- Good afternoon. My name is Regina and I'll be facilitating this training session. Welcome and about us. Next slide please. I am Regina Dyton. I am a 68, almost 69 year old African American woman, tall, round, brown and proud, living with a disability. I have shoulder length dreadlocks that are curly and my pronouns are she/her and today I'm wearing a black blouse with red roses on it. Project Alive is brought to you by April, the association of programs for rural and independent living and led by Elissa Ellis for this project. I'm going to turn over now to one of our co-directors, Shaylin Sluzallis, who's going to introduce the team.

- [Shaylin] This is Shaylin and thank you, Regina. And thank you all for joining us. As Elissa mentioned, Project Alive was brought to you by April, the association of programs for rural independent living. Elissa, just wanna check and see if you would like to add any words or say hello.

- [Elissa] Just welcome. Thank you guys all for making the time to be here. And I appreciate it. I appreciate you. Thank you.

- [Shaylin] Thanks Elissa. And this is Shaylin. Alongside me as German Parodi. We are the co executive directors of the partnership for inclusive disaster strategies. You met Priya Penner, and also on the line as Melissa Marshall and Jean Grover, and also for the sake of time, and I know we all met each other earlier this week. Want to just recognize who all is on the line today, from Mainstream Center for Independent Living, we have Rita Byers and her team. Verna Bone, Lisa Croft-Coleman and . From Spa Area, Independent Living Services. We have Brenda Stinebuck and from Southeast Arkansas Independent Living Services also Brenda and Benny Esanu and Lakesha Whitman. Apologies if I mispronounce any names and did I miss anybody? Great, thank you all again for joining us. We're looking forward to another great training, please. don't hesitate to call out, inject and reach out and wanna hear your participation throughout. So thank you so much and back to you, Regina.

- All right. Thanks Shaylin. So let's get started. Project Alive, accessible life saving integrated vaccine equity is a short term, February through July, 2022 focused effort to remove barriers to COVID-19 vaccinations for people with disabilities, living in the rural areas of Missouri, Montana and Arkansas. And the goal is to help people with disabilities, wanting a vaccine and needing support to access one. Next slide, please. The population focus of Project Alive. Project Alive's focus is on people with disabilities in rural areas of Arkansas who desire COVID-19 vaccines. That is the primary series and the booster and experience barriers accessing them. It is also for people with disabilities who are hesitant, but are still open to getting COVID-19 vaccines. Next slide please.

Little disclaimer here. The material presented does not constitute legal or clinical advice and is for informational purposes only. If you are seeking legal or clinical advice, please contact a qualified attorney or clinician. Next please. A few very basic ground rules, not too many. Maintain confidentiality. Ask questions whenever and wherever in this presentation, you have questions and have some fun. Are there other ground rules you'd like to suggest, anyone? Okay. If not, we'll move to the next slide. The objectives. By the end of this presentation, you will be able to understand some causes of COVID-19 vaccine hesitancy and how to respond. You will also be able to identify barriers to accessing COVID-19 vaccines, the primary series and boosters, and know how to respond. Next please.

Now we're going to move on to understanding vaccine hesitancy, uncertainty and rejection. Next please. Understanding vaccine hesitancy. The working definition of hesitancy we'll use for today is the delay in acceptance, reluctance or refusal of vaccines, despite the availability of vaccine services. All right, next slide, please. Some people move from hesitancy to acceptance. A study in the journal of community health found that 62.4% of people uncertain about getting vaccinated and 30.7% of vaccine rejectors receive vaccines over the one year period of the study. Next please. Reasons for vaccine uncertainty and rejection. Major reasons for uncertainty and rejection were faith-based beliefs, political affiliation and racial ethnic identities. Continuing reasons for vaccine uncertainty and rejection, faith-based and political beliefs and racial, ethnic identities are core and constant beliefs and values. It would be disrespectful and inappropriate to try to persuade anyone to change that. Next please.

Moving from hesitancy to acceptance. Next. Why and how do people move from hesitancy to acceptance? The best educators are peers. You already know that, as people working yourselves, you know that. People identify peers based upon some of the things that they identifying peers on is disability, race, and/or ethnicity, culture and/or language. As SIL staff, you should address people's concerns about information in an open, unbiased, welcoming manner. Next. Continuing why and how do people move from hesitancy to acceptance. People also move to acceptance because of life experiences such as getting COVID-19, when watching a family member or friend struggle with the virus. Next. Now it's your turn to talk. Moving from hesitancy to acceptance, questions for you here. Does anyone have examples of people who were hesitant and moved to acceptance? If so, what was that like? And what can we possibly learn from it? Anyone have such a story to tell? Melissa, and I do, I'm gonna ask Melissa to tell it.

- [Melissa Marshall] Sure. Thank you. I'm Melissa Marshall. And I'm the co-executive director. No, I'm not the co-executive German and Shaylin are the co-executive directors. I am the director of operations. I was multitasking and I apologize, German and Shaylin and everyone, that is not what I intended to say, but that word was in front of me. Anyway, I'm the director of operations for the partnership and Regina and I have a mutual friend and she's someone who's into lots of alternative medicine and she doesn't always want to go to doctors or hospitals. I think Regina just nod and say, if I'm fair.

- Yes.

- [Melissa Marshall] She's also part of a group of people who have been lied to and abused and terrible things have happened through the medical profession and that she's a black woman. And so she has all that baggage and she's someone who does alternative medicine. So she announced at the beginning of COVID and we are part of a group that meets and we would start meeting virtually. She announced at the beginning that she wasn't getting vaccinated. I kinda took a breath and said, "Okay". And she said, "But I'm not leaving the house". Okay. So she's not getting vaccinated and she's not leaving the house. So she's not infecting other people. And she's less likely to get it herself. Okay. Couple months after that and that was before, there's a vaccine, she wasn't gonna get vaccinated and the vaccine came out and she still wasn't gonna get vaccinated. Few months later, she decided to get vaccinated 'cause one compound word, grandchildren. Regina, do you wanna talk about the grandchildren part of it?

