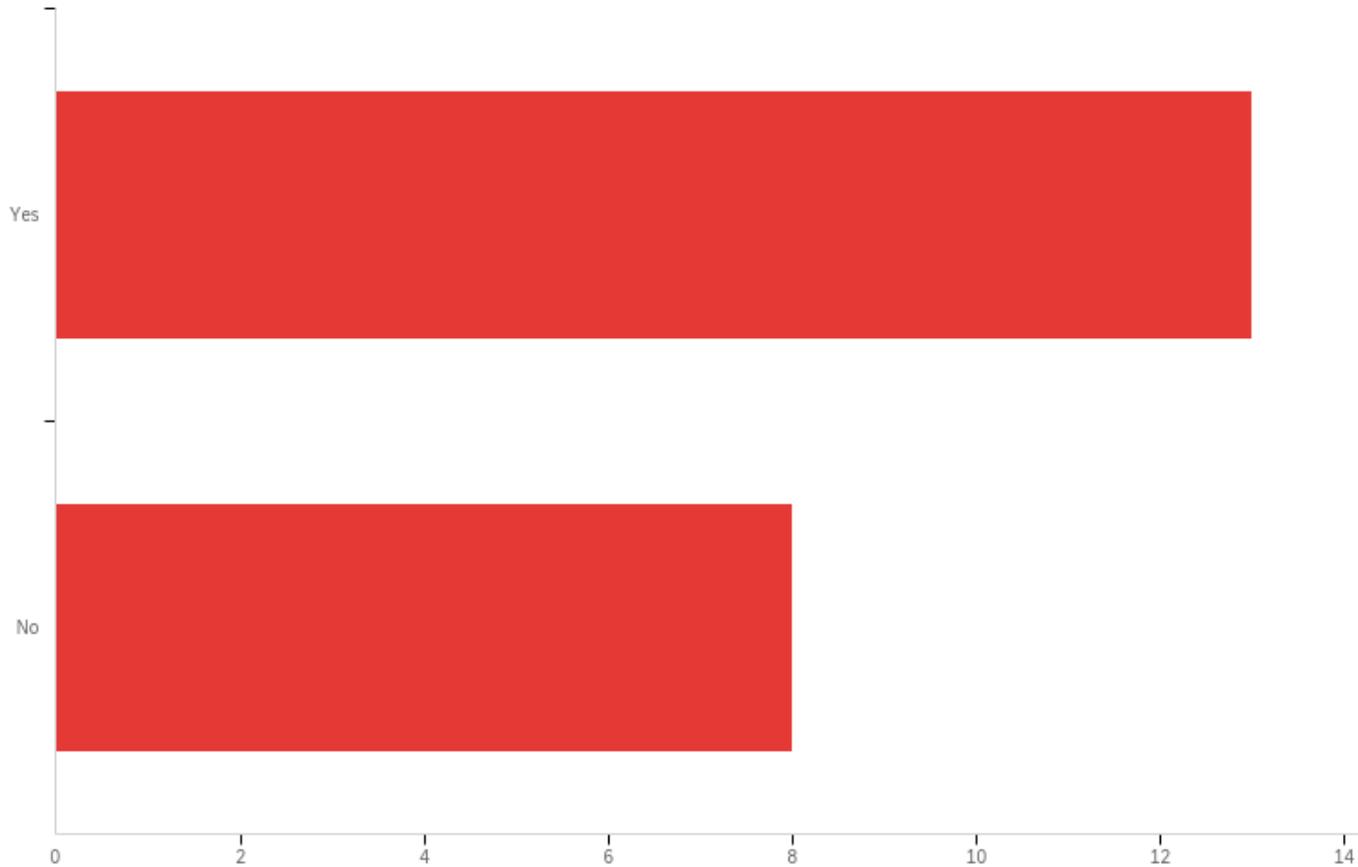
Homeschool

Again we are doing these in tandem with school therapists and finding toys, etc. we have at home.

