

COVID HESITANCY STUDY

A Survey of Arizona's Parents of
Children with Disabilities

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Fears Linger Among Parents Regarding Vaccinating Children with Disabilities

Recent survey findings highlight some of the fears parents have around vaccinating their children with disabilities. In conjunction with DAMES, the Arizona Developmental Disabilities Planning Council conducted an electronic survey with Arizona's parents of children with disabilities from July 7 to August 17, 2021 to determine what is preventing them from getting themselves or their children vaccinated. 370 parents responded.¹ The survey was also available in Spanish.²

The findings were telling of how education efforts have fared so far:

- The majority, 76%, of parents who answered the survey had been fully vaccinated.
- Among those who didn't get the vaccine, 50% said they wouldn't because they worry about possible long-term side effects, 44% didn't trust the safety or effectiveness of the vaccine, and 40% were unsure of vaccine ingredients.
- When parents who were both vaccinated and unvaccinated were asked if they would vaccinate their child, 62% said yes, 22% said no, 8% were still unsure and 8% did not answer.
- Among vaccinated parents, 6.9% said they would not vaccinate their child and 7.7% were still unsure.
- The most frequently stated reasons why parents did not want to vaccinate their children were: they were worried about the long-term side effects (53%); they didn't trust the safety and effectiveness of the vaccine on their child's disability (43%); or they worried about the short-term side effects (33%).

The survey also allowed parents to post comments about their concerns. While the majority of parents did not share any, those who did expressed similar issues regarding vaccine efficacy on those who have had COVID-19 and the vaccine's effect on disability:

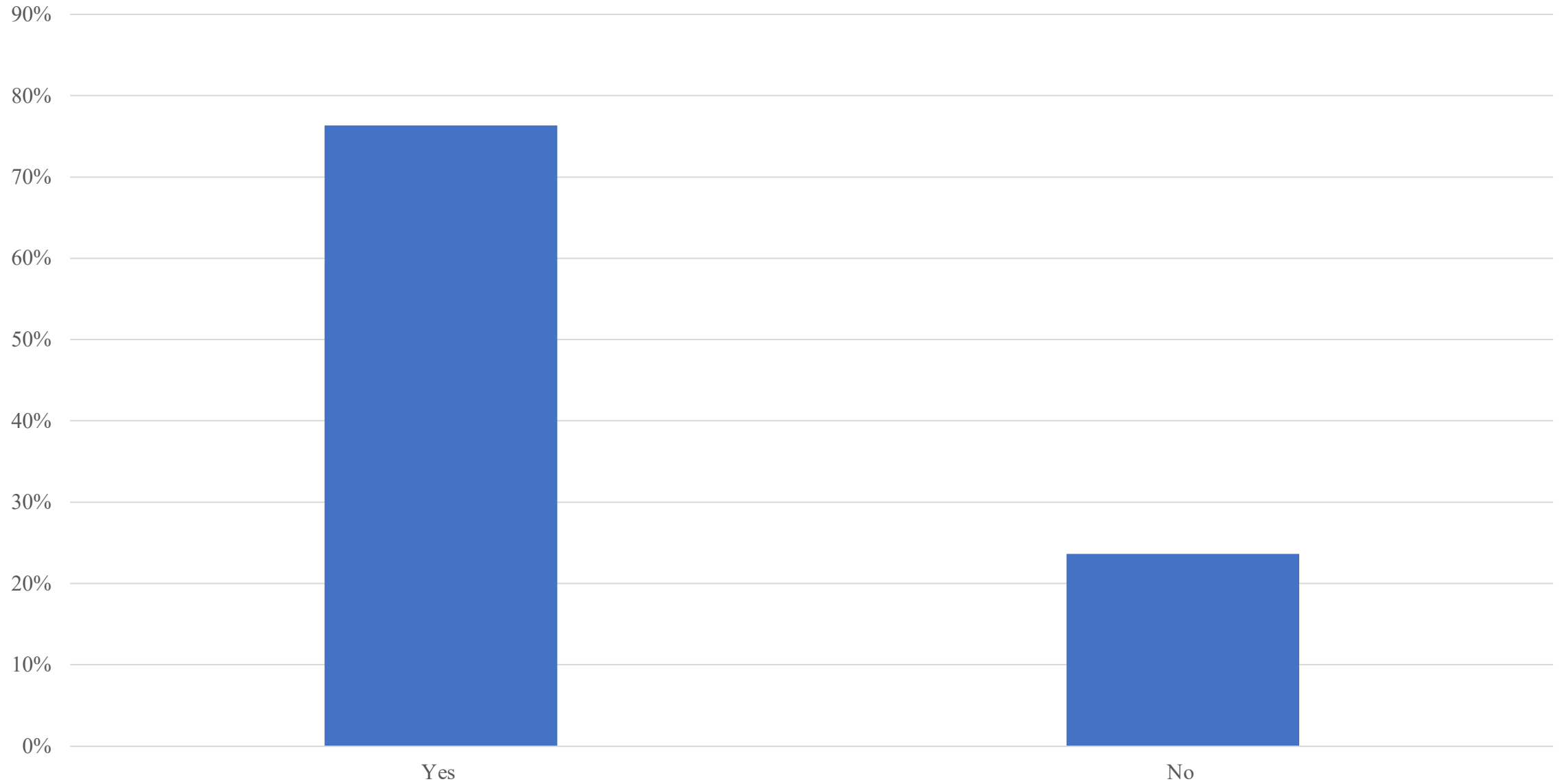
¹ Parents were contacted through the Arizona Early Intervention Program and AHCCCS' Arizona Long Term Care email lists. Parents were also alerted to the survey through organization Facebook pages, such as DAMES Charities Inc, Raising Special Kids, AZ Special Mamas, and AZ autism moms).