- Oh yes. Well, she certainly missed her grandchildren. Her grandchildren were vaccinated. Her daughter and her grandchildren were vaccinated. And you know, her daughter was pretty clear on what she needed to do if they were gonna be, you know, spending time together. And she was used to spending a lot of time with them pre COVID. So this idea of I'm just gonna stay in my house wasn't working out too well, you know? And so really, yeah. Wanting to be connected, did it for her. Yep.

- [Melissa Marshall] And I think that's really important. And I think that's been a lot of people's journeys. Some people who are part of groups that have been disenfranchised and have had bad experiences with the medical profession wanted to wait. I think that was part of her feeling, is she wanted wait till some, you know, middle class, white people had it.

- Yes. She wanted to see if it was gonna kill them, what was it gonna do? I see Brenda had her hand raised.

- [Brenda Stinebuck] I was going just give an experience that we had here. And it was with the deaf community. Hot Springs is still in many ways, a very small town. And most of the deaf community attended church together. And they were given a lot of misinformation at church. And one of our employees, we ended up mandating the vaccine for our employees here at the center. And she was deaf and belonged to this church, but she did go ahead and move to acceptance because she needed to because of where she worked. But then once she got the vaccine and did some research on her own and then she was able to reach out to the deaf community and say, "You know what, do your own research"?

- Excellent. This is an excellent story.

- [Melissa Marshall] This is Melissa. Sorry, Brenda, it's good to see you today. Did the deaf community then go and do its own research?

- [Brenda Stinebuck] Some, some did, not all.

- [Melissa Marshall] Okay. Fair enough. As people are, as people do.

- Yeah. But thank you for that. All right. Next slide, please. Reasons and responses to vaccine hesitancy. Next. So some reasons for vaccine hesitancy are distrust of media to provide accurate information, distrust of government to provide accurate information and distrust of the medical profession based upon history of ableism, racism, and other forms of bias and abuse. Next slide, please. Responses for hesitancy and ways to respond. Here's an issue. A consumer knows of someone else who got the vaccine and still got COVID-19. How might you respond to that consumer? If they said, "My friend got the vaccine and still got COVID, so I don't need a vaccine". Well, let's look at our suggested response. Our response is to let the person know the purpose of the vaccine is beyond not getting COVID, it's to reduce the chances of dying or being hospitalized. Doesn't seem like that wants to pop up. Sorry. Oh, here it is. Okay. Yay, Priya.

- [Melissa Marshall] This is Melissa. If I can just interject for a second, if that's okay.

- Sure.

- [Melissa Marshall] And one thing that people didn't want to understand, and I was one of them. I wanted getting the vaccine to mean that I would not get COVID. That's what I wanted it to mean. Cause pretty much when I get a vaccination for measles, when I got the booster shot when I was six and I still remember it, 'cause it hurt a lot and was much worse than the COVID vaccine. But anyway, when I got the vaccine for measles, that meant pretty much I wasn't gonna get measles. I could still, but you know, I wasn't. And what I was told was I wouldn't get measles. Now I know a flu shot's kind iffy. And it depends on the season. It depends on the flu variant. And it depends on the luck of the draw. And I confess, I was someone who didn't get flu shots until COVID happened. And so I think people wanted to be one way or they wanted to be binary. You don't get the shot you get COVID. You get the vaccination, you don't get it. And it's gray. And my friends in public health that I talk to all the time and my friend at Red Cross that joins our calls all the time has always said the goal of the vaccine is to reduce deaths and people getting so sick that they have to go to the hospital. So I had a bunch of friends who got the Omicron variant and they're sick for a week. They're sick for two, some got more long term COVID effects, but none of 'em were afraid they were gonna die.

None of them went to the hospital and that's the goal of the vaccine. So I think we need to be careful in our public messaging about people and saying to people, "Yeah, the vaccine doesn't mean you're not gonna get it. I know your friend got it. But think of how much sicker they'd have been. They probably would've had to have gotten the hospital and it's conceivable they could have died". So I think I understand why people come to that. I shouldn't get the vaccine cause it's not working. Well, it is. It's just doing a different job than I think the public messaging has led us to believe. Does that make sense to people?

- Certainly makes sense to me. Thank you, Melissa.

- [Melissa Marshall] Thank you, Regina.

- And that is our suggested response, is to let this consumer know that the purpose of getting vaccinated is beyond not getting COVID-19, it's to reduce the chances of dying or being hospitalized. Okay. Next slide please. In this instance, a consumer thinks the vaccine will make their disability worse. How might any of you respond to that? Well, our suggested response is to have the consumer speak, that's there you go, Lisa. I see Lisa said it, speak with their physician. Yes. Seek advice from your medical provider. Yes, because Brenda also gave that example of people who were getting some misinformation at church and then were encouraged to research other areas and other places for information. So similarly, not the same. No layperson can really say, "Oh yeah, the vaccine will or won't affect it". You can just say what you know. The best thing for that person to do, to get some sense of advice that they can feel confident in, is to speak with their medical provider, with whom they already have a relationship and hopefully trust.