Play doh and slime

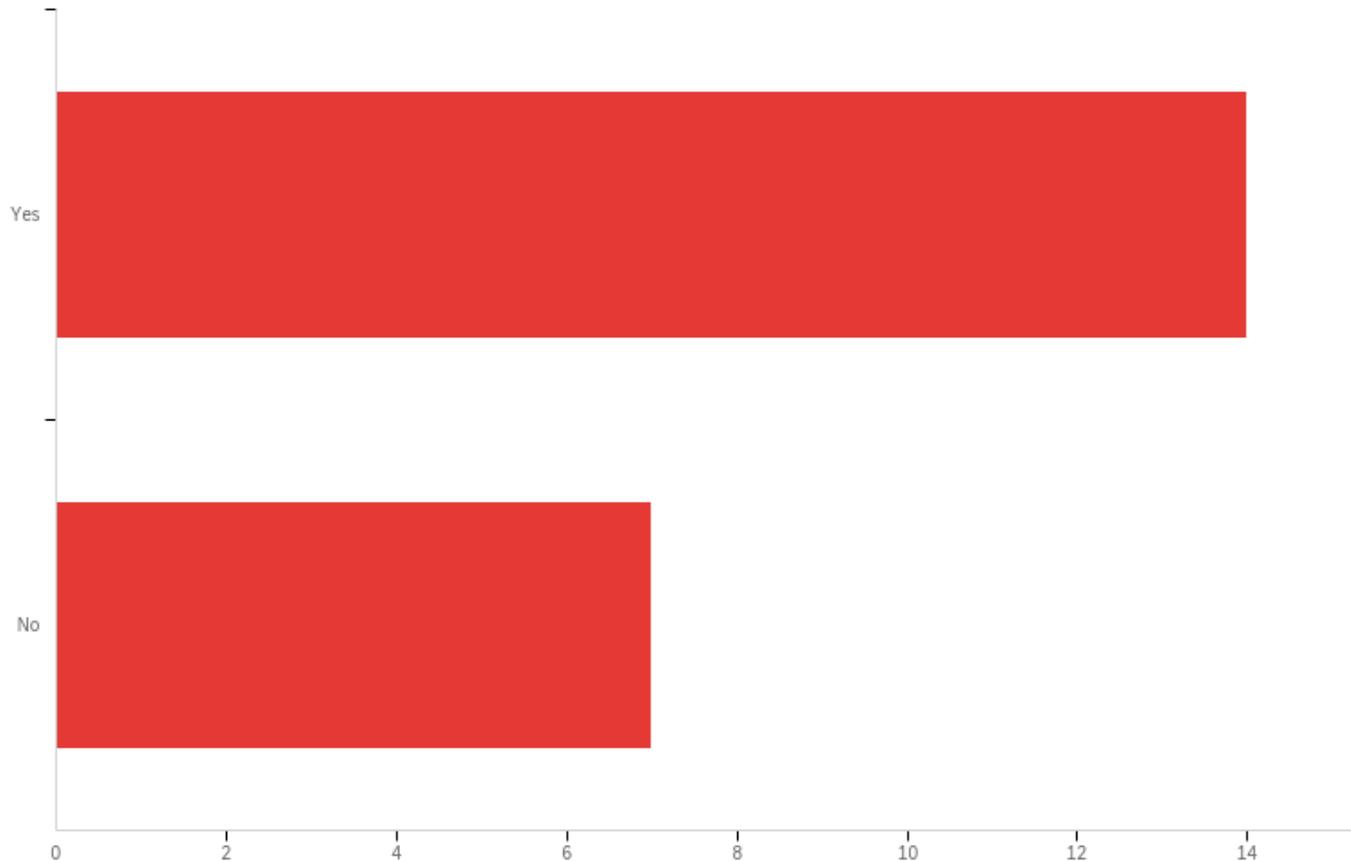
## 29 - Has your child been happy at home during the pandemic?

Answer	%	Count
Yes	61.90%	13
No	38.10%	8
Total	100%	21



### 30 - Have you noticed any stressors for you and/or your child with special healthcare needs?

Answer	%	Count
Yes <i>(see next slide for follow-up question)</i>	66.67%	14
No	33.33%	7
Total	100%	21



31 - 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.**

If I have too much tv news on she gets upset. She misses seeing her friends and relatives.

anxiety, not able to get supplies

Not getting rest

Increased frustration with staying in

Loved one refused to take this seriously!

Also His sister (my daughter) is in New Orleans she lives in Orleans parish(the epicenter) she also has had Diabetes since 18 months of age

Change in routine is rough, I'm not sleeping so my patience is short, and stress and of course he feels that stress

Getting my son into a routine. He has ICD and ASHD along with Autism and is nonverbal.

Me: lack of sleep. No respite. Constant yelling, jumping and being the only one who here changing diapers, cleaning feces smears, etc. I have no breaks.

Child: head banging, pica, Increase in behaviors, sleeping very little(?even with medication)

*Responses continued on next slide.*

31 - 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.**

I am a single parent and the “villain” for making him do everything (therapies, schoolwork, chores, etc) but we’ve also enjoyed this time together and have bonded so it isn’t all bad

He seems very bored - hopefully that will lessen now that he has online sessions with teachers and therapists, but he doesn't tend to pay a lot of attention to screens so I don't know how successful it will be. The whole situation is stressing me out!

He is getting impatient with non-routine (ritual) issues such as not going to school

lack of routine

Anxiety for me

Disruption of routine and social isolation for child

Her physical occupational and speech therapy and horsebackriding has ended and she misses friends at school

32 - Please describe what you are currently doing to alleviate stress in you and/or your child.

*(Responses appear as entered by participant.)*

**Please describe what you are currently doing to alleviate stress in you and/or your child.**

Limiting exposure to news reports - using FaceTime and phone calls to be in touch with others

making do with what we have, taking breaks, limiting the news we watch, playing classical music during work times at home

Trying to be in touch with family overseas

Keep her engaged in activities such as reading, movies, cooking, going in the yard, rides in the car.

Not a damn thing  
Not sure how

Lots of screen time 😞

Deep breathing, swinging, walking, reassuring him things are fine, distracting activities

Prayer...not many other options available

Exercise, frequent breaks, reward systems for both of us, getting outside, lowering expectations

My child and I are cuddling a lot. We are trying to involve him in family activities, but everyone is busy with their own responsibilities, so we will take turns being in the same room as him, but I don't think it's very stimulating for him.

Taking him outside

just reacting, trying to keep him safe. Just not equipped to provide the sensory environment and supports he requires.