² 10 parents responded to the Spanish survey. Due to the low number, the results were aggregated with overall survey findings.

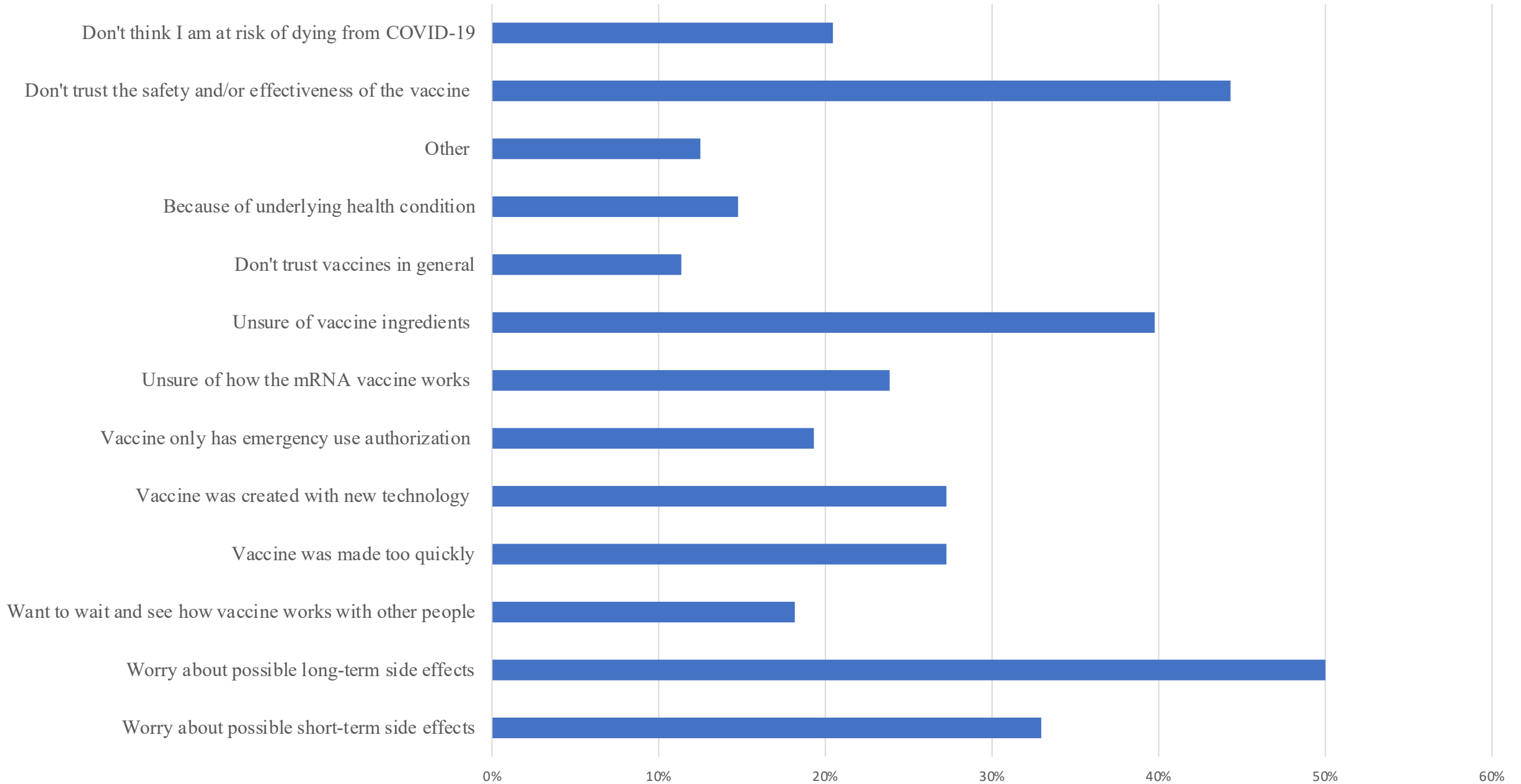
- *We had COVID, and have heard and read the studies on natural immunity. I don't feel like taking a possible risk for something that will give us about the same immunity that we already have.*
- *My Daughter has Down Syndrome and Heart problems. There has not been any testing on Kids with Down Syndrome.*
- *I've already had Covid so what's the point of getting the vaccine. It does not prevent Covid only lessens the symptoms and I am not willing to make the short term more comfortable when there could be unknown long term effects since this is the first mRNA vaccine on the market.*
- *The death rate in children is so low that the risk of long term side effects is of greater concern.*

