

Autism and COVID Vaccines

Webinar Q&A

Below are questions submitted to our Autism & COVID Vaccines webinar held Wednesday, January 27, 2021. Responses are provided by Autism Speaks staff.

Panelists contributing to the COVID Vaccines and Autism webinar:

Moderator, **Stuart Spielman**, Senior Vice President of Advocacy, Autism Speaks

Dr. Georgina Peacock, MD, MPH, FAAP, Director, Division of Human Development and Disability, CD

Arun Karpur, Director of Data Science, Autism Speaks **Christopher Banks**, President and CEO, Autism Society of America **Alison Singer**, President, Autism Science Foundation

Vaccination and Health

How are folks with autism responding to the COVID vaccine so far? Any higher risk of side effects from the vaccine or interactions with medications?

We do not have evidence that people with autism have had different responses to the COVID vaccine than the general population, including side effects and medication interactions.

What about adults who are living at home with families?

Adults who are living at home with their family are also recommended to get the vaccine as soon as they are eligible. You should always talk with your health providers about vaccine decisions and other health concerns.

Where can we find the app for v-safe?

You can register for V-Safe [here](#) to report any side effects you may have after getting the COVID-19 vaccine.

Do kids with autism have a higher risk for complications if they do get COVID – aside from exposure risks due to behavior challenges - just because they have autism (assuming no other medical conditions)? What are the differences between how the COVID-19 pandemic has

the map or finding it in the list [here](#).

affected individuals with disabilities and people with autism?

We do not have any scientific evidence that autism alone is a risk factor for complications from COVID or severe disease, in children or adults. The data that we do have is linked to residential settings and behavioral and communication challenges that increase exposure risks, as well as other health conditions that increase risk for complications. Autism Speaks is currently studying private hospitalization data, obtained through Fair Health, to find out whether an autism diagnosis is linked to greater risk for hospitalization from COVID and other health outcomes.

Do scientists fully understand the cognitive effects of COVID?

The CDC provides some details about cognitive effects of COVID infection [here](#).

Will caregivers or parents be given priority access to the vaccine as well?

Many direct support professionals may be eligible for vaccine access in Phases 1a, 1b or 1c, depending on how your state decides to distribute its vaccine allocation. Please check your state's vaccine rollout plan for details on when you may be eligible based on your type of job. Many state departments of health, developmental disability divisions, and/or

governor's websites offer relevant information on these plans. Parents of people with autism, absent other qualifying status in phases 1a, 1b or 1c, would be eligible in Phase 2.

Is seizure disorder considered an underlying medical condition that would increase my child's risks for complications from COVID? What are the risks of vaccination for people with autoimmune conditions? What are the underlying conditions that put someone at increased risk for complications or severe disease?

Yes. The full list of conditions that increase risks are available [here from the CDC](#). People with [autoimmune conditions](#) may get the vaccine. Your state may also include other medical conditions in their vaccine plans. Check your state's vaccine plan [here](#).

Do masks provide better protection than the vaccine? Should we continue to wear masks even after we have the vaccine? Can someone who has been vaccinated still pass along the virus, even if he doesn't get sick himself?

The vaccines currently in use are [95](#) (Pfizer) and [94.7](#) (Moderna) percent effective in preventing COVID19. Protection using masks varies widely depending on whether both people are wearing them, materials, and how they are worn. We also [don't yet know](#) whether getting a COVID-19 vaccine will prevent you from spreading the virus. That's why the CDC recommends vaccination as well as everyone who is vaccinated to continue to protect others by wearing masks, social distancing, washing hands regularly and avoiding large gatherings.

Will the vaccines protect people from new variants of the virus?

These studies are also [underway](#). The two vaccines that have EUA appear to be effective against new variants of this coronavirus.

Were the vaccines tested on anyone in the autism community?

People with disabilities who met the study criteria were included in the clinical trials, so the data on side effects, safety and efficacy are represented in what we know about the vaccines currently in use. The data do not go into detail about autism as a specific diagnosis.

My family recently recovered from COVID. Should we get blood tests for immunity after 90 days? I would not want us to get the vaccine if we still have immunity.

The [CDC recommends](#) that people who have had COVID should still get the vaccine when they are eligible. We do not yet know how long people who have had COVID are immune, or if they can pass it to others. You should also continue to protect yourself and loved ones by wearing a mask when interacting with people outside of your household, social distancing in public, washing hands frequently and avoiding large gatherings. If you have recently recovered from COVID, you should wait 90 days before receiving a vaccine.

How have they defined "high risk conditions?" NY is in Phase 1b but hasn't defined it.

The CDC has detailed the high-risk conditions that increase someone's risk for severe disease. States have the discretion to modify this list to some degree based on their health data, needs and populations. New York state's vaccine plan is available [here](#).