Trying to keep her busy

FaceTiming teachers and friends and therapists to stay connected

33 - What other services/supports might help relieve some of the stress you and/or your child are feeling? *(Responses appear as entered by participant.)*

**What other services/supports might help relieve some of the stress you and/or your child are feeling?**

I think we are doing ok for now

behavioral supports via telehealth

Home health aid support

?

I don't know

If SSI recipients received a stimulus so we could buy things online, if food delivery services accepted SNAP, if insurance covered home PT/OT , sensory equipment

Unknown

RESPITE

Longer summer session—- zooming teachers and staff is more stressful than anything else. This forced way to get school hours makes it more stressful for my kid and me. He has ADHD too— literally never sits still, even with meds. This approach is not even practical with Brennen kids

More telehealth therapies so I'm not the only one making him do things- it also reinforces things and gives me a short break... would be nice to have tele-tutors to work with kids with special needs

*Responses continued on next slide.*

33 - What other services/supports might help relieve some of the stress you and/or your child are feeling? *(continued - Responses appear as entered by participant.)*

**What other services/supports might help relieve some of the stress you and/or your child are feeling?**

Not sure....

Not sure - dancing and playing games - lots of water play

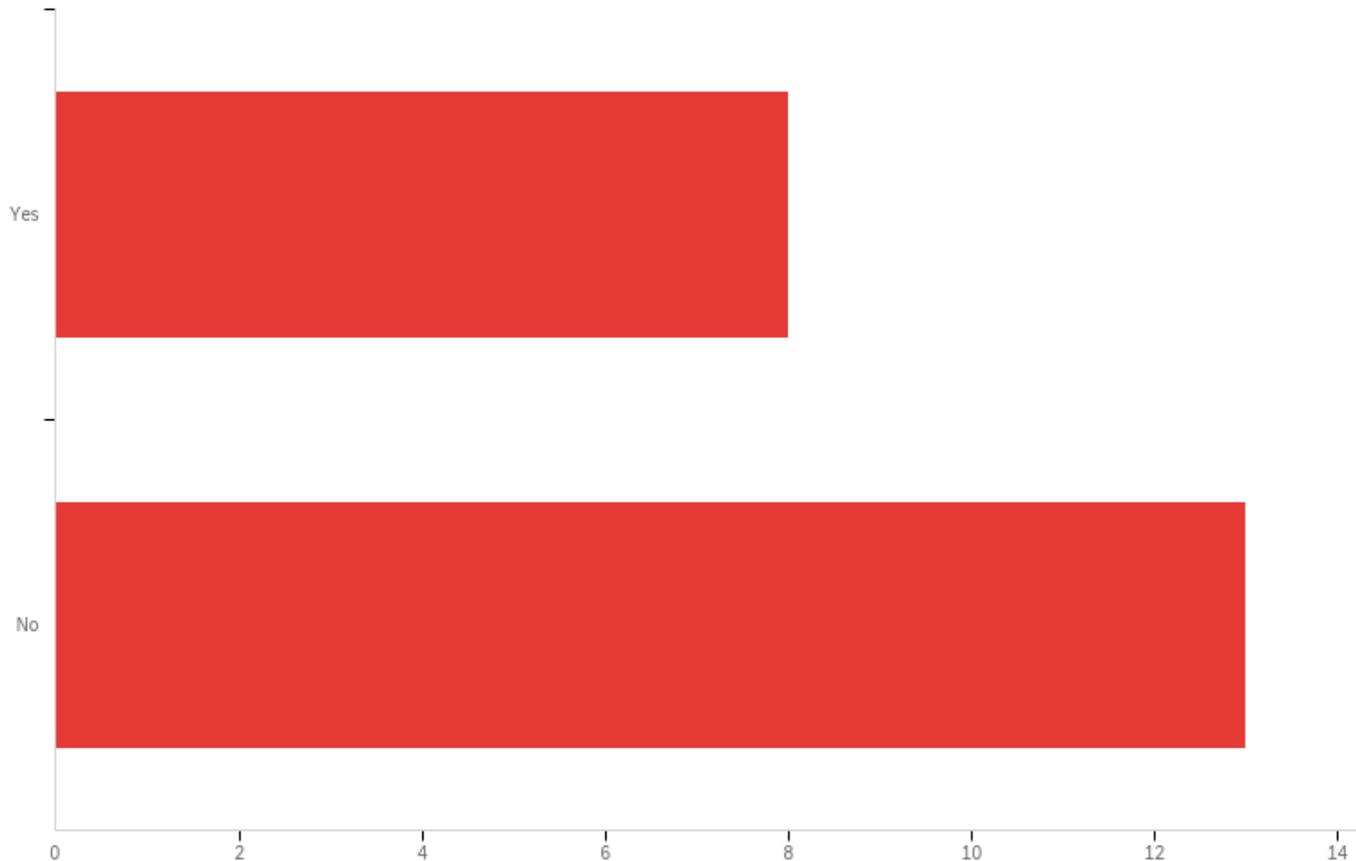
I dont know in lighth of covid 19, and the need for self isolation from others. My son requires a lot of one on one supports.

None I can think of

Somehow resuming therapies but not even sure how that's safely possible

34 - Prior to this pandemic, did your family have a plan in place for an emergency such as this?

