Project ALIVE's Navigating Vaccine Hesitancy for Montana's Centers for Independent Living

2022

- All righty, we're gonna go ahead and get started. Hello and welcome everybody to Project ALIVE's Navigating Vaccine Hesitancy for Montana's Centers for Independent Living. My name is Priya Penner, and I'm with The Partnership for Inclusive Disaster Strategies I use she, her pronouns and I'm a brown woman with long curly black hair. Today, I'm wearing a purple dress and a blue gray cardigan. On the screen, you have a title slide with text that reads, Navigating Vaccine Hesitancy for Montana's Centers for Independent Living. Above the title is the Project ALIVE logo, which includes the text that reads Project ALIVE. In the word alive, a red bandaid in the shape of a V replaces the text, V. Under the text, here are five symbols in white that have a blue background. From left to right, the symbols are the international access symbol, which is a person pushing themselves in a wheelchair, a symbol with a white cane, a white cane for the blind, an ear with a dotted line through it, the interpretation symbol, which shows hands and the ASL sign for interpretation and an outline of a head. Below the symbols is additional text that reads an Accessible Life-Saving Integrated Vaccine Equity. I'm gonna first get us started with some accessibility and technical support reminders, and then we're gonna fully get started and I'm gonna pass it off. So first and foremost, this training is being recorded. An accessible archive of today's training will be available in the coming weeks. The archive will include the areas on interpretation that we have here today, as well as captioning, as close captions. Today, we have American Sign Language or ASL interpretation on screen, as well as Communication Access Realtime Translation or CART captions available. Today's ASL interpreters are Kenya McPheeters and Brenda Wharton. They're already pre-spotlighted for you. So everyone should be able to see them. If you're having trouble seeing them, you can change the sizing of the Zoom boxes, as well as the shared screen. To change the size of the boxes, change the frame, you can do so by dragging the frame, separating the interpreters from the slides. You can drag that left or right to change the size of the screen. CART is provided today by Ai-Media and is already embedded in Zoom. You can access the CART captions via the CC button at the bottom of your Zoom navigation bar. Click once on the CC button to show subtitles on Zoom. You can also use the little caret in that CC button to edit the captions, what they look like and make the size bigger, the font change, et cetera. If you prefer to have the captions in a separate window, please do follow the link put in chat. If chat is not to accessible to you, please do email Priya@disasterstrategies.org. That's P-R-I-Y-A@disasterstrategies.org. So we have a number of great opportunities just like last time to engage in the presentation. We definitely don't want to be, you know, just hearing our own voices. We wanna hear from you guys as well. So to ask or respond to questions, you can use the raise your hand feature at the bottom of your Zoom screen. You can type in chat, or you can simply just come off of mute at an appropriate time and share your thoughts with everybody. You can use the same process, either raising your hand or typing in chat for any technical assistance, issues that arise. Again, if chat is not accessible to you, please do submit your questions to Priya@disasterstrategies.org, And then finally, some friendly reminders regarding accessibility during this event and access for the post production. First and foremost, please do identify yourself every time before you speak. This provides access to anyone who is following along in CART and or who will be watching after the fact, in the post production, of course. Do keep yourself on mute when you're not talking. Again, this helps folks following along in CART, but it also helps us create a clean and accessible post production. We do prefer if you can keep your camera off, unless you're talking, if you're having any trouble with these- if any trouble muting yourself or keeping your camera off, we're more than happy to assist. And then finally, please do avoid using acronyms whenever possible. We wanna make sure everybody is on the same page and that helps, avoiding using acronyms helps us do that. And with that, I am going to turn it over to you, Regina. Thanks.

- Thanks, Priya. Welcome and about us. Yes, please pull up the Welcome and About us slide. Welcome and About us. Next slide. 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. The goal is to help people with disabilities, wanting a vaccine and needing support to access one. I am Regina Dyton. I'm a 68-year-old African American woman. Tall, round, brown, and proud, living with the disability. I have dreadlocks that are currently twisted into short coils. My pronouns are she, her. And today, I am wearing a white dress. And I'm gonna turn it over now to Shaylin Sluzalis, who is going to introduce the team, the other people here.

