Autism and COVID Vaccines FAQ

These Frequently Asked Questions (FAQ) about COVID vaccines and the autism community were prepared following the Autism and COVID Vaccines webinar, held virtually on Wednesday, Jan. 27, at 4:00 p.m. ET. Find a recording of the webinar here. Please click on the hyperlinks in this document to find resources and information from our webinar partners and the scientific community.

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, CDC
Dr. Arun Karpur, Director of Data Science and Evaluation Research, Autism Speaks
Christopher Banks, President and CEO, Autism Society of America
Alison Singer, President, Autism Science Foundation

How does COVID affect people with autism?

Most of what we know is not specific to people with autism, with a few exceptions. For example, autistic people who live in residential settings with many other people, which we call congregate facilities, are more likely to contract COVID, much like older people in nursing homes. But also, people with autism have higher rates of underlying health conditions, and those conditions put them at risk for severe disease if they get COVID. People with behavioral or developmental conditions like autism may have other difficulties with preventive measures and communication. Some states have found people with intellectual disability, some of whom also have autism, may have a greater risk of dying from COVID if they become infected. And, for people who need direct support, that also comes with greater exposure risk because service providers often see multiple people in a day or a week and close contact is unavoidable. All of these are reasons it is critical to get one of the approved COVID vaccines as soon as you are able.

We also know that the pandemic has increased food and housing insecurity as well as disrupted access to learning supports for people with autism. Autism Speaks is also researching hospitalization data to find out more about how COVID affects autistic people. These findings will be released in spring 2021.

Who is distributing the new COVID vaccines?

Each state or territory decides how to distribute its vaccine supply. The federal Advisory Committee on Immunization Practices recommends who should get vaccinated first, based on what scientists know about COVID infection and risks for exposure and severity of the disease. Once people were grouped into phases, the CDC shared that guidance with states so they could plan how to best deliver vaccines to their residents based on each state’s needs.

Leadership in all 50 states, the District of Columbia, territories and tribal areas will communicate about current and upcoming phases of vaccine rollout where you are. You can find your state or locality’s COVID immunization plan and contact information by clicking on your state on the map or finding it in the list here.

How do I know if I am part of the current phase?

Talk with your healthcare provider about your health
conditions, living situation and their advice about vaccination. Your unique health situation will determine your phase. In general, if you have a medical condition that puts you in the risk category for the current phase your area is in and you meet the age criteria, it is recommended that you get a vaccine as soon as you are able. Your state or local health department will determine what is required for proof of your eligibility.

What do we know about the vaccine and people with autism?

The clinical trials for the vaccines currently in use included people with disabilities who met the study criteria. However, the public data does not go into detail about autism as a specific diagnosis.

I’m nervous about getting the vaccine. Are the vaccines safe and effective for people with disabilities like autism?

People with disabilities who met the study criteria were included in the clinical trials for the vaccine candidates that recently received emergency use authorization from the FDA because they were shown safe and effective in the trials. Because of what we know about how COVID affects people with disabilities, including autism, getting a vaccine is the best way to protect yourself and your loved ones from severe complications from COVID.

Once you get your vaccine, you can check in with your healthcare provider to let them know how you are feeling. The CDC also offers the v-safe health check, an app where you can report any side effects, even mild ones, so they can keep track of how the vaccine is affecting people who get it.

When will I or my loved one with autism get the vaccine?

It depends on what state you live in, what phase your state is in and your situation. Children under 16 will not be eligible for the vaccine until after the FDA approves a vaccine for use in children, which will likely happen much later this year. If you live in a group housing facility or have one of the medical conditions in the guidelines, you may be eligible now to make an appointment. If your county is in a different phase, you would need to wait until that phase begins in your area. In addition to the state information, you can also call or check the website of your county health department to find out how to get the vaccine near you. Many counties have set up a system where you can enter your phone number or email address so they can notify you when the vaccine is available, and when new phases of the rollout begin.

Visit cdc.gov/vaccines/covid-19 to select your state from the drop-down list to find your state’s vaccine plan and contact information for your local health authorities. They will have the most updated information about how to get a vaccine near you.

Can children get one of the new vaccines?

The two vaccines currently in use are not available to young children. The Moderna vaccine is only for people age 18 and older, and the Pfizer vaccine is only for people age 16 and older. The federal science committee that oversees the vaccine guidelines met on Jan. 27 and shared that clinical trials are ongoing with teens. Studies with younger children are still in the planning stages.

Where can I learn more about the vaccines with accessible tools?

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.

**My adult child has autism. How do I prepare them for this vaccine?**

You know your child best, so think about how they best receive information. The CDC has tools and resources to help explain the vaccine and what to expect after receiving the vaccine. You may also find a teaching story or other visual support helpful. When you share this information is also important. Give your child the time they need to best process the information before the appointment and your plan for helping them feel better if they experience side effects. The CDC also offers its COVID information center in Spanish, Chinese, Vietnamese and Korean, and several of its resources in other languages.

A recording of the webinar is available on the Autism Speaks YouTube channel, where you can turn on automatic closed-captioning in English, Spanish and other common languages for additional support.

If you are interested in volunteering to help us advocate for policies that benefit people with autism and their families, please visit autismspeaks.org/advocacy to join our Grassroots Advocacy Network and learn more.

Our Autism Response Team can answer your questions, connect you with tools and resources, and help you find autism services and supports in your community. Call 1-888-AUTISM2 (en español 1-888-772-9050) or email help@autismspeaks.org.