# COVID-19 Vaccine Hesitancies & Barriers

Centers for Independent Living (CIL) are the best experts in addressing and removing barriers for people with disabilities. Throughout the country, COVID-19 has caused additional barriers to our community. It is important that all CIL staff understand the hesitancies to have a better understanding of the concerns the consumers may have.

Vaccine hesitancy for people with disabilities is often related to their past experiences or fear of how the vaccine will impact their disability. A lot of disability-specific hesitancies and barriers are not considered or included in the public information. Therefore, it is critical for CILs to include disability-specific information, education, and solutions to barriers when putting out information about COVID-19 vaccinations.

People with disabilities can be considered a high-risk population. On the national level, one in four people has some type of disability. Lack of access to healthcare is the biggest barrier people with disabilities face when seeking COVID-19 prevention, treatment, and education.

## Common Disability Vaccine Hesitancies

Below you will find the common vaccine hesitancies among people with disabilities. Although this is not an exhaustive list, it is encouraged to collect information about vaccine hesitancies that may be unique to your service area.

### Hesitancies

1. Not trusting the safety and/or effectiveness of the vaccine and the impact on their disability
2. Fear of worsening or aggravation of a person’s current disability or underlying medical conditions
3. Fear of side effects from the COVID-19 vaccine
4. Concerns about any long-term side effects of the vaccine
5. Previous trauma and reactions to vaccines
6. Lack of trust in medical professionals from experience
7. Not trusting the information about vaccines because it doesn’t include information about people with disabilities and/or it’s not accessible

### Responding to Disability Vaccine Hesitancy

It is important to provide information and facts about how COVID-19 vaccines and boosters are safe and that science can be trusted. You can respond to vaccine hesitancies through outreach and education, one-on-one services, during the information and referral process, and whenever you learn about the fear around the vaccines. The Question and Answer (Q&A) section in this education toolkit can also be helpful when addressing vaccine hesitancy.

### Strategies to Use to Address Vaccine Hesitancy

* Debunk misinformation by providing facts and addressing disability-related concerns.
* Provide accessible information that addresses disability-related concerns. Ensure you have alternative formats and information available in other languages. Remember, the lack of accessible information is one of the disability community’s biggest barriers, so it’s critical for your CIL to provide the extra steps to ensure the information you are sharing is accessible. You can learn more about making your information accessible in the accessibility section of this education toolkit.
* Elevate the stories of leaders in the disability community who decided to get vaccinated. People with disabilities have had experience with their own hesitancies and concerns. Because disability stories aren’t being released within general education, it is important for CILs to make sure they are sharing these stories, so your consumers know they aren’t alone.
* Provide education about how people with disabilities are at an increased risk of getting very sick or dying from COVID-19. [Check out the CDC’s high-risk groups](https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html). Remember, disability or a diagnosis may not be the only reason someone may be considered high risk. They could also be at increased risk due to social determinants, barriers with understanding information, support needs that prevent them from following safety protocols like social distancing, and other related concerns.
* Respond to hesitancies individually and within safe groups. You can provide peer-to-peer support to build trust so concerns can be addressed by trusted people.
* Listen, don’t be judgmental, and provide assistance navigating and processing their concerns.
* Share personal stories of people with disabilities getting vaccinated.

### Other Strategies to use When Addressing Vaccine Hesitancy

#### Side Effects are Normal

Vaccine side effects are normal for people with and without disabilities. Not everyone will experience a side effect but providing education about what your consumers may experience is important. Below are the common temporary side effects from the COVID-19 vaccine:

* Pain, redness, or swelling where you received the shot
* Fever and chills
* Headache
* Nausea
* Tiredness

If your consumer has any of these side effects, it can mean the vaccine is working, and their body is learning to protect itself against COVID-19. Side effects should go away after a few days. If your consumer is worried about any side effects and how it may impact their disability, direct them to their medical doctor.

[V-Safe](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/safety/register-for-v-safe.html) is a great resource to share with your consumers to track any side effects they may have. V-Safe lets your consumers tell the CDC about any side effects they may have after the COVID-19 vaccine. Depending on the side effects they disclose, someone from the CDC may follow up with them if there are concerns.