Answer	%	Count
Yes <i>(see next slide for follow-up question)</i>	38.10%	8
No <i>(see questions 36-37 on slides #45-47 for follow-up questions)</i>	61.90%	13
Total	100%	21



35 - Can you share how you and your family prepared and what was included in your emergency plan? *(Responses appear as entered by participant.)*

### Can you share how you and your family prepared and what was included in your emergency plan?

Stocked up on food and essentials

It wasn't written down, but we sort of had a plan. We realize now it wasn't enough. We keep some supplies on hand, like gloves and pain relievers and cleaning supplies, extra paper products. But we need more of these and other supplies we don't typically keep. We have now written out a plan so our child can have concrete information about what we will do and where all the supplies are in the house.

We always try and keep an emergency supply of essentials, but only have a month worth, nothing longer...

We were in CO when the emergency declarations began and we self isolated upon returning once we learned about the cases in CO. We were not exposed and did not have symptoms but wanted to err on the side on caution.

Emergency manual

We always ensure we have a lot of supplies at home - food, medicine, diapers, etc. My husband and I can both work from home and have technology set up for us and our daughters, and our son has access to technology although it doesn't interest him very much.

Communication plan and grab and go kits

Just make sure we always have enough food and water to last a couple of weeks

36 - What are the top three suggestions, that would have helped your family the most, in this situation? (*Responses appear as entered by participant.*)

**What are the top three suggestions, that would have helped your family the most, in this situation?**

knowledge have more medicine and food on hand

Make sure to have medication refilled as early as possible.  
Have all computers and phones updated.  
Stock up on supplies for the house.

Extra caring hands, extra supplies and food items

Keep extra supplies on hand  
Utilize telemedicine  
Be flexible

I don't have 3 suggestions, just listening to the experts.

Start trusting your inner thoughts and act on them, stop listening to people who tell you your over reacting and causing problems

Nothing was needed at this point.

Online academics  
Frequent check calls from his Teacher-0  
Fun suggested activities while at home

How to get more supplies covered by the insurance company in preparation  
Mental health supports for caregivers

*Responses continued on next slide.*

36 - What are the top three suggestions, that would have helped your family the most, in this situation? (*continued - Responses appear as entered by participant.*)

**What are the top three suggestions, that would have helped your family the most, in this situation?**

More access to doctors online, more resources for ADHD, more resources for Epilepsy.