- [Melissa Marshall] This is Melissa. I'm gonna jump in. I'd be lying if I said one more time, 'cause I might jump in again. But I'll jump in briefly and just know that there are physicians out there in the world who are saying, it's one thing to get misinformation from your church, that happens. People are getting misinformation sometimes from medical providers and I don't quite know what to do about that. There are physicians out there saying people shouldn't get vaccinated, which flies in the face of all the evidence, or they don't need a booster which also is contrary to all the evidence in the world and all the science. And for someone like that, you might refer to a CDC website or something like that. But it's just a problem that's out there that we need to acknowledge. Now I'll let you go, Regina, sorry about that.

- No, that's no need to apologize at all. Next slide please. All right. Another consideration, thing to think about is that some people cannot be vaccinated for medical reasons and the vaccine isn't effective for some people because they're immunocompromised. Those of us who can be vaccinated can absolutely be helpful to others in protecting them by getting vaccinated ourselves. All right. Next slide. Questions and comments. Have you heard of other reasons for hesitancy? Anybody heard any additional? Let's see. Okay. Afraid of shots. Okay. There you go. This is from what says business manager at Mainstream and said so afraid of shots. And also some believe that all of the data has not been released regarding the virus or the vaccine. Okay.

- [Priya Penner] This is Priya, Benny, I also see a couple things I see that you put in chat, some believed wild conspiracies, which we have run into that as well. But I see your hand up. Did you wanna add to that?

- [Benny Esanu] No, that was just what I was gonna chime in with, some of the most loony information, disinformation that's out there could also be a reason as well. For sure.

- [Priya Penner] For sure. Is there any particular conspiracies that are especially prevalent in Arkansas?

- [Benny Esanu] There are some folks that I am not friendly with, but aware of who absolutely believe the you've been micro chipped with the vaccine, nonsense. So, it's out there.

- And what if I could ask is the purpose of the micro chipping, after the government puts this chip in you, what are they going to do with you?

- [Benny Esanu] Your your guess is as good as mine.

- [Elissa] This is Elissa.

- It's Bill Gates tracking you.

- [Brenda Stinebuck] Uh huh.

- [Benny Esanu] Yeah. That is part of it as well. Yeah, so that's kind of a lost cause to try to combat with. So.

- Yeah, you can't really argue with that, Benny.

- [Priya Penner] So that was Benny. I think their hand is still up and that's fine. I can help you put that down if that would be helpful.

- Okay.

- [Priya Penner] Okay. Got it. Great. And then before we, no worries. No worries at all. Before we move on, we do have a couple more comments in chat. Lisa, shared some believe that the vaccine is a mechanism for tracking people like Benny shared. I think a good question, like you said, Regina is what's happening with that data. Where's that going? The purpose of it, but that's neither here nor there. And then we do also have another comment. Some were waiting on the results from those first participants who received the vaccine.

- Yeah. That's what my friend Denise, said that, Melissa and my friend, she was gonna wait and see, you know, if the vaccine, if people started dropping as a result of getting the vaccine. So that was one thing. It's interesting to me. And I don't know this to be true. 'Cause first of all, I don't know of, you know, I haven't had direct conversations with any of the people who believe there's a microchip in it, but in terms of the government tracking you, the way I look at it is with all of the social media, in which people participate and put their business out there and all the apps they use and all of that stuff, there's already the ability to track, you know, each and every one of us, I mean, privacy has been gone. It's a thing of the past. So I don't know it, but it would be interesting to me if the people who had that concern, use social media and technology.

- [Melissa Marshall] Yeah. And this is Melissa. If they own a smartphone, they can be tracked.

- Yes.

- [Melissa Marshall] The exact same way. Regina, I was gonna ask if you can elaborate or talk more about, and I can't remember if we talked or if you're talking about this later, I talked about it last week about people that are afraid of shots.

- Oh we did. And it comes up. It does come up later. So if we can, yeah, because it's actually one of the scenarios.

- [Melissa Marshall] That's right. That's right. I knew it was somewhere, thank you so much.

- No, that's all right. Any other questions or comments at this point? If not, we'll go to the next slide. We're gonna talk a little bit about who is at risk for COVID-19. Next slide please. Who is at risk? Well, some people with disabilities may be more likely to get COVID-19 or have severe illness due to chronic medical conditions. Adults with disabilities are three times more likely to have certain chronic health conditions. People with disabilities are more likely to live in congregate settings, putting us at higher risk. And I also wanna note here that most people don't have one disability or condition. It's common to have more than one which is referred to as comorbidity. Next slide, please.

People with one of these disability types might be at increased risk for COVID-19 and its effects. People with limited mobility or sight who cannot avoid coming into close contact with others. People who have trouble understanding information or practicing prevention measures like hand washing and social distancing. Next please. Also people who may not be able to communicate symptoms of illness and people in congregate settings, such as nursing homes, group homes, psychiatric hospitals, prisons, shelters. Next please. Medical conditions that increase risk. Some medical conditions include cancer, chronic kidney disease, chronic liver disease, chronic lung disease, cystic fibrosis, dementia, or other neurological conditions, diabetes, type one or two and heart conditions. Next please. Continuing on that list. Some medical conditions include cerebral palsy, congenital disabilities, developmental and intellectual disabilities, learning disabilities, spinal cord injuries, certain mental health conditions, sickle cell disease, or thalassemia. Next please. It's important to address all forms of risk reduction. Remember, that someone who doesn't want a vaccine may be willing to practice other forms of risk reduction, such as masking, social distancing, hand washing and isolating. Discuss risks specific to the individual, help the individual to do a risk benefit analysis regarding practicing risk reduction behaviors, explore risk factors, such as age, specific disability. For example, people with respiratory issues like asthma, people with diabetes and other chronic conditions. Also explore environmental factors such as being in close proximity to an attendant. Explore requiring attendants to use mask, gloves, et cetera. Next slide please.