This survey highlights the need for pediatricians to work closely with parents to help them understand how the vaccine will interact with their child's disability. In response to these survey findings, ADDPC also created a [parent guide](#) to address some of the concerns expressed. This guide will be updated monthly as new concerns and information comes to light. More in-depth responses are enclosed in this report. For information about what ADDPC is doing around COVID-19, contact addpc@azdes.gov or visit <https://addpc.az.gov/newsroom/tips-covid-19-resources-disability-community>. For additional disability resources, also visit <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/disabilities.html>

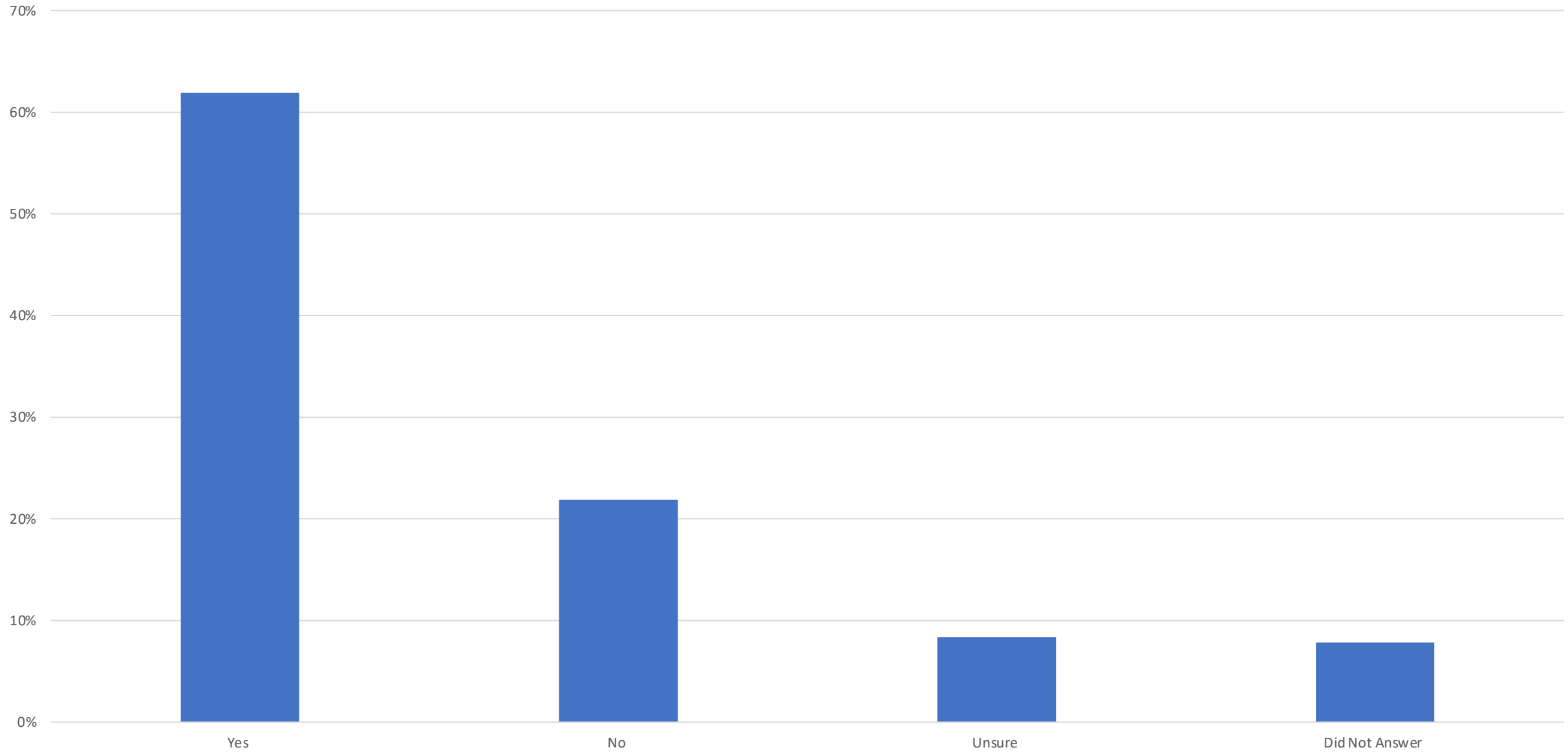
Are you fully vaccinated against COVID-19 (Fully vaccinated means both doses of Moderna and Pfizer or one dose of Johnson & Johnson? (N=361)