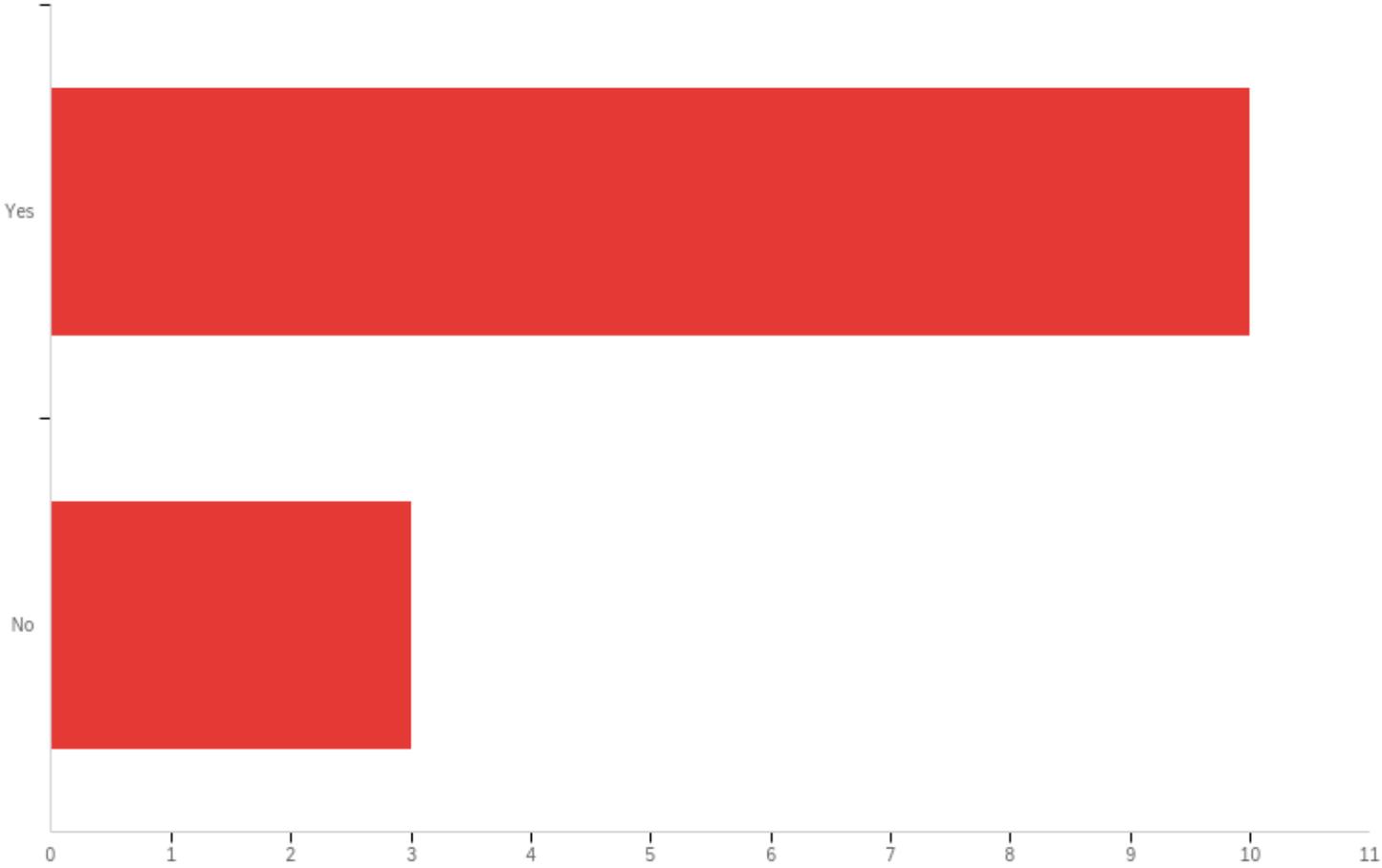
Had more prescriptions in place

Back up caregiver , supplies like masks, ability yo get additional meds and supplies

Keeping extra back up supplies

37 - Would extra supplies (pre-ordered/sent early) help settle the stress level of running out of needed materials?

Answer	%	Count
Yes	76.92%	10
No	23.08%	3
Total	100%	13



38 - If as a caregiver, you get sick, do you have a back-up plan for someone else to care for your child with special healthcare needs?

Answer	%	Count
Yes	52.38%	11
No <i>(see next slide for follow-up question)</i>	47.62%	10
Total	100%	21



39 - What would help in this situation? *(Responses appear as entered by participant.)*

What would help in this situation?
Don't know
I do not know
An emergency on call respite network, preferably with a listing of providers that my child is familiar with.
Respite More qualified and reliable HHA's who are Non-smokers, who want to actually help
In the current isolation situation, I would have to ask his father to help. But I have the primary caregiver and breadwinner- I am a single mother.
Food assistance, financial help
We have the two of us and some family, but no one if multiple people got sick, given the nature of this pandemic.
I dont know
Not sure
Staying calm and using humor to get through one day at time

40 - What advice do you have or lessons learned can you provide for other caregivers from a planning perspective for this type of situation? *(Responses appear as entered by participant.)*

**What advice do you have or lessons learned can you provide for other caregivers from a planning perspective for this type of situation?**

be prepared, have a back up caregiver

Definitely have medication info available and updated - be aware of refills, expiration dates etc.

Be patient. Have games and things to keep the children entertained and learning

too much to type here! But definitely have a plan, and put it in writing, and tell family members where they can find it. Put in the plan where all the supplies are located in the house; even my husband wouldn't know where I keep some of the things unless I told him because they aren't things we use all the time (like the gloves)

Should be well prepared

Make sure prescriptions are up to date  
Have supplied such as diapers, wipes, cleaning supplies  
Have OTC medical supplies in case of illness

Just listening and doing what the experts say.

Listen to yourself

Make sure you are able to get all of your supplies

*Responses continued on next slide.*

40 - What advice do you have or lessons learned can you provide for other caregivers from a planning perspective for this type of situation? *(continued)*

*(Responses appear as entered by participant.)*

**What advice do you have or lessons learned can you provide for other caregivers from a planning perspective for this type of situation?**

1 month of supplies is not enough,

Create fun activities that involve the child's interests and while instructing, let the child lead.

None— everything is systemic.

Maybe call legislators and see if they are willing to help... not likely bc I have contact legislators and unless it's something that impacts the majority of their constituents, they won't help

Enjoy the time together, do not over plan or expect too much of yourself or your child,

app

Find doctors who can work remotely.

No one could plan for this our primary income just got furloughed today. No income

Stuff your garage and pantry with your just-in-case supplies, and the minute you hear that there might be something going on in the world, get ready because our kids need us to be prepared!