#### The Vaccine and the Impact on Disability or Health Condition

COVID-19 can cause severe sickness or death consumers don’t do everything possible to protect themselves. Adults with specific disabilities and medical conditions have a higher risk of getting sick and dying from COVID-19. Clinical trials show that COVID-19 vaccines are safe and work in people with disabilities and medical conditions.

Sources:

* [Underlying Medical Conditions Associated with Higher Risk for Severe COVID-19: Information for Healthcare Providers](https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/underlyingconditions.html#ref_15)
* [People with Certain Medical Conditions](https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html)

### Address Misinformation about Safety and Effectiveness

#### Consumers may think that the vaccines give people COVID-19. Is this true?

No. None of the COVID-19 vaccines approved in the United States contain the live virus. The vaccines approved in the United States are the Pfizer vaccine, Moderna vaccine, and the [Johnson & Johnson (J&J) vaccine](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/different-vaccines/janssen.html). These shots do not use the live virus. They can’t make you sick with COVID-19.

Source:
[Myths and Facts about COVID-19 Vaccines](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/facts.html)

Additional Resources:

[CDC’s Johnson & Johnson’s Janssen COVID-19 Vaccine Overview and Safety](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/different-vaccines/janssen.html)

#### Consumers have seen people still get COVID-19 after being vaccinated. How should we explain this?

In most cases, the COVID-19 vaccine will prevent you from becoming sick and going to the hospital if you test positive for the virus. Below are some facts:

* Most of the people in the hospital with COVID-19 have not been fully vaccinated. This means they have not received all the recommended doses of the shot.
* You can still catch the virus from someone after you get the shot. This is called a breakthrough infection.
* If you got the shot and still get COVID-19, you will most likely have mild symptoms. The vaccine helps you not get as sick as you could if you were not vaccinated.
* Getting vaccinated is your best chance at protecting yourself from getting very sick, going to the hospital, or dying from COVID-19.

Source:
[How CDC Monitors COVID-19 Vaccine Effectiveness](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/effectiveness/how-they-work.html)

**Consumers may think they don’t need the vaccine or booster because they already had COVID-19. What do we tell consumers?**

It is possible to become sick with COVID-19 more than once. Scientists have learned that getting the shot may protect you from COVID-19 better than natural immunity. Below are the facts:

* After getting sick with COVID-19, you may have “natural immunity.”
* Natural immunity from COVID-19 happens when your body produces antibodies to fight off COVID-19 after you have been exposed to or gotten sick with the virus.
* It may offer some natural protection, but experts do not know how long it lasts.
* Natural immunity may not protect you from COVID-19 variants.
* Consider getting your COVID-19 vaccine to protect yourself and your community.

Sources:

* [Types of Immunity to a Disease](https://www.cdc.gov/vaccines/vac-gen/immunity-types.htm)
* [COVID-19 Vaccines for Moderately to Severely Immunocompromised People](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/immuno.html)
* [Answering Patients’ Questions about COVID-19 Vaccination | CDC](https://www.cdc.gov/vaccines/covid-19/hcp/answering-questions.html?s_cid=11716:%2Bnatural%20%2Bimmunity%20%2Bvs%20%2Bvaccine:sem.b:p:RG:GM:gen:PTN:FY22)

### Talking to Consumers about Distrust

Because of past or historical experience, people with disabilities often distrust the medical industry. Below are some of the areas of concern your consumers may have:

**Your consumer may be worried about the speed of the creation of the COVID-19 vaccine and have fear or distrust. How do you educate them on this?**

The three COVID-19 vaccines available in the U.S. (Pfizer, Moderna, and Johnson & Johnson) were developed in response to the global COVID-19 pandemic. Below are the facts:

* Research that led to these types of vaccines has been going on for over 50 years.
* The COVID-19 vaccine went through the same safety steps as other vaccines.
* The COVID-19 vaccines were just made quickly to save lives.
* COVID-19 vaccines were made thanks to funding and scientists around the world working together.
* The COVID-19 vaccines are safe and are proven to work for people with disabilities.