Reasons and responses to vaccine hesitancy. Now we talked about reasons a little earlier. Now we're going to look at the reasons and match them with responses. Next please. So here we have an issue of distrust of the media to provide accurate information. How might you respond to that? The response that we suggest is to provide access to a variety of media and public health websites to allow a person to make an informed decision. Next please. The next two issues are distrust of government to provide accurate information. So we know that's a common mistrust these days.

- [Priya Penner] This is Priya. Regina, I just wanted to note that we are having difficulty hearing you, make sure you're facing the camera.

- Thank you. All right. I guess I backed up there a little and didn't know it. Thank you. So I'll repeat, the issues that we're looking at now are distrust of government to provide accurate information. And we know that is an issue for many people, also distrust of the medical profession based on a history of ableism, racism, or other forms of abuse. Any suggested responses from any of you to those two. But we suggest that you respect an individual or a community's history with government, media and the medical profession and their perceptions of them that we not try to argue with them to say you should trust the government or the medical profession, remembering that your relationship with this consumer, your ongoing relationship is more important than any one time meeting. Next please.

All right. Two other issues. Uncertainty about the long term effects of the vaccine and fear that the vaccine will cause illness or infertility. We suggest responding by supporting the person in a risk benefits analysis to really outline what are the risk of my getting COVID-19 and what harm might come to me. And what's the benefit of getting the shot. Also, we wanna help them to assess right, the current risk of getting it and the long term effects of getting the vaccine. And you may wish to discuss with them post COVID condition, also known as, or previously known as long COVID. Next please. Some of the common symptoms of post COVID condition or long COVID. Some of those symptoms are fatigue, breathing difficulties, insomnia, pain, and brain fog. Post COVID can negatively affect organs like kidneys, lungs, pancreas, and heart. Next please.

Another issue here is fear of the vaccine because it was developed so quickly. A lot of people speak about that. Our response here is to provide education about how the vaccine was developed. And it's interesting. It was developed with a cooperation, you know, and teamwork of people across political lines. And so I say on this one, offer your consumers whatever information you think is most helpful to them. Among the things to learn is that president Donald Trump championed operation warp speed in order to develop and mass produce safe vaccines. For others, you may want to hold up is Kizzmekia Corbett, the African American viral immunologist who led the team that developed the Moderna vaccine. Next slide please.

- [Elissa] Regina, this is Elissa. If I could also just really quickly note that the MRNA technology has been out there for 10 years. So it wasn't an overnight thing.

- Thank you. That's exactly what I was gonna say.

- [Elissa] Okay, I'm so sorry.

- No, you don't need to apologize. You do not need to apologize. Yes. That's what I was going to mention is that the...

- [Priya Penner] Regina.

- Yes.

- [Priya Penner] We missed that first part, I apologize.

- I'm sorry?

- [Priya Penner] We missed that first part.

- Oh, I'm sorry. Okay. I said that's exactly what I was about to say is that a partnership of government science and industry used a new model to do in nine months, what would usually take five to seven years? And that was after 10 years of research and development had already gone on that scientists had been working on this type of vaccine for a decade. So for many people that's new information. Next please.

- [Priya Penner] As we move on to the next slide, apologize. This is Priya. As we move along to the next slide, I see Benny that your hand is up. Do you have comment question?

- [Benny Esanu] Yeah, this is Benny again. I was just gonna mention that MRNA vaccine, that all of the Moderna, Pfizer J&J have, is not the only one available now. Coming here shortly there's also a protein based one. That's gonna work as well that doesn't use the MRNA technology. So you can kind of use that as ammunition, if you ever run into that kind of hesitancy.

- Okay.

- [Melissa Marshall] This is Melissa. Also, I just wanna jump in. My understanding is that J&J was not MRNA.

- [Benny Esanu] That's correct.

- [Melissa Marshall] And it didn't work as well. Just saying, but yeah, I'm pointing out that there's another option if someone's saying they don't want the other option. I forget the name of it. And it's just got recommendation for approval from the FDA yesterday, I wanna say, or the day before, something like that.

- Wow.

- [Melissa Marshall] I forget the name of it.

- It's not fully approved yet, I'm trying to remember in the back of my head, I just read about it last night and I forget the name of the vaccine, but yeah, that's not an MRNA. So if someone doesn't wanna have MRNA, J&J is not really feasible anymore, but this new vaccine is and could be. So that's a really good point, Benny. Thank you.

- Thank you very much. So on development of the vaccine, you might also wanna share with people that the federal government oversaw the process of the development instead of the pharmaceutical companies under operational warp speed. And it meant that steps were taken simultaneously. And in doing that parallel development, testing it while you're producing it, it increased financial risk to manufacturers. Usually a pharmaceutical company doesn't want to lose money, right? It wants to know that something works before it mass produces it. As we know, government subsidized the production of it. And it was produced while the research was going on. Both things happened at once to get it out faster. And so it decreased the risk for the public, but it did increase a financial risk to manufacturers.

- [Melissa Marshall] And this is Melissa. They've been using MRNA technology in treating cancer for a long time.

- That's an important thing to add.

- [Melissa Marshall] Yeah.

- Yes, indeed.

- [Priya Penner] This is Priya. As we move on to the next slide on, Lisa shares that it's the Novavax.

- [Melissa Marshall] Thank you, yes.

- Thank you so much.

- [Melissa Marshall] Thank you. Thank you, Lisa.

- All right. We can go to the next slide. An issue here in responding to vaccine hesitancy, a consumer doesn't think, or is not sure that they're in a high risk category. How might you respond to that? Okay. Well our suggested response.