Not sure

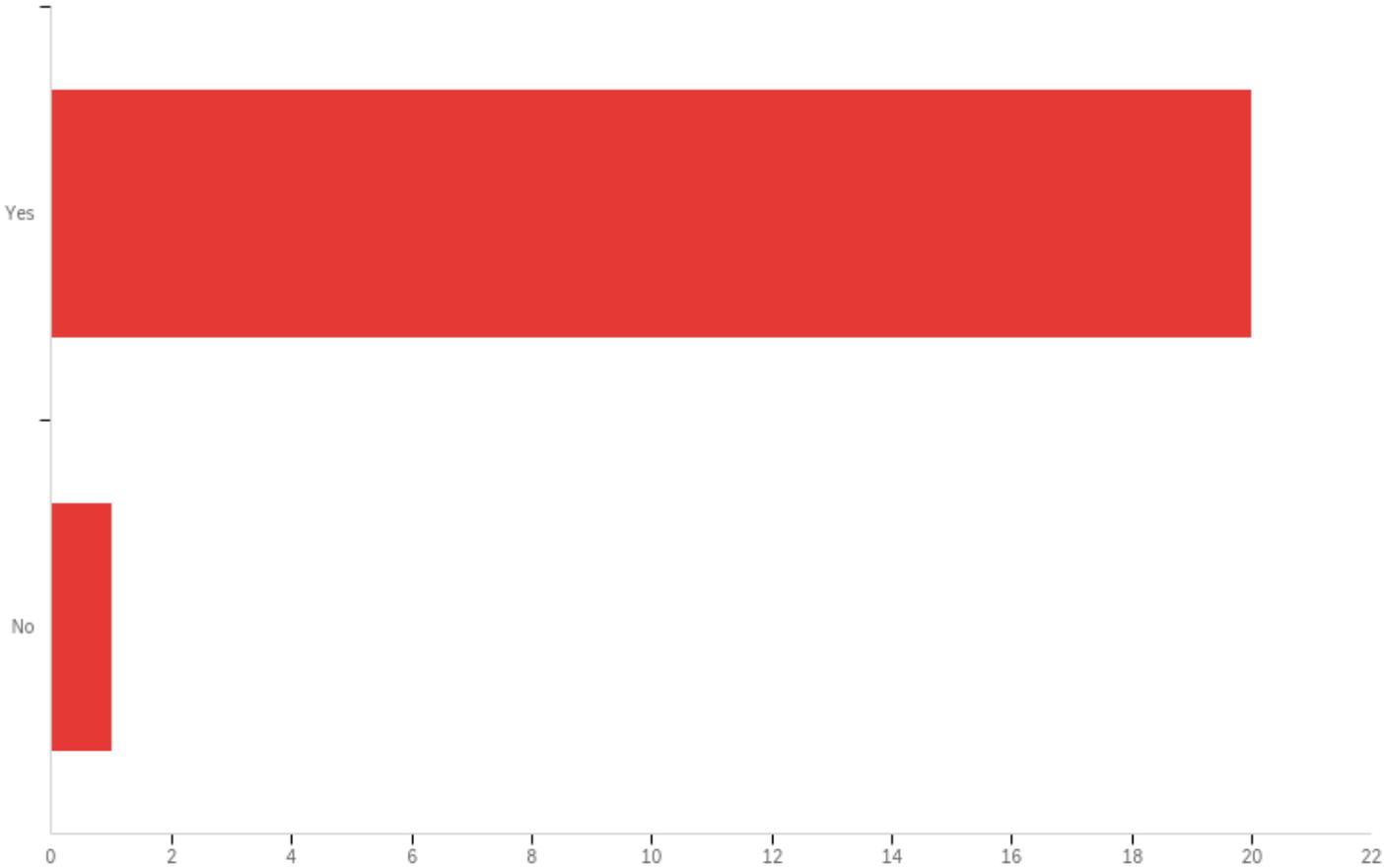
talk to medical providers and the school to find out about respite for situations like this

Don't know

Staying calm and present

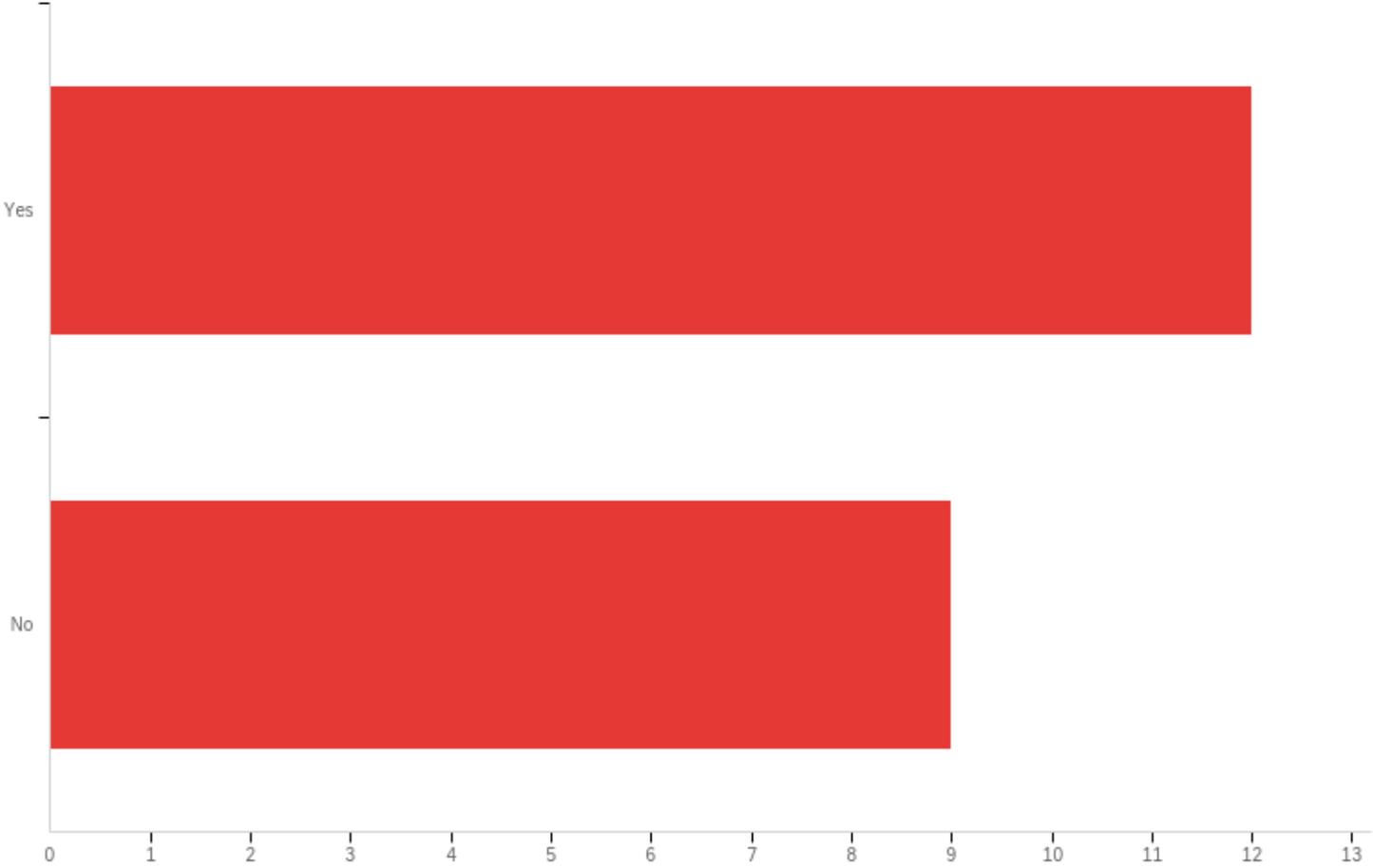
# 41 - Do you have internet access?