Sources:

* [Myths and Facts about COVID-19 Vaccines](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/facts.html)
* [People with Disabilities | COVID-19](https://www.cdc.gov/ncbddd/humandevelopment/covid-19/people-with-disabilities.html)

#### What if consumers may have been told to wait to get vaccinated by their doctor?

 If a consumer’s doctor initially told them to wait to get vaccinated, they should either ask again or get a second opinion. We know COVID-19 vaccines are safe for many people with disabilities.

#### What are some other facts that may ease concerns about getting the vaccination?

* Evidence shows COVID-19 vaccines are safe for people without and with disabilities.
* The vaccines help slow the spread of COVID-19 and lower the chances of getting very sick or dying from COVID-19.
* Many independent groups, including those led by doctors of color, have done their work to test the vaccines. They say the vaccines work and are safe.
* Many government officials, including all living U.S. presidents and current governors, got COVID-19 vaccines.

Sources:

* [Fact check: Viral post on vaccinated politicians, doctors a little off](https://www.usatoday.com/story/news/factcheck/2021/09/02/fact-check-viral-post-vaccinated-politicians-doctors-little-off/5670809001/).
* [Finding Credible Vaccine Information](https://www.cdc.gov/vaccines/vac-gen/evalwebs.htm)
* [NMA COVID-19 Task Force on Vaccines and Therapeutics](https://www.nmanet.org/news/544970/NMA-COVID-19-Task-Force-on-Vaccines-and-Therapeutics.htm)

## Addressing Barriers

People with disabilities may have a higher risk of getting very sick or dying if they get COVID-19. Certain barriers that people with disabilities commonly experience can put them at greater risk.

These barriers include:

* Living in remote or rural areas
* Limited or no access to transportation
* Limited options for in-home vaccinations or mobile clinics
* Limited or no internet access
* Limited or no access to specialists or medical professionals knowledgeable about specific disability risk factors
* Limited income
* Limited or no health insurance
* Lack of accessible vaccine clinics and websites
* Lack of easy to understand, accessible information about vaccines
* Lack of telehealth options
* Stigma surrounding disability
* Lack of legal identification documents or proof of citizenship

### Geographical Barriers

Here are some common scenarios that your consumers may experience related to where they live:

* Some people with disabilities live far away from COVID-19 vaccination centers, testing sites, and doctor’s offices.
* Some people with disabilities may live in a healthcare facility where they rely on staff for medical appointments and treatment.
* Some people with disabilities may need a special type of medical doctor that does not have an office near them.
* Some people with disabilities may not have their own transportation or live in an area without access to public transportation.
* Some people with disabilities live in rural areas far away from medical help, making it more difficult to get the help they need. It could also cause them to get help much later, and they would be sicker before getting treatment from a doctor.
* Finding information on the vaccination process in someone’s local area without internet access can be difficult. ​People that disproportionately lack internet access include:​
	+ People in rural and remote areas​
	+ People living in poverty​
	+ People who are unhoused

### Potential Solutions for CILs to Assist

#### Transportation Access

* Your CIL can offer transportation services or services to connect people with local, accessible providers.
* Your CIL can partner with local public transportation systems to give free rides for vaccines.
* Your CIL can pay for and arrange rides through rideshare companies:
	+ Uber is offering free rides to and from your vaccine through their partner, Go Go Grandparent. To book your ride, call (855) 921-0033, and make sure to tell the phone operator you’re booking a ride for your vaccine.
	+ Lyft is offering free rides to and from vaccine appointments. Complete [this online screening](http://www.lyft.com/vax) to find out if you qualify.
* Your CIL can offer gas cards or reimburse mileage to those seeking vaccination.

#### In-Home Vaccination

* Your CIL can assist consumers with identifying a provider in the state to provide in-home vaccinations.
* Your CIL can develop partnerships with local health departments and hospitals to schedule mobile clinics.
* Your CIL can assist with advertising and outreach about these options for consumers.
* Your CIL can assist with advocacy, organizing, and education.