I'm not hesitant, but I have not been fully vaccinated because ____ (N=88)

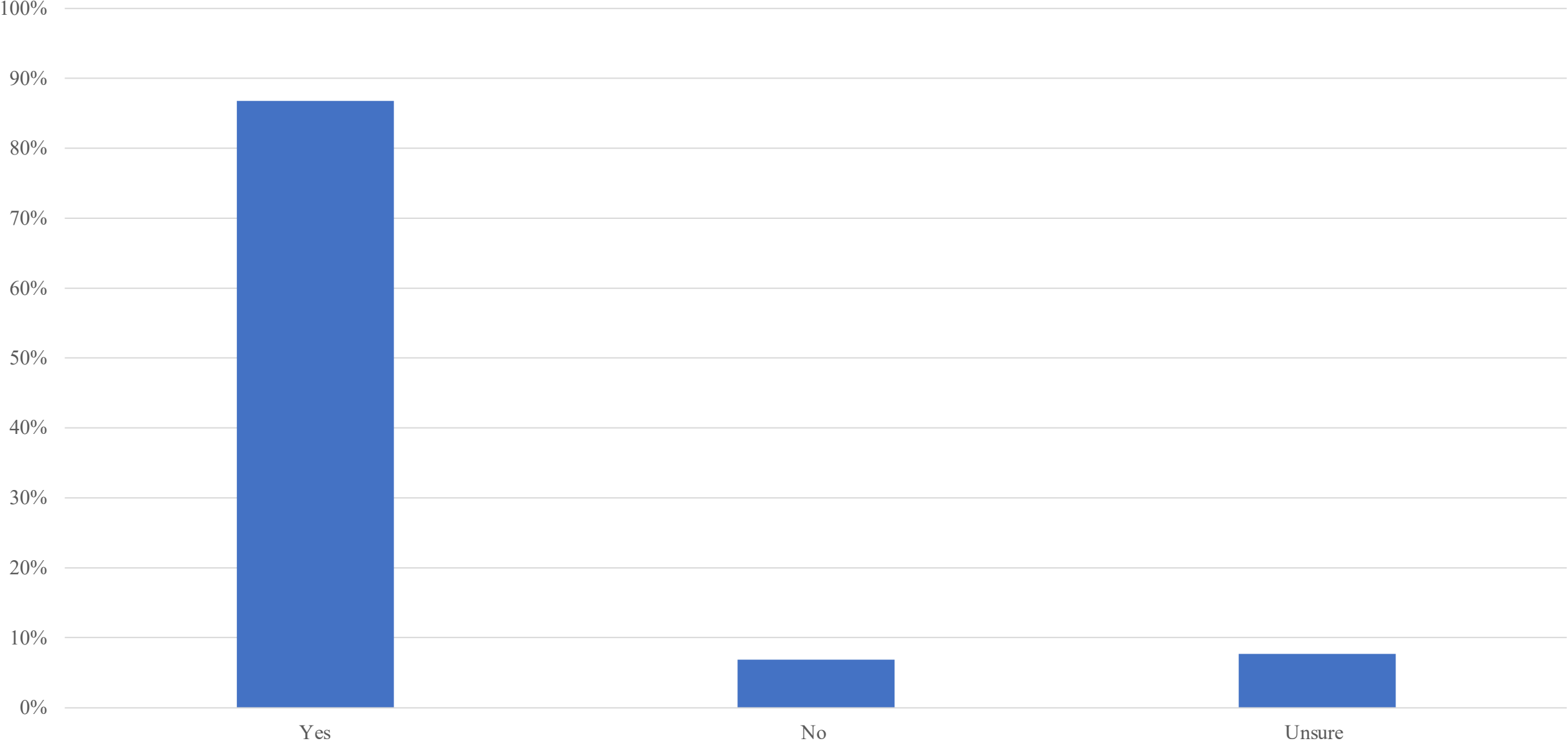


If you are vaccinated, do you plan on vaccinating