- [Shaylin] This is Shaylin. Thanks, Regina. And thank you all for joining us again today for this training, Project ALIVE training. Just wanna recognize folks on the line, but first wanna also identify our project lead, this Project ALIVE being brought to us all by APRIL, the Association of Programs for Rural Independent Living and Elissa Ellis and Sierra Royster are with us in spirit today, having other things happening today, where they will certainly be in touch and can be contacted following and all support from them. And thank you so much for that. Also want to recognize our colleagues on the line from Montana, from Living Independently For Today and Tomorrow, Carlos Ramalho, Nancy Gretzky and John Robison are on the line. And thank you all for joining us. And on the line today from Summit Independent Living Center is Tami Hoar, Travis Hoffman. And I believe I see, is that Mariah on the line as well, Mariah Armstrong? I believe so. And I think that's all of us. If I missed anyone, please don't hesitate to shout out.

- [Susan] Yeah, Mariah is here and this is Susan as well.

- Thank you.

- Hello, everybody. This is Mariah.

- [Susan] We're in our conference room.

- [Shaylin] Great. Thank you both, Susan and Mariah. Glad you're both here. Cool. With that, I'll pass it back to you, Regina.

- All right. Thank you. Next slide, please, Priya. The population focus of Project ALIVE is on people with disabilities in rural areas of Montana who desire COVID-19 vaccines, that is the primary series and booster, and experienced barriers accessing them. As well as people with disabilities who are hesitant, but are still open to getting the COVID-19 vaccines. Next slide. A disclaimer, that 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 slide. A few ground rules. Please maintain confidentiality, ask questions, and as serious a topic as this it is, it's still okay to have some fun. Do you have any ground rules that you'd like to suggest? If not, I'll ask to go to the next slide, please.

- [Priya] This is Priya. I don't see anything in the chat.

- Okay. 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. And you'll be able to identify barriers to accessing COVID-19 vaccines, that is the primary series and booster, and know how to respond. Next slide. Understanding vaccine hesitancy, uncertainty and rejection. Next slide, please. Understanding vaccine hesitancy. The definition of hesitancy we'll be working with today is the delay in acceptance, reluctance or refusal of vaccines despite the availability of vaccine services. There are also different levels of hesitancy. And we'll talk somewhat about that and I'll be asking for your input as we go along. Next slide, please. Some people move from hesitancy to acceptance. A study of 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 a study that was conducted by the Kaiser Permanente Group. Next slide, please. Reasons for vaccine uncertainty and rejection. The major reasons for uncertainty and rejection were faith-based beliefs, political affiliation and racial, ethnic identities. Next slide. Reasons for vaccine certainty and rejection continued. It's important to realize that faith-based and political beliefs, as well as racial and ethnic identities are core and constant. It would be disrespectful and inappropriate to try to persuade one to change. Next slide. Moving from hesitancy to acceptance. Next slide, please. Why and how do people move from hesitancy to acceptance? The best educators are peers. People identify peers based on several things, amongst them are disability, race, ethnicity, culture, and language. Still staff should address people's concerns about information in an open, unbiased and welcoming manner. Here's the great thing is that as you know, as CIL staff, you've got the power of peer support and advocacy. It's one of your core services and one of the things you do best. You may be a peer on one or more of the bullets in this slide. I'd like to take a moment now and see if anyone has any comments about being a peer and supporting people with disabilities in various ways. But in this case, around COVID-19 vaccination hesitancy. Anyone got stories to share? If not, let's move on our next slide. And in this next slide, we're also continuing to talk about why and how people move from hesitancy to acceptance. People also move to acceptance because of life experiences, such as getting COVID-19 or watching a family member or friend struggle with the virus. Next slide, please. Moving from hesitancy to acceptance and questions for you. Does anyone have examples of people who were hesitant and move to acceptance? If so, what was that like? And what can we possibly learn from it? Okay, I'm going to ask if, once again, if anybody has an example and I'm gonna call on members of The Partnership team, see if they've got any examples of people who were hesitant and move to acceptance.

- [Melissa] This is Melissa. And if I can add a story that actually came from you, Regina, that we shared together, is that okay?

- Yes, that would be great. Thank you.