#### Navigating Lack of Internet

* Your CIL can assist consumers without internet access by providing printed materials in places where people may go regularly.
* Your CIL can assist consumers by helping them schedule appointments over the phone when they lack access to the internet.
* Your CIL can also assist consumers by partnering and promoting organizations in the community that provide internet access, such as the local library.

### Costs: Upfront and Hidden

Here are some common scenarios that your consumers may experience related to costs or expenses:

* People with disabilities might need health insurance to help pay for healthcare treatment related to COVID. Without insurance, they might be less likely to go to the doctor or hospital because of the cost.
* People with disabilities may have other “hidden” costs like childcare, transportation, parking, or missing work that might make it harder to get to a free COVID-19 testing or vaccination site.
* If you can’t get tested, you don’t know if you have COVID-19. If you don’t know if you have COVID-19, you can accidentally give COVID-19 to other people. If you don’t know you have COVID-19, you might get very sick before getting help.
* You might not want to go to the doctor. If you don’t go to the doctor you might not learn you are sick until much later, when you could be much sicker, have a hard time getting better, and have to get more costly treatment.

### Potential Solutions for CILs to Assist

#### Education that the COVID-19 Vaccine is Free

COVID-19 vaccines are 100% free to all people in the United States. The vaccines are free because the federal government has agreed to pay back providers of COVID-19 vaccines.

COVID-19 vaccines are completely free to people with and without health insurance.

Referring people with disabilities to free clinics and helping them navigate the Medicaid application process can be additional solutions for people who may need additional medical care.

It is against the law for someone giving the vaccine to:

* Charge money for a COVID-19 vaccine
* Charge money for any fees, co-pays, or coinsurance
* Refuse to give a vaccine because you have no health insurance or are out of network
* Charge money for an office visit if the only service was a COVID-19 vaccination
* Require that you get any other services when receiving a COVID-19 vaccine
* If you do get other services, those services can be billed as usual

If someone tells your consumer they need to pay for the COVID-19 vaccine, they can report the person or office to the Office of the Inspector General, U.S. Department of Health and Human Services, by calling 1-800-HHS-TIPS or the website [TIPS.HHS.GOV](https://oig.hhs.gov/fraud/report-fraud/index.asp).

Source:

[COVID-19 Vaccines Are Free to the Public](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/no-cost.html?s_cid=10473%3Ais+the+covid+vaccine+free+without+insurance%3Asem.ga%3Ap%3ARG%3AGM%3Agen%3APTN%3AFY21)

### Difficulty Navigating Healthcare Information and Systems

Here are some common scenarios that your consumers may experience related to lack of access to healthcare, information, vaccination sites, and disability stigma:

* People with disabilities are at higher risk of experiencing hesitancies toward vaccines because of having a history of negative experiences with their medical care, particularly for those within the BIPOC community.
* People with disabilities may not have the same access to healthcare as everyone else due to a lack of accommodations or disability-specific expertise.
* People with disabilities may not have been able to get to medical exams because the doctor’s office is not accessible.
* People with disabilities may not have received proper care because the devices or medical tables were not accessible.
* People with disabilities may have felt like the nurses, doctors, or other medical staff had a negative attitude toward their disability.
* People with disabilities may have had a hard time understanding what their doctor or medical staff were telling them.
* People with disabilities may have felt their disability was ignored.
* People with disabilities may have felt that the doctor or medical staff didn't understand their disability.
* People with disabilities may have gone to the doctor before and felt they didn’t believe them.
* People with disabilities who do not speak English may have felt ignored by their doctors because of language barriers. There is a strong implicit and bias against people who do not use standard English.​​ This bias informs material development and the way that people are treated during the vaccination process.​
* People with disabilities may have felt that they did not get the treatment they needed.