your child against COVID-19 when they are eligible? (N=341)*



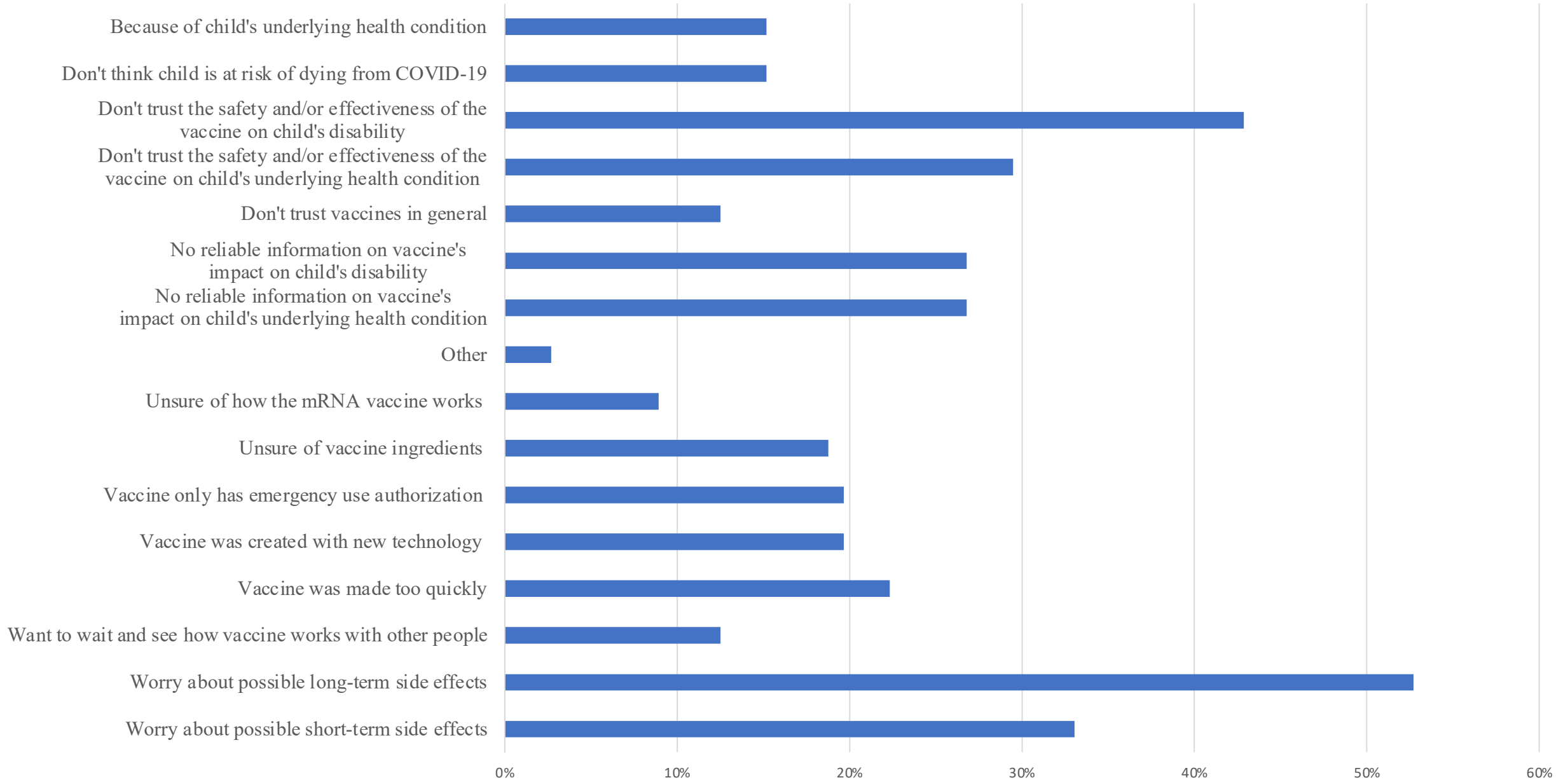
* Data shows answers from vaccinated and unvaccinated parents