- [Melissa] Regina and I have a friend and she's someone who is, she's a Black woman with the disability. I believe she has a disability but is older and she doesn't seek out medical treatment and likes to take care of things natural and likes to take care of things by herself. And very early on in the process, as soon as there was a vaccine, she said, "I'm never getting a vaccine ever, ever, ever." Then, she kind of paused and said, "I'm not gonna leave the house." So she was gonna be socially responsible and protect other people and protect herself, which was never, ever gonna get a vaccine. Yet, now she's vaccinated. Regina, can you talk about how that happened? 'Cause I'm quite aware of the process, except that one day she got vaccinated, I was like, yes.

- Yes, I am so glad she got, well, first of all, as a Black woman, who said, well aware of the history of the mistreatment of Black people by the medical profession, she was, "I'm gonna see if it kills white people." I'm just gonna tell you the truth. She's like, "I'm gonna see what it does." Like as part of that was watching, right? So it meant it wasn't killing anybody, but the other one for her was that she has grandchildren and her daughter was getting the grandchildren vaccinated. And so really kind of like the appeal and the example, really the experience of loving her grandchildren, not wanting to remain quarantined from her family, made her say, "Okay, let me go ahead and do this thing." And then later on, she did catch COVID and was very glad she was vaccinated because, well, because she's still living to talk about it. And she did have, you know, pre-existing conditions that would make things harder for her. So I'm really glad she did.

- [Melissa] And she's still in, Regina, correct me if I'm wrong, who've been medically resistant in the past. Like had another condition where she didn't wait, she waited to go to the hospital until like the last minute kind of thing?

- Oh yeah, yeah, exactly. Exactly. Yeah. She's been very distrustful of the medical profession and I mean, as people with disabilities, we understand that, as people of colors. Yeah, whatever, tribal members, we understand that, but it's really, I think-

- It's like-

- We'll talk about that later and talk about doing like a risk benefit assessment. You wanna take the best care of you that you can.

- [Melissa] And it wasn't like we cajoled her into taking the vaccine 'cause when she said she wasn't gonna take, okay, that was fine. And she said, she wasn't gonna go out of the house. That's really fine. That's really responsible. And I just kinda watched the process unfold. So she saw other families modeling, getting the vaccine and also the potential deprivation of companionship with family members, her grandchildren who she adores.

- Yes, absolutely. Yeah.

- [Melissa] So that wasn't a technique, so to speak, it's kind of what unfolded or you could ask someone, you know, do you have grandchildren? Your children, are they getting vaccinated? What are they doing? Are you still gonna be able to see them as freely? And grandparents are moved by their grandchildren.

- Yes, indeed. You know what, it made me think. She didn't say this, but she also saw all of her friends getting vaccinated and not having anything bad happen to them.

- [Melissa] Right.

- And that, you know, I'm sure that meant something as well.

- And-

- So it's another way when we do something good for ourselves, we're also doing something good for other people. Great.

- [Melissa] One of things that I do when I find out someone's been vaccinated is, in their Facebook post, I'm on Facebook a lot, I'll post, congratulations. You know, you've done a good thing for the world, not just for yourself. And I think it's reminding people of that as well.

- Thanks for that, Melissa. That's really great. That's something we might all wanna think about those of us who uses social media or even if you're not doing it on social media to just thank people and remind them they've done a great thing for a lot of people. That's great. All right. Next slide, please. Here we're gonna talk about reasons for, and responses to vaccine hesitancy. Next, please. And so some reasons for hesitancy are distrust of media to provide accurate information, distrust of government to provide accurate information, and as we were just talking about, a distrust of the medical profession, based upon history of ableism, racism, and or other forms of bias and abuse. Next, please. So we're looking at reasons for hesitancy and ways to respond here. Looking at some examples. The issue here is, I guess they have to wait for the next clicker to come up, here we are. A consumer knows of someone else who got the vaccine and still got COVID. How might you respond to that consumer? If somebody says I'm not getting a vaccine because my friend Mary got it and Mary still got COVID. Well, one response that we can pull up now, is to let them know that the purpose of the vaccine-

- [Priya] This is Priya. Regina, I'm just gonna jump in here and say, we're having some difficulty hearing you if you wanna make sure you're-

- Oh my goodness. Thank you so much. Is this better?

- [Priya] That is much better.

- Wow. Yeah. Say that if that happens