Source:

[Risk of Exposure to COVID-19](https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/racial-ethnic-disparities/increased-risk-exposure.html)

### Potential Solutions for CILs to Assist

#### Accessibility Accommodations for Inclusive Information

Because of the Americans with Disabilities Act, or ADA, people with disabilities are guaranteed certain accommodations when getting their COVID-19 vaccine. These accommodations include:

* Vaccine sites that are physically accessible to people with physical disabilities.
* Access to American Sign Language (ASL) interpreters.
* Vaccine materials that include accessible formats, including:
	+ Braille
	+ Large print
	+ Digital
	+ Plain language/easy read
* Your CIL should provide accessible information about vaccines by providing image descriptions, alternative languages, and more. See the accessibility guide for additional resources.
* Your CIL should share information about consumer disability-related concerns, needs, and facts—consumers aren’t getting these resources anywhere else!
* Your CIL should assist the consumer with advocating for accommodations related to their vaccine appointment.
* Your CIL can provide advocacy and education if local websites and online registration systems are not accessible.
* Your CIL should make a complaint to the state if needed and report inaccessible vaccine sites. Make a complaint by contacting your local Protection and Advocacy system and the [Office for Civil Rights within the US Department of Health & Human Services](https://ocrportal.hhs.gov/ocr/cp/complaint_frontpage.jsf). Better accessibility is best for all!
* Your CIL should partner and provide guidance on how to make vaccine sites more accessible. See the accessibility guide for additional resources.

#### Navigating Healthcare/Telehealth Options

Your CIL can:

* Provide assistance with navigating and finding a healthcare provider and telehealth options.
* Provide education and advocacy efforts to your Medicaid agency regarding the need to continue telehealth.
* Assist the consumer with advocating for accommodations needed to participate in healthcare visits.
* Assist the consumer with contacting a medical provider through your health department if they have questions about the vaccine and concerns they may have regarding their disability.

#### Navigating Vaccine Sites

Your CIL can:

* Ensure vaccine sites are accessible before assisting consumers with scheduling vaccines.
* Provide education to vaccine sites and local health departments about accessibility and working with people with disabilities.
* Assist consumers with arranging accommodations at the vaccination site, such as:
	+ Drive-thru vaccinations
	+ Modified hours for people who may need additional assistance
	+ Extra time before and after vaccines
	+ Wait time reduction
	+ Communication needs (ASL, plain language, accessible forms, etc.)
	+ Accessible information

#### Scheduling Appointments

Your CIL can:

* Assist consumers with identifying vaccine locations and a time and date that would work best for them.
* Assist consumers with scheduling appointments.
* Assist consumers with a plan for navigating transportation.
* Assist with arranging any appointment accommodations if needed.
* Remind consumers of their appointments and follow up with them afterward.

#### Dispelling Stigma

Your CIL can:

* Provide disability awareness trainings to local health departments and clinics.
* Educate providers about disability and program accommodations to ensure everyone has access to vaccinations.
* Provide education about the overall needs and barriers faced by the disability community to demonstrate the need to be inclusive.

### Other Barriers that Impact People with Disabilities, including Members of the BIPOC Community

Here are some common scenarios that your consumers may experience:

* Consumers may be told that they are required to have an identification card.
* When they go to get vaccinated, someone may ask for an ID or Social Security Number.
* People may be told that they must be U.S. citizens to receive the vaccine.

### Potential Solutions for CILs to Assist

#### Education that no legal identification card is required

You do not need an ID to get a COVID-19 vaccine.

* Workers at the vaccine site may ask for ID, but you do not have to show it to them.
* No one should be sent away, including children, for not showing an ID.

Source:

[Answers to Common Questions about Immigrants' Access to the COVID-19 Vaccines](https://www.nilc.org/2021/04/12/immigrant-access-to-the-covid-19-vaccines/)

#### Education on Citizenship Status

People who are not U.S. citizens can get the vaccine for free:

The vaccine is free and available to everyone over the age of 5 in the United States. This includes people who are not citizens, documented, or undocumented.

It is against the law to have to prove that you are a citizen to receive a COVID-19 vaccine.

Source:
[COVID-19 Vaccines Are Free to the Public](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/no-cost.html?s_cid=10473%3Ais+the+covid+vaccine+free+without+insurance%3Asem.ga%3Ap%3ARG%3AGM%3Agen%3APTN%3AFY21)

#### Education: if someone is undocumented will they risk deportation if they seek the vaccine?

*No*. When they go to get vaccinated, someone may ask for an ID or Social Security Number.