Has anyone who has received the vaccine gotten COVID19?

The current COVID vaccines take effect two weeks after receiving the second dose, so it is possible that you can contract COVID if exposed to infected people before that time. That is why the CDC recommends [vaccinated people](#) continue to practice social distancing, wear masks and wash hands.

Should pregnant women get vaccinated?

Yes. [According to the CDC](#), there is currently no evidence that antibodies formed from COVID-19 vaccination cause any problem with pregnancy, including the development of the placenta.

How many participants on the autism spectrum disorder enrolled in Phase 3 trials for both the Pfizer and Moderna? Any adverse reactions in this population not related to other underlying risks already known?

The exact number is unknown because the publicly available data does not specify autism as a condition separated in the analysis.

How long will the vaccine protect someone from COVID?

The vaccine offers protection from severe disease and complications. Because long-term follow-up is still being conducted, we don't know how long immunity will last.

I am unable to get a flu shot because of Guillain-Barre Syndrome. Is it safe for my son with underlying health conditions to get it since I cannot?

Please ask your healthcare provider about whether the vaccine is appropriate for your personal health situation.

Some people have experienced allergic reactions to the vaccine. Have there been any cases of people who may have autistic symptoms showing a change in the presentation of those symptoms?

We are not aware of any cases showing a change in autism symptoms due to the COVID19 vaccine. Find out more about allergic reactions and adverse reactions reported [here](#).

Accommodations, Vaccine Priority and Access

Our state is offering the vaccine in a setting that is not appropriate for my loved one's needs and will cause her to be overwhelmed or trigger behaviors that will keep her from entering the site. Can we request an accommodation from the site in advance to have her vaccinated in the car or another manner? Who do I ask for accommodations?

You should ask for needed accommodations, and we have been told that in various locations throughout the nation there are drive-

through options, clinics where the staff will provide the vaccination outside on the sidewalk when needed, or other options you might consider. Most state and local governments, and in some cases vaccination site operations staff, have contact numbers or email addresses for their vaccination programs and we recommend starting there. We recommend trying to make those arrangements in advance if possible, and also discuss with the site staff when you arrive to ensure any advance plans for accommodations are implemented. Patience and persistence may be necessary to get to the correct person to help. If that fails, we recommend talking to your loved one's primary care provider about this.

Can I choose not to get the vaccine? I'm concerned that my nonverbal child can't express side effects.

Vaccination is a personal choice you should discuss with your health provider. However, side effects in the clinical trials were found to be minor. The CDC has some [tools](#) to help explain to your child what to expect from a vaccine, including what side effects they may have. You may also find [this teaching story](#) helpful.

What are the criteria public health authorities are using to prioritize various disabilities?

Dr. Peacock elaborates on the [vaccine recommendation process](#) in her presentation. The Advisory Committee on Immunization Practices reviews all available clinical trial information to [provide recommendations to federal, state, and local governments](#) about who should be vaccinated first. While CDC makes recommendations for who should be offered COVID-19 vaccine first, each state has its own plan for deciding who will be vaccinated first and how they can receive vaccines.

Some health care institutions are allowing family members of health care employees to get vaccinated. What advice would you give if you are getting the run around on providing a vaccination to those with disabilities?

States are deciding how to distribute the vaccines and are responsible for adhering to priority access

recommendations. Many are experiencing much higher demand than they have supply and it has been difficult to get an appointment. If you or a loved one are eligible under your state's vaccine plan, we suggest you contact your county and state health departments to find out where vaccine sites are in your area and how you can sign up for an appointment. Patience and persistence are required, given the unprecedented nature of this situation and the way vaccinations are being rolled out across the nation.

When will the vaccine be available to all autistic people?

Under the current guidelines set by the ACIP, autistic people who don't fall into one of the Phase 1 groups – in congregate facilities or with an underlying health condition – will be eligible when access opens to the general public. Check your [state's vaccine plan](#) to see if people with disabilities or autism specifically are included in earlier phases.

Could you provide more detail on who will be vaccinated in Phase 2? Under what circumstances would someone be recommended for the vaccine and by whom?

The CDC's vaccine distribution phase recommendations are [here](#). Generally, Phase 2 means that people not covered under early phases – the general public – would be eligible to receive the vaccine.

I have an adult son with autism that is afraid of receiving a shot. Do you think there will be other alternatives such as nasal doses?

We are not aware of alternative delivery methods currently in development.

Advocacy and Support

Some individuals with autism cannot wear a mask or understand what social distancing means. Why isn't Autism Speaks and DDS advocating to vaccinate people with autism that do not understand how to protect themselves?

Autism Speaks is advocating for people with autism and other disabilities to have priority access to the vaccines. We [joined](#) Autism Society of America, Autism Science Foundation and other disability groups in calling for priority access to the vaccines for people with autism and other developmental disabilities. Those decisions are made by each individual state. We are also analyzing health data that looks specifically at autism as a risk factor for health outcomes from COVID. This will be useful in advocating for priority access to the vaccines for the autism community.

Can a person who has Autism have a family member go in the hospital with them to advocate for them now?

Early in the pandemic, families and advocacy groups realized that prohibiting family members or support people for persons with disabilities was preventing them from fully participating in their healthcare decision-making. Autism Speaks [advocated](#) for states to allow access to a support person for people with disabilities, including autism, when receiving health services. Many states issued explicit guidance to healthcare organizations operating in their jurisdiction to allow this accommodation.

My child has significant support needs and self-injurious behaviors. He requires 24-hour care. My state is only offering the vaccine to people with autism when it is coupled with another illness. I was told he would be put in general population category for the vaccine which would take a very, very long time. Is there anything more I can do?

We suggest talking to your child's healthcare provider for any local advice, if you have not already done this, and if necessary seeking out assistance through any consumer help line in your county or state or through your member of Congress' constituent services staff.

Will the vaccine be mandatory for people who work with people with disabilities?

There are no mandatory vaccination schedules in the

U.S. Childhood vaccines are recommended by the ACIP and other professional medical organizations like the [American Academy of Pediatrics](#). Many health-related employers require annual influenza vaccinations and other medical screenings for employees with direct patient care. Check with your employer to find out if these policies may apply to you.

How can I advocate that my teenage son who has autism should receive this vaccine in an early phase? He is not able to wear mask and doesn't understand distancing?

The CDC recognizes that people with [behavioral and communication challenges](#) with health and safety practices may have trouble following health practices, communicating symptoms or side effects, and accessing or understanding information. The ACIP recommended that those with underlying medical conditions, living in congregate facilities and working in frontline roles get priority access because of the data showing these populations pose a significant exposure risk and risks for severe disease.

Does the autistic population have a higher risk of fatality vs. the broader population in general? Can we assume younger folks in that group fare better?

Most of the data that we have about mortality is associated with other diagnoses that often overlap with autism. In some [states](#), individuals with intellectual disability have been found to have a higher mortality rate from COVID.

How can we talk to our family members with autism about vaccines when they do not understand language?

The CDC has developed [some materials](#) to help people understand [how the vaccines were developed](#), as well as a [toolkit](#) that features one-page flyers, images, audio and video resources about COVID infection, the vaccine and [what to expect](#) when getting the vaccine. There are also several organizations and state developmental disability agencies who have developed vaccine education materials: [New York](#)

[OPDD](#) and [SARTAC](#) are two examples. Check your state disability agency's website for additional supports. [Autism Speaks](#), [Autism Society of America](#) and [Autism Science Foundation](#) also each have COVID resources specific to the autism community.

What documentation does the autistic person need to provide to verify their condition?

Check with your county health department or the vaccine clinic provider about the documentation required in your state.

COVID Vaccines and Children

If you are a teen or child under 12 and have autism and/or ADHD and are otherwise in good health, are you as at risk as people in nursing or congregate homes?

With no other underlying medical conditions and if the child is living at home, there is no evidence that autism or ADHD increase risks for developing complications from COVID.

Is the vaccine safe for teens and children 5 and above?

Clinical trials about the safety and efficacy of the COVID vaccine candidates are under way for teens and are still in the planning stages for young children. So, we don't know the answer to this question yet. The Moderna vaccine that has EUA from the FDA is approved for people 16 and older, and the Pfizer vaccine is approved for people age 18 and older.

How should we handle a child who is under the age of 5 to wear a mask? Are face shields as effective as masks? We are trying to find alternatives for our toddlers who can't wear a mask.

The CDC [does not recommend](#) using face shields or goggles as a substitute for masks. To support those who struggle with wearing a mask, Autism Speaks has videos for [autistic adults](#) and [caregivers/parents](#) to work on learning this skill.

What is the outlook for children under 18 to receive the vaccine?

The Moderna vaccine is available to teens age 16 and 17 in addition to adults. Clinical trials about the safety and efficacy of the COVID vaccine candidates are under way for teens and are still in the planning stages for young children.

How do we keep children under 16 safe if they're not eligible for a vaccine yet?

The best way to [protect yourself and loved ones](#) is to continue to wear a mask when interacting with people outside of your household, social distance in public, wash hands frequently and avoid large gatherings.

What is your medical professional judgement regarding teens with ASD and comorbidity conditions receiving the COVID-19 vaccine?

You should talk with your health provider about your or your child's unique health situation to decide about vaccination. In general, teens who are age 16 and 17 with one of the underlying health conditions listed here should receive the Moderna vaccine, which is approved for those ages, as soon as they are eligible.

A recording of the webinar is available on the [Autism Speaks YouTube channel](#).