- [Priya Penner] This is Priya, right before we move on to the suggested response, I do see a response in chat.

- Yes I do.

- [Priya Penner] They say again, advise them to speak with their physician.

- Yes, absolutely. And we also recommend providing education about COVID-19 universal risk and risk for people with disabilities, preexisting conditions, racial, ethnic, gender, and other COVID-19 information. And to emphasize that anyone and everyone can get COVID-19, that many children and young adults who are very healthy have gotten COVID-19, been hospitalized and died. The majority of cases are now with people between the ages of 18 to 44. Next please.

Two other issues. Someone says the vaccine is gonna alter my DNA and that natural immunity is better than vaccine immunity. Any thoughts on how to respond? Well, it may or may not convince anyone, but we say that it's important to let people know that there's no known substance in the vaccine that can alter DNA and that getting a COVID-19 vaccine is a safer and more dependable way to build immunity to COVID-19 than getting sick with COVID-19. Next please. Now we're gonna talk some about vaccine hesitancy as a result of barriers. Next please. Hesitancy due to barriers. Some people may be hesitant due to barriers to accessing the vaccine. That is the primary series and booster. The barrier could be actual or assumed. Next please. Some barriers to vaccine access include lack of transportation, lack of accessible transportation, lack of sign language interpreters, lack of spoken language interpreters, lack of physical access for wheelchairs and other mobility devices. Next please.

Some additional barriers include lack of sensory accommodations, such as a scent free environment, low level lighting, a quiet room, et cetera. No support person at the vaccine site. Fear that the site won't allow a service animal to enter. Fear that undocumented immigration status will be discovered. Next please. Additional barriers to vaccine access include bad experiences with vaccines in the past, disability bias, lack of accessible information about the vaccine process. We all know that people with previous negative experiences based in disability bias may be hesitant to seek healthcare in general, including a vaccine. Next please. Other barriers include lack of accessible registration, such as easy read, large print font, screen reader accessible and other forms. Another barrier is that the consumers attendant conservator or guardian does not want them to be vaccinated and will not assist them. Next.

Responding to some of these barriers. Educate the consumer on disability rights and advocacy around what is and is not legally required for the consumer and for the vaccine site. Focus on your consumer specific concerns or fears. Call ahead to advocate for accommodations. Accompany the person to the site if they desire and if that is possible. Thank you, next please. An issue here is a fear that undocumented immigration status will be discovered or that a person who is documented will be suspected of being undocumented, even if they are not. How might you respond in this case? Okay, well, we wanna recommend that you provide education about healthcare and immigration status law. It is against federal regulation to deny, first of all, to question immigration status in the process of delivering healthcare. So they're not even allowed to ask and if they have any reason to think or suspect, they're still not allowed to do anything about that. You can also offer to accompany a person to a vaccine site and refer them to legal aid or similar services for further education and advocacy. Next please.

You might also want to let them know this, that the department of Homeland Security released a statement in February, 2021, ensuring that it will cooperate with the Federal Emergency Management Agency, FEMA, and will not conduct enforcement operations near or at healthcare facilities. This includes popup clinics, wherever they pop up becomes a healthcare facility and of course, hospitals and other facilities. Next please. How about if your consumer had bad experiences with vaccines in the past? Well, you might respond by inquiring about the previous bad experiences, asking such questions of, did you have a medical reaction? Was there a lack of accommodations? Next please. Here's the issue. The consumer had a previous negative experience, with healthcare which caused hesitancy to seek any healthcare services, including this vaccine. We would recommend that you listen without judgment, that you provide disability rights, education, and advocacy, and that you offer peer support at the vaccine site if you're able to do that, that it can be helpful to many people. If that's what they want. Next please. How about if your consumer says my attendant, conservator, guardian, family member, whoever does not want me to be vaccinated and refuses to assist me? What might you tell that consumer? Okay. You should refer them to Disability Rights, Arkansas. Next please.

How about if information about the vaccine process is inaccessible? We suggest that you provide education about the process and that you advocate for accessible information for the vaccine site. Next please. Here the issue is inaccessible registration. In which case we suggest you provide information and education to public health about legal requirements for materials in alternative accessible format. Any questions, comments at this point? If not, we'll go to the next slide. In which we start some scenarios. So here's where the fun comes in. Next one, please. Scenario one. Consumer calls to tell you that after their friend got very sick from COVID, they want to get a vaccine, but their family is against it. This person depends on their family for transportation and personal assistance. What do you need to consider in this scenario and how should you respond? Excuse me. What do you do here? This person is right there with you or they're on the phone. And they call you because they're pretty sure you can help. Any suggestions from the partnership team?

- [Priya Penner] This is Priya. Before we jump to suggestions, just wanna remind folks, you can respond in chat. You can raise your hand and you can also simply come off of mute and join the conversation.

- [Melissa Marshall] This is Melissa. I'll jump in once again. I think this is probably our trickiest scenario because they're depending on their family for support and it's not like a vaccine that's not gonna show or their arm won't be sore. Your arm is gonna be sore for a while. So if they're helping you with physical support, they're gonna notice it and they're gonna know. So maybe it's transportation and having the person understand, training the person to understand that they have a sense of agency and that it's their body. They get to decide what they do. And maybe you, you know, ask the consumer if they want you to help facilitate a family meeting or something like that. But basically to me, this points out there's a red flag in this where an adult human being is not being allowed to have agency and do what they want to do with their own body because of other people. And that's kind of flies in the face, that goes against independent living philosophy. I see Brenda has something to say, so I will stop.

- Thank you, Melissa. Yes, Brenda.