Answer	%	Count
Yes	95.24%	20
No	4.76%	1
Total	100%	21



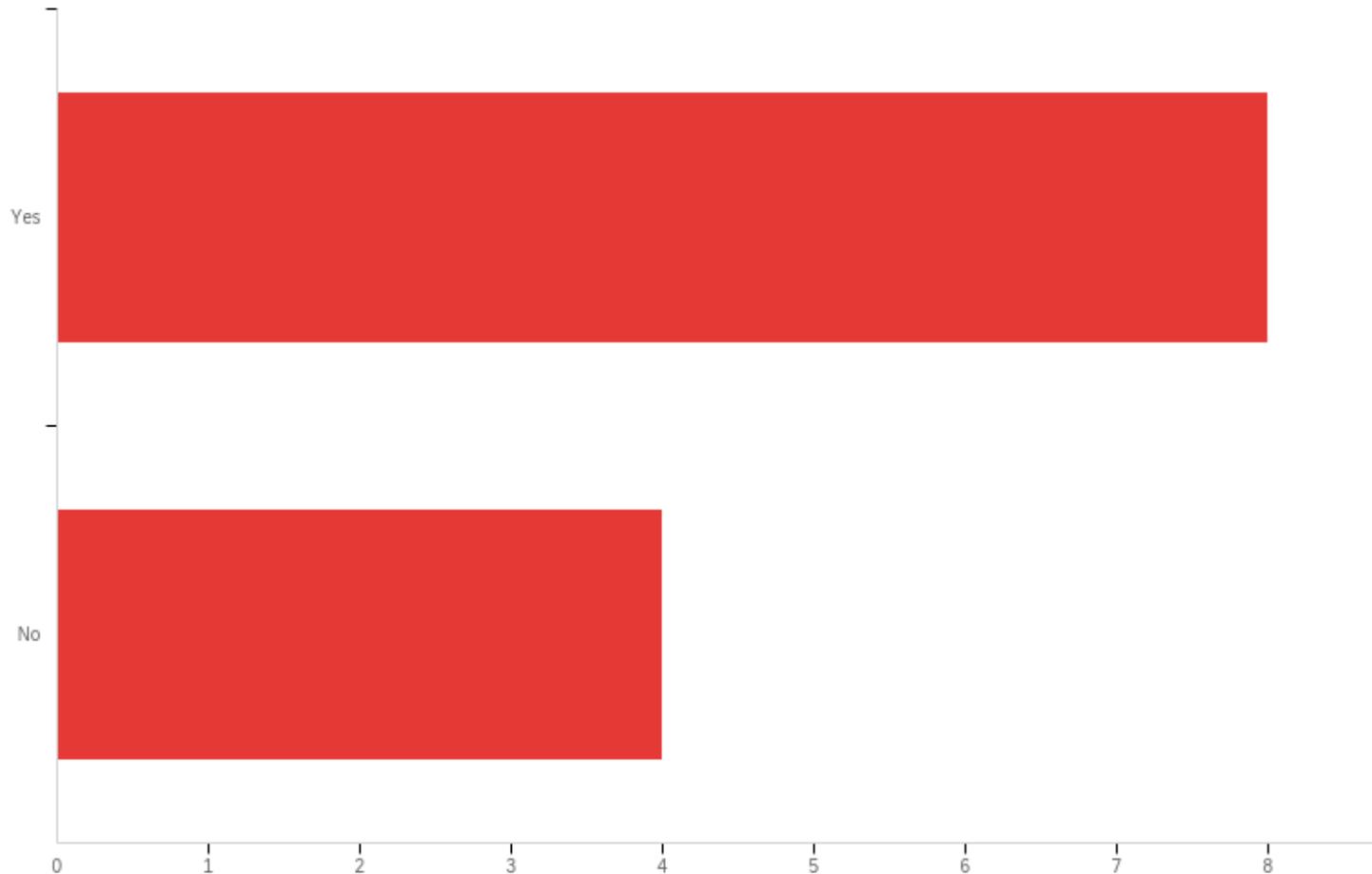
# 42 - Are you working from home?