If you are vaccinated, do you plan on vaccinating your child against COVID-19 when they are eligible?* (N=273)



* Data filtered by parents who reported being fully vaccinated

If you said no, or if you are unsure, why? ** (N=195)



* Responses from vaccinated and unvaccinated parents

Survey Appendix

Answer question to the following question: Please share your concerns about being vaccinated against COVID-19.

Worry about possible short-term side effects

Will there be any adverse reactions.

What should I pay attention to after vaccination.

What should I pay attention to after vaccination

What are the adverse effects of fear.

We had COVID, and have heard and read the studies on natural immunity. I don't feel like taking a possible risk for something that will give us about the same immunity that we already have.

We don't know long term side effects of this vaccine- hasn't been studied long enough.

unsafe

Too much unknown for future health issues

The whole family already had Covid-19 in November 2020. We already have immunity.

The vaccine has not been out long enough to have long term studies and know possible side effects. Everyone I know who receives the vaccine gets sick.

The vaccine has just been developed, for fear of side effects.

The vaccine has just been developed, for fear of side effects.

The only concern is the safety of the ingredients.

t don't worrid

Scare tactics , new world order

Safer than not be vac.

Question 3: Please share your concerns about being vaccinated against COVID-19

Pregnant. Just waiting till after baby is born just incase of side effects.

None

No long term studies yet to prove effectiveness or long term side effects.

No data on long term affects. Media is not honest with deaths from the vaccine. If you look off google sites, several articles.

My husband and I are fully vaccinated I am hesitant for our 14 year old daughter with neurological problems. Just scares me a bit as my migraines have been worse since the vaccine.

Medical issues and vaccine reactions in the past.

It's too new. I have had major long term consequences due to medicine I was forced to take. So until I know it's safe I may or may not get it

It is not FDA approved and they did not do the YEARS of testing they do for vaccines (up to 10 years)

It has not been approved by the FDA It has not been tested on people long enough, My Daughter has DownSyndrome and Heart problems, There has not been any testing on Kids with DownSyndrome.

I've had covid. I fully believe data has been skewed and that the numbers the CDC presents are not done in integrity. If I believed they were, I might be concerned, but there has been way too much spinning data to fit an agenda.

I've gotten the first shot after a lot of hesitation

I've already had Covid so what's the point of getting the vaccine. It does not prevent Covid only lessens the symptoms and I am not willing to make the short term more comfortable when there could be unknown long term effects since this is the first mRNA vaccine on the market.

I'm not sure if it's safe

I'm afraid of side effects

I'm afraid of side effects

I'm afraid it's bad for my health

I'm afraid it's bad for my health

I think it's risky

I think it's a big risk.

I don't know the composition or the risks of COVID-19

I don't know if there's any risk to my health problems

I don't feel at ease about this epidemic now hospitals have no way to treat and there is no specific medicine how can the vaccine work

i don't worrd

I am vaccinated to protect myself and my family/friends

I am concerned about fertility and DNA long term effects. And it is not FDA approved.