- [Brenda Stinebuck] Well actually getting them the shot is the easy part here. You know, it's the being so careful around the relationship with that family. I think that Melissa's suggestion about facilitating a family meeting is good, or just making sure that everybody's got all the information that they need to make an informed decision about the vaccine. And I mean, this consumer also needs to talk to her doctor and let the doctor know her concerns about needing the vaccine and see if there are any risk and stuff like that, but yeah, it'd be easy to just go in there and get 'em the shot but it's the personal aspect of this one that's difficult.

- [Melissa Marshall] And you don't want this consumer, this is Melissa, to get kicked out of their house or something like that.

- [Brenda Stinebuck] Right.

- [Melissa Marshall] There's a situation that will happen. But they might make their life pretty unpleasant.

- [Brenda Stinebuck] Yes.

- [Melissa Marshall] But even if the shot is contraindicated, I mean, first of all, it's indicated for just about everybody, but even if the shot is contraindicated, I'm an adult. And if they'll gimme the vaccine, I have the right to make bad decisions like everyone else. I don't have an obligation to ask a parent if I can get a shot because they don't think it's a good idea. There have been lots of medical decisions. I've made that my family might have agreed or might have disagreed with. I'm somebody with a disability, but they didn't get a vote in that because I wasn't living at home and I had different sense of self and they didn't care what medical decisions I made. They had opinions and they certainly expressed them, but they knew my decision was my decision. I think it's communicating that to consumers throughout the process and to the family, but you also don't wanna alienate the family so they'll throw the person out, you know or injure the relationship, Brenda, so I think those are really good points. And I think it's that balance.

- It is. Yeah. This is a scenario that could go a number of ways. Let's see what the next slide says. So for one to consider the legal status of the family member to the consumer, is this a legal guardian? Is this an attendant? And also as we've discussed a little bit, what repercussions may result from this person going up against their family and, you know, exercising their full right to make decisions about their own body, but what might, you know, happen as a result of that? So those are important things to examine and explore with the consumer while supporting their right to run their life and do what they want to do with it.

- [Melissa Marshall] And this is Melissa. I apologize if I said this to you earlier in the week, we're doing a bunch of trainings, but I just want to recognize, or have you recognize it? If someone's parents are personal assistants, they're their own guardian. They have their own rights. Just because someone is a conservator or a guardian and the conservator or guardian says no, that doesn't mean that no is a final decision. There's instances where you can go to probate court. And that's the kind of thing that Disability Rights, Arkansas is gonna wanna know about because that's a legal situation. And when it's for something like a vaccine, it's not that complicated, get that lifted for that purpose. So someone thinks they can't get it because of that reason. Again, you have to preserve the relationship with the family and all of that, but it's not a slam dunk that that person doesn't get to have the vaccine that they want.

- Right. And also, I would suggest too, don't be in a hurry. You, like Melissa, you don't want them to get kicked out. You don't wanna ruin the relationship. I think that if the family's being that controlling, it certainly is a red flag. You know, you may want to do some work and sensitive kind of investigation into what is really going on. You know, here are there issues of abuse or, you know, are a person's rights just being violated in other ways. So next slide please. Other responses on that is to refer it to Disability Rights, Arkansas, and to discuss that level of family resistance, possible outcomes, look at the family's openness to education. And if it's possible, provide some education to the family members, it might not happen tomorrow, but it might happen. Okay, next please. So in scenario two, a vaccination site tells a consumer they cannot accommodate the need for a quiet place to receive and rest after the vaccination. What do you need to consider and how should you respond? Okay. Any responses from the partnership?

- [Jean Grover] I would say that, this is Jean, by the way, I would say that that should be, Melissa, correct me here. I would think that would be their right under the ADA.

- [Melissa Marshall] Yes, it is.

- [Jean Grover] If it's specially related to their disability and oh yeah, go ahead, Melissa.

- [Melissa Marshall] That's in, it depends. My scholar legal answer is, it depends. If they can provide a quiet place and they can do that without it being a fundamental alteration to the nature of the program, then they're required to do that. And so that's one of the things that you wanna consider is what are their rights? Do they have a legal right to it? Absolutely no, but they might be required in some circumstances. And it's just asking for this is, you know, everyone's goal in a vaccine site is to get, like I said on Tuesday, is to get people vaccinated and you might wanna remind the person, you know, we can get this person vaccinated. It can make all the difference if we can figure this out, let's brainstorm.

- [Jean Grover] Right. Showing them how easy it could be. You know, do you have another room on the premises? Do you have another classroom that you could just open up just for a minute, you know, just for a few minutes for this person and showing them that it's not a big deal, they don't have to have a special padded room or anything like that. It's just a little quiet hallway or something.

- [Melissa Marshall] Or quiet section of the pharmacy.

- [Jean Grover] Yeah. Yeah.

- [Melissa Marshall] And those things are important. And I think an approach that's important to take as a CIL staff person, when someone calls you from public health, or you find out a situation or consumer calls you is like, "I don't know the answer, but we're gonna figure this out together. I dunno what the answer is. I have no idea how we're gonna get it, but I'm confident that amongst the three of us or between the two of us, we can figure this out together".

- Absolutely. Thank you both. Let's see what the next slide says here. So consideration and responses for scenario two. Inform the consumer that the site may be required to provide a place to rest, but can't assure it will be quiet. So as CIL staff, you might wanna call that site to advocate for a quiet space. Emphasizing there may be a legal obligation to make a reasonable modification to a policy or procedure, as Melissa just said. Next please. All right, here, you have an consumer that is just saying, I refuse to get a vaccination because it's going to alter my beautiful DNA. What do you need to consider and how should you respond? Well, we suggest, as I've said before, you don't argue with them, but you do provide factual information. Listen and encourage a consumer to tell you more. You want to maintain and strengthen the relationship. The relationship is the priority. Not whether they get a shot today. Tomorrow's okay. You wanna maintain that relationship? Encourage other risk reduction behaviors, such as masking, hand washing, social distancing. Okay. Next slide please.