Answer	%	Count
Yes <i>(see next slide for follow-up question)</i>	57.14%	12
No	42.86%	9
Total	100%	21



## 43 - Do you need additional support while you work from home?

Answer	%	Count
Yes <i>(see next 2 slides for follow-up questions)</i>	66.67%	8
No	33.33%	4
Total	100%	12



#### 44 - What support have you received so far in this situation?

*(Responses appear as entered by participant.)*

##### What support have you received so far in this situation?

Since both my spouse and I are working from home, we have been able to “tag team” caring for our child during work meetings

None

Not really

He has had some telehealth appointments, I’ve paid for housekeeping

Football

just our family, but I don't know what else we could use since we don't want anyone else coming into the house. It's just hard to juggle work, all of the kids, our son's therapy sessions, keeping him engaged, an older parent, etc...

home health aide

Nursing care but hasn’t been consistent

## 45 - What other supports would be helpful to you in this situation?

*(Responses appear as entered by participant.)*

### What other supports would be helpful to you in this situation?

An extra person dedicated to caring for my child

Those I mentioned- calls from teacher, online academics work tailored to child.

More qualified, reliable HHA's. Not even 1/2 of my kids hours are filled on a daily basis.

Tutoring, therapies - as a form of respite and reinforcement

swim

Don't know since we want to stay quarantined. Maybe having the types of tools our son uses at school but we kept him home when this all started, and then school shut down, so we don't have his wheelchair tray, voice output device, switches, etc that he would normally use at school so being home long-term is not as productive as it could have been.

professional to assist and train home health aide to work with my son, especially since she is having to work about 8 hours a day.

It is always chaos with a lot of screaming and chasing around the house.

Maintaining nursing and maybe figuring out occupational speech and physical therapies

## 46 - What is of most concern to you during this pandemic?

*(Responses appear as entered by participant.)*

### What is of most concern to you during this pandemic?

staying healthy

The health of those in our home as well as elderly family members living elsewhere.

My child getting sick

that we don't really understand the virus and how my child will fair if my husband and I get very ill

Keeping everyone safe and not getting sick

Havinh food items and job in place

Running out of or not being able to get medications for my child

None

Families Health

My child getting sick

If we get sick , what will happen to the rest of the family, losing power, the uncertainty

*Responses continued on next slide.*

46 - What is of most concern to you during this pandemic? *(continued)*  
*(Responses appear as entered by participant.)*

**What is of most concern to you during this pandemic?**

Regression

Regression, SIB's

Work/life balance for long term mental health

Daily life is very inconvenient

My family's health.

Internet

Keeping everyone healthy, keeping germs out of our little bubble

Transportation from my son's residential facility in PA

how i am going to survive another month like this

Keeping everyone safe

My child loosing skills she's gained and worked so hard for

47 - Is there anything else you would like to share that would help your situation?

*(Responses appear as entered by participant.)*

Is there anything else you would like to share that would help your situation?

n/a

No

No

I feel terrible for families with younger kids or kids with more severe conditions right now. The debate in some fields around providing services versus Do No Harm is a tough one, but in the end, life itself is most important in my eyes. I don't want to spread the virus if I can help it, and I want to protect my child's health in every way I can.

Need support in place since the beginning to not to have such crisis

No

None

No

No

Just what I've already said

*Responses continued on next slide.*

47 - Is there anything else you would like to share that would help your situation? *(continued)*  
*(Responses appear as entered by participant.)*

Is there anything else you would like to share that would help your situation?
No
Mental health services for nonverbal children
Hipaa and telemedicine with children and behavioral health concerns me.... I think there should be a network of tutors, therapists, etc to work with kids with special needs
NO
N/A
Help with getting WiFi
I assume there are no lending libraries of equipment like Easter Seals or UD open during this time?
None
No support for a low functioning autistic with behavior issues is troubling.
No
Implementing home based therapies might be helpful

48 - While you may be able to sustain your current situation for 6-8 weeks, what concerns do you have beyond that time frame if the stay-at-home order is extended?

*(Responses appear as entered by participant.)*

**While you may be able to sustain your current situation for 6-8 weeks, what concerns do you have beyond that time frame if the stay-at-home order is extended?**

having my child have more social interactions.

Not having therapies in person , delays on bloodwork , lack of social interaction with peers , general mental health

No concerns

Too much to write here

Engaging kids, ongoing therapies hampered and no rest for caregiver

Availability of seizure meds, heart meds, reflux meds, diapers, g-tube supplies needed for my child

None

Being with my son 24/7 will put a major strain back on our relationship

I do not have any

I'm already low on supplies, insurance should allow supplies to be filled for 3 months at a time., we may have to move in with others to combine resources

*Responses continued on next slide.*

48 - While you may be able to sustain your current situation for 6-8 weeks, what concerns do you have beyond that time frame if the stay-at-home order is extended? *(continued)*

*(Responses appear as entered by participant.)*

**While you may be able to sustain your current situation for 6-8 weeks, what concerns do you have beyond that time frame if the stay-at-home order is extended?**

Exhaustion

Everything I listed before...

Sustainability of work and caretaking- financial implications, meeting educational needs

Health

If my child's health will suffer.

Employment for husband

Same as above, plus a real backslide in my son's skills if I am his only hands-on therapist.

No, we will have to do an transfer from PA within the next few weeks.

i cant even think that far. 6 to 8 weeks is scary enough!

Don't know

Again loading skills and regression in all many needs child has