I already had covid-19 and believe that my antibodies are more effective than the shot. I also have underlying medical conditions and I am not willing to get a shot that hasn't been adequately tested.

i have no worrid

First of all this isn't a vaccine. It is a shot. Because it is not proven to provide immunity. I have family /friends that have had severe long lasting side effects from taking the shot. i.e. shingles, paralysis, Guillain-Barré syndrome, and many have still experienced COVID19 symptoms.

Fear of side effects

Family does not receive any vaccinations

Don't believe in the safety of vaccines

Death rate for vaccine has not been in media but in other countries sharing real data.

Autoimmune issues & multiple doctors have told me to wait.

all in the house have been vaccinated except our 12 yr old. Husband has serious concerns about the vaccine when it comes to our son. His friends' child is one who was a healthy child now has issues since the vaccine was given. My husband and I have been having lasting issues constant headaches and joint pain since getting the shots. So will wait for now on our son.

Que no sea efectiva y tenga complicaciones

Answers to the following question: Please share any additional information regarding concerns you have about vaccinating your child against COVID-19 or about the COVID-19 vaccines in general.

Worrying about possible side effects

Worry about vomiting

Worry about side effects and safety

Worry about side effects

Worried about the side effects of the vaccine and the safety of children

Worried about swelling

Will there be any adverse reactions.

Whether to the body health side effects.

Whether the ingredients in the vaccine have side effects

What are the side effects.

We are hopeful our kids (7 and 9 yrs old) will be eligible to be vaccinated soon. I am more concerned about my sons (especially my son with Down syndrome) getting COVID-19 than I am about the COVID 19 vaccine. I have done research regarding the vaccine.

Waiting for the age limit to be lowered more to make sure all my kids are protected
unsafe

This is a life-death issue. The vaccine doesn't kill. the virus could.
there is no

The vaccine has no side effects in children under the age of 18

The vaccine has just been developed, for fear of side effects.

The vaccine has just been developed, for fear of side effects.

The only concern is the safety of the ingredients

The main concern is about the safety of the vaccine

The heart inflammation issues among young men receiving the Pfizer vaccine are concerning. But, when considering the extremely low incidence of that particular side-effect and the comparative risks of contracting COVID-19, the vaccine still seems to be the best option.

The death rate in children is so low that the risk of long term side effects is of greater concern.

Temporarily no

Temporarily no

Tell me exactly what's in the COVID-19 vaccine.

swelling

Sorry we read everything put out on the vaccines and felt very comfortable vaccinating our children. So happy I have teenagers who can be vaccinated.

Side effects and safety

She is too young. She is 12 months old and isn't eligible

Security issues

Same as above. The known risks doesn't out the way unknown benefits.

Same as above

Safety and side effects

Safety and side effects

Pregnant women and children were excluded

Overall I believe risk is low for both of our children, especially our son with autism. Possible exposure is low since he is at home, and most that interact with him are vaccinated or have low exposure as well.

Our child received both doses of the Pfizer vaccine. The second dose really knocked him out. Had a fever (100.8), ate very little, and slept for almost an entire day. We kept rotating ice packs, offered water, and plenty of popsicles. Everyone reacts differently to the vaccine. Parents should just be prepared that their child may experience some of these symptoms (even if they didn't when they received the vaccine).

Not sure about the long term effect.

Not applicable

None. All of my children who are eligible for the vaccine are vaccinated and we are impatiently awaiting authorization for my younger children.

NO WAY would I ever give my child this vaccine. Even if it was not emergency status.

Need more studies with children with Ds. Don't know long term effects. More likely to have mild symptoms anyway if get Covid.

N/A

My son already has 3 heart issues. I definitely don't want to give him the vaccine with possible side effects.

My only concern is that it's not available for younger children yet and AZ is not allowing schools to mandate masks. Kids will get sick! This is not safe!

My kids don't believe it's safe

My kids don't believe it's safe

My husband is concerned about giving the vaccine to our children at this time. So we are going to hold off.

My children had covid. One has a runny nose for 36 hours, the other coughed for 48. This has been blown so far out of proportion it's unreal and we need to take our government back from this nonsense.

My children are terrified of vaccines

My children are fully vaccinated. Everyone in house is.

My child is afraid of its side effects

My child is afraid of its side effects

My child is afraid of injections

My child is 19 years old. I am his guardian.

my child has been fully vaccinated for several months

My child has already received the vaccine.

My child already had the Covid-19 virus last year. She already has immunity to it.

It would be child abuse to do this to any child with not having long term data to show how it would affect the child long term.

I'm just concerned how effective the vaccine will be on my child with his underlying health issues. Also, will the vaccine make their underlying health issues worse and if they will have greater side effects from the vaccine due to their disability.

I would like to know more about the composition of the COVID-19 vaccine.

I worry about my child having an allergic reaction but worry more if they catch Covid from school. Especially now that no one is wearing masks.

I will discuss with my child's doctors when it becomes available and decide at that time .

I was very concerned as I believe he reacted horribly to his 1 year old vaccines and that this was associated with his Autism and his numerous medical conditions thereafter. With COVID-19 and his compromised immune system, I felt I had to vaccinate him, which I did.

I was advised to not get vaccinated as an immunocompromised adult due to a genetic condition. I chose to get the more traditional J&J vaccine AMA even though my genetic specialist told me not to. After I had several conversations with my PCP & other MDs and researched any allergies to the J&J ingredients, I decided to take the J&J vaccine anyway. I hope to get a Covid antibody titer test to see if I made antibodies. Because my condition is genetic, the MDs said that my children should only receive the J&J vaccine and not the mRNA vaccines. Since the J&J vaccine is not available to those under 18, my children will have to wait to get the J&J vaccine unless it is approved for children in the future. My children are also not eligible for J&J child clinical trials. And, yes I have had extended side effects from the J&J vaccine as all of the MDs thought I would. The MDs who have patients who have received the mRNA vaccines told me that in patients like me immunoresponses were severe and expected mine to be as well; so they agreed that I or my children should not take the mRNA vaccines. Not all of us are against vaccines, but I, my family members, and my children have had severe allergic reactions to other vaccines and are cautious.

I vaccinated my children as soon as they became eligible and I'll continue to do the same for my younger children. As a family, we have all worked hard to keep my oldest and medically fragile daughter safe so getting the vaccine is just part of that mission.

I vaccinated my 16 year old dd son the first day he was eligible. He was able to go back to in-person for the last 5 weeks of school. :)

I trust in science, that about covers it.

I spoke to my daughters' pulmonologists and they told me to absolutely protect them with vaccination. Both of my 12-17 year old very medically complex children have been vaccinated along with all other 12-17 year old children in our home.

I have to know what's in the COVID-19 vaccine and all the risks.

I have concerns about other people NOT getting vaccinated.

I don't want them to get sick from the vaccine and I don't know what long term side effects there are. To me, the risks outweigh the alleged benefits.

I don't believe the vaccine will be as beneficial as the government is stating. I believe there to be greater risk for long-term side effects and I do not want my children to be a science projects.

I don't believe that children need to be vaccinated. They are healthy and the majority have no symptoms.

I am very frustrated at the states push for members and families to get vaccinated. It is an individual choice. Yes it should be available to those who want it but it should not be pushed on those who don't.

He's 3 and already has a lot against him. Not sure I want to put him at risk of anything we don't know the long term effects of right now.

For fear of health risks to their children

Fear of uncertain risks

Fear of Side Effects.

Fear of Side Effects.

Fear of Side Effects

Don't feel it should of been released to soon with out being tested more.

Don't believe in the safety of vaccines

Daughter is type 1 and step son autistic

Children who are physically healthy have a 1 in 500,000 chance of dying from Covid. And a much higher risk of having severe adverse reactions from the vaccine. When the risk for the vaccine is far higher than the risk for Covid, it's a no brainer. If people would do real research and not just listen to main stream media they would realize this. Pushing vaccines on healthy children is disgusting

Better Safe than Sorry

As soon as eligible and after reading about the vaccine I got it for myself and family. I did this for my family and to protect those who cannot get vaccinated because a medical professional told them they cannot get vaccine.

All household members including children who can be vaccinated, have been vaccinated.

Todos en el hogar incluyendo los niños de 12 en adelante estamos completamente vacunados

Propiedad política

Mi hija de 12 años ya está completamente vacunada. Desde el primer día que fue elegible la llevé para su primera dosis. Ella tiene autismo.

Yo estoy de acuerdo con la vacuna, puesto que si ya hay vacunas para otros virus o enfermedades ?

Porque no creer en esta ?

Nuestros hijos con discapacidad , estan deviles , pues a ellos les ataca mas fuerte cualquier enfermedad, yo estoy de acuerdo y mi hijo de 22 años ya tiene las 2 dosis....