A consumer tells you that his personal assistants refuse to get vaccinated. He needs personal assistance services to live independently. What do you need to consider and what would you do in this situation? Okay, let's go to the next slide and see what we thought. Try brainstorming alternate sources of assistance with the consumer and think about preexisting conditions of the consumer that increase risk. Next slide please.

- [Melissa Marshall] This is Melissa. If I can just interject. I live in Connecticut, as does Regina, which is a state that's about 95% vaccinated. And most of my friends that use personal assistants can't get personal assistants that are vaccinated. So that's gotta be a really common problem. I hope it...

- I, yeah, but I know of some people for whom it's a problem, and I'm sure it's a widespread problem, but you wanna provide sources of personal protective equipment and to have the consumer require their attendants to wear masks and gloves, frequently wash their hands, use sanitizer. And you know, you want the consumer to take those precautions, similar precautions, as well as having his or her attendants assistants wear mask, gloves and wash their hands and use sanitizer, You want to, you know, do what you can, unless you've got a line of assistants, you know, waiting to just go help people who are all vaccinated. Well, we have to do the best we can. Next slide, please.

- [Priya Penner] This is Priya. Before we move to the next slide, I think an important part of this conversation is, you know, talking about where to find effective PPE and how to, you know, be able to provide that for attendants who aren't vaccinated. I know that sometimes CILs are able to provide some PPE for consumers or may know of other areas or programs, agencies, et cetera, that might be able to connect. And, you know, at the end of the day, you could always connect with potentially with your public health and see if they'd be able to connect the consumer with other ways to find PPE. So I think that's an important part of all of this.

- Yes, it did. Indeed it is. So our final scenario here is a consumer tells you they cannot get vaccinated because they are afraid of needles based upon their experience of being forcibly medicated in a psychiatric facility. Now, I think this is the situation that Melissa or Elissa, I don't remember now, which it was brought up. What do you need to consider and how would you respond in this situation? Consumers said, "I'm definitely afraid of needles. They used to lock me up, tie me down and stab me with needles. You know, I'd wake up, God knows how long later, and this is just too traumatizing". So what do you think you could do in this case, this person would like to get vaccinated and just saying, "I don't think I could do it".

- [Melissa Marshall] This is Melissa. And I think even before we get to this step, that consumer has given you a gift because they have owned their fear. And that is a hard thing for people to express, especially men. As a woman, it's more acceptable. They say, "Oh, I'm afraid of needles". But as a male, that's harder. I know of someone who passed away and said to his wife, you know, he felt really badly that he should have just gotten a vaccine. And he didn't because he was terrified of needles and there's nothing wrong with being afraid of needles. It doesn't matter why you're afraid of needles. He hadn't been locked up in an institution. He just was, and that's a hard thing. So sometimes it's getting the response. Sometimes, maybe someone says, "I don't want a vaccine". Huh. Too bad. And you draw 'em out a little bit and you find out it's not so much about the changing their DNA or the chip they're putting in, as the needle is scary. And that's a really hard thing in our society for particular males to admit.

- Yes, indeed.

- [Melissa Marshall] So that doesn't get you any further in this scenario, but.

- No, it's what Brenda here says, talk about the advantages of being vaccinated, and absolutely agree there. Let's look at this next slide and see what the consideration and responses are.

- [Priya Penner] This is Priya. As we move on to responses, just wanted to highlight what Brenda said as well, respect their feelings. That's so important, Melissa acknowledged, you know, that this is a huge gift. You know, even that person coming up to you and saying, "Hey, I have this fear". That's so important in resolving the issue. But first step in all of this, and as it says on screen I'm sure, is, you know, as Brenda said, respecting their feelings, that's so important.

- Absolutely.

- [Melissa Marshall] How much must they trust you to be able to disclose that to you?

- Yes, absolutely.

- [Melissa Marshall] You've done a good job. You've built a really good relationship with that person.

- That's true. People don't admit their fears easily. And Lisa put in the chat that it was very important, you know, to respond with kindness.

- [Melissa Marshall] Yes.

- In this situation.

- [Melissa Marshall] Empathy.

- Yes. Yes. And you might wanna ask what has helped you in the past? It's very unlikely that this person has escaped needles ever since that bad experience, because they're afraid, maybe they have, but probably not. So what helped in the past and some other responses are to suggest they have a support person with them on site, and you have to feel this out case by case, but you might wanna recommend meditation or breathing techniques. And then as well, faith-based practices.

- [Melissa Marshall] And my friend who is a female, who's afraid of needles who was in this situation. I have permission to develop scenarios and use their name anytime I want. But she's someone who was locked up and hers are specifically around blood draws, but any kind of needle she's phobic about. And she could say, she's really able to express what she thinks and what she feels. And, you know, said to them, "This is my support person. I'm bringing him with me". And she had instructed her support person and they kind of put up a fight and she says, he's like this big guy who's like six foot two, six foot three, 250 big guy. And she said, she kind of just let him absorb her. And he doesn't know how to do the advocacy. So, she instruct him "No, just don't move". And he just kind of stood there, not knowing what to do. And she said, "He's staying", and they just let him stay. And she was a good enough advocate to get him in. And she's a good enough advocate for herself to get him in. Yet she has the phobia of needles and could articulate that.

- That's great.