* You do not have to give anyone an ID or Social Security Number to get the COVID-19 vaccine.
* It is against the law to keep you from getting a vaccine because you don't have an ID.
* Vaccines sites can’t keep you from getting a vaccine because of your citizenship status.
* If someone asks you for any kind of ID or Social Security Number, you can say no.
* The US Department of Homeland Security said it will not enforce immigration laws at vaccination sites.
* Information collected in COVID-19 vaccinations can only be used to help the COVID-19 public health response.
* No group can get or send information that tells who you are.
* It is illegal to use information about people who have gotten the vaccine to prosecute them.
* People can’t use information from your vaccine appointment to enforce immigration laws.

Sources:

* [Answers to Common Questions about Immigrants' Access to the COVID-19 Vaccines](https://www.nilc.org/2021/04/12/immigrant-access-to-the-covid-19-vaccines/)
* [COVID-19 Vaccines Are Free to the Public](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/no-cost.html?s_cid=10473%3Ais+the+covid+vaccine+free+without+insurance%3Asem.ga%3Ap%3ARG%3AGM%3Agen%3APTN%3AFY21)
* [DHS Statement on Equal Access to COVID-19 Vaccines and Vaccine Distribution Sites](https://www.dhs.gov/news/2021/02/01/dhs-statement-equal-access-covid-19-vaccines-and-vaccine-distribution-sites)
* [Data Use and Sharing Agreement to Support the United States Government's COVID-19 Emergency Response](https://www.cdc.gov/vaccines/covid-19/reporting/downloads/vaccine-administration-data-agreement.pdf)

## Be the Solution: What Can Your CIL Do about Barriers?

* Your CIL can provide services to assist people in making vaccination appointments, plans, and seeking transportation.
* Your CIL can educate people on their rights to vaccination and help them advocate for those rights.
* Your CIL can encourage the community to get the COVID-19 vaccine and booster shots and ask friends, family, and caregivers of people with disabilities to also get the vaccines.

Here is some information your CIL staff should know so that they can provide information about disability rights laws to the people with disabilities you are assisting.

### Know the rights to access vaccines

People with disabilities have civil rights. These rights mean that people cannot treat them unfairly just because of who they are as a person with a disability. They have the same rights to vaccines as people without disabilities. Make sure you educate your consumers!

* **The Americans with Disabilities Act (ADA)** states that you cannot be treated unfairly because you have a disability. The ADA requires public and state agencies to provide accommodations, so people with disabilities have the same access to services as people without disabilities. The ADA also requires that agencies make sure that these accommodations are available for people with disabilities to get information in a way that meets their needs. This includes any type of equipment to assist with providing services and accessible technology (Sources 26 - Americans with Disabilities Act, 1990).
* **Section 504 of the Rehabilitation Act of 1973** is a national law that protects people with disabilities from being treated unfairly because of their disability. This law applies to organizations that get financial assistance from any Federal department or agency. This includes many hospitals, nursing homes, mental health centers, and human service programs (Sources 27 - Rehabilitation Act, 1973).
* **Section 508 of the Rehabilitation Act** is a national law that states that federal agencies have to provide information in a way that is accessible to everyone with disabilities. If you need information in a different way because of your disability, federal agencies have to provide this (Sources 27 - Rehabilitation Act, 1973).
* **Title VI of the Civil Rights Act of 1964:** This law is extra protection for multi-marginalized consumers. The law states that you cannot be treated unfairly or left out of programs or denied services because of your race, color, or national origin (Sources 28 - Civil Rights Act of 1964, 1964).
* **Section 1557 of the Affordable Care Act** states that you cannot be treated unfairly because of your race, color, national origin, age, disability, or sex. This includes making sure language assistance is available for people who speak limited English and making sure there are accommodations for people with disabilities so that they have access to services (Sources 29 - Patient Protection and Affordable Care Act, 2010).
* Your state’s Protection and Advocacy (P&A) system may also be a good resource! You can find your state’s P&A at the [National Disability Rights Network’s state directory](https://www.ndrn.org/about/ndrn-member-agencies/).