- [Melissa Marshall] And the vaccination site was like, well, "You don't have to do this if you don't want to". And so that was, you know, and she knew that was for her second shot. And she said, part of her thought about running and no, I can't do this, but I think it's having that person there and giving that training. This is not someone, the support person is not briefed as an advocate, but just giving us some quick briefing. And that he's kind of a shy unassuming guy. And she's little and petite and you know, is the real strong advocate. It's interesting. It's kind of, you know, one might think from appearance. But it was having that person there who made all the difference for her. And I've heard other people say the same thing, but not everyone is introspective enough or has had enough time to think about and as part of the Disability Rights movement, to be able to say, "I had this bad experience, that's why I'm afraid".

They might be afraid to admit they were in a psych institution as a child, or they might just know, they just not know I'm afraid of needles. I don't know why, needles are scary bad things and not have had the luxury and the privilege to have thought about that. And the why kind of doesn't matter. It's the, that that matters. And I say to people, you know, my major phobia in life is spiders. And if someone said I had to go in order to get the vaccine, I had to be near a spider or touch a spider. You'd have a really hard time getting me to touch that spider, even though it gave me protection from COVID. And I need to put into perspective, everyone has a thing they're afraid of. And for some people, it's needles.

- That's very...

- [Melissa Marshall] Everybody has something.

- Yeah. But that's really important that people look at yeah, what they're afraid of, to help bring the empathy out, you know, yeah, that's really gonna help.

- [Melissa Marshall] And at least her phobia caused her pain and needles cause pain, mine doesn't, but it still makes a lot more sense to me to be afraid of spiders than needles. You know, it's totally visceral, you know?

- Yes, indeed. Well, Melissa, going off just a bit, I was privy enough to hear a piece. I wrote a poem. I wrote about my extreme fear and anxiety around technology. And part of what I've said to people is see, you could put a snake on my desk and tell me to go about my work and I'd be fine. And most people go, "ah", cause I like snakes. And I'm like, okay, that's the feeling I get, yes, when I've gotta move that mouse to a new place or go into a program or something that I don't know. So we all have something, I'm not afraid of needles, but if I were to think, woo, this is a new program. This is something you haven't done. This is a file you haven't seen in a long time and you've gotta find it. I can be much more empathetic to that person I'm trying to help, who's afraid of the needle. So you might also call on people to try meditation or breathing techniques or utilize whatever faith that they have and as always, I didn't put it on, always, if you can accompany someone, then be with them to do something they're afraid of. It's really helpful. Next slide please.

- [Priya Penner] I just wanna add something quick. That one thing we offer to do for someone once and end up not having to do it 'cause she had a really good physician, is go in with someone virtually by phone 'cause she lives in a far away state and we have a group that meets together every night at 6:00 PM. And we're thinking we could all go with you. 10 of us could go with you, or one or two of us could go with you. But she also had a physician who was saying, "Your blood pressure is at this rate". You're you know, "I can't breathe". "Yes, you can, I'll get a pulse oximeter on you, your oxygen level's just fine". "My heart's gonna explode". "No, this is what your pulse rate is. You're not having a heart attack". And was able to reassure her through all those things and no you're okay. These are the facts. You're not having a heart attack. You are breathing, you are getting oxygen. And that was just a really good physician that could do that. And she did her physician's office just because she knew her physician knew her best.

- Good. Good. All right. Next slide please. So at this point I'd like to know what other scenarios you've experienced or do you think you might consider, might encounter rather and what would be some considerations and responses to the scenarios you've either actually been through or that you think about? Okay, if not, we'll go to...

- [Priya Penner] This is Priya. I do see a comment from Brenda.

- Oh, I just saw that.

- [Priya Penner] No worries. And Brenda shares that the whole pandemic is a hoax and yes, that is definitely one that I've heard as well, that, you know, the COVID-19 isn't real or it was created by the government as form of population control. Yes. That is definitely something I've heard as well.

- Okay. For people who don't believe it's real, I don't think you can convince them that it is. But if anybody's got any suggestions on staff, how you convince someone it's real, we all need to hear that. In my experience, it's been one of maintaining a relationship, being there. And if something happens in their life where they then decide or believe it's real, they're really gonna need to talk with you because they're probably in an environment or in a culture that says it's not real. And they risk really being alienated. If they come into their inner circle and say, "Oh, it's real. I believe it now". So I would say, don't argue with them and risk weakening the relationship, you just remain there, you do what things you can to strengthen the relationship. And should they, at some point start to change their mind about what they believe or what they want to do, they can come back to you without any shame or feeling that you've put them down.

- [Melissa Marshall] You wanna leave open that door?

- Yes.

- [Melissa Marshall] Just wanna leave, open that door. They might not come back to you today or this month, but they might later, they might have other questions later and be that safe space for them to be able to say things.

- Yes, indeed. Right. Are there any final questions or comments? Cause we're coming up on the very last slide. Ah, and yes, we've got this message here from Shaylin and German, we appreciate you taking a few minutes by providing some feedback on today's session.

- [Priya Penner] Shaylin and German. Do you have any final comments to wrap us up today?

- [Shaylin] This is Shaylin. And just wanna thank you all for joining us, for your participation and for your time. As Regina said, we do have another survey in the chat for folks. We will send that out, following in an email as well. And we will be following up shortly with the slide deck that was shown today and the transcript of today. And then in the weeks ahead, we will be sharing the post production archive of both today's training and Tuesday's training, so much more ahead and forthcoming and appreciate all of your time and all of the work that you all do in Arkansas and beyond. And if there's any questions, please don't hesitate to reach out to us at any time. Thanks so much, stay safe and take care.

- All right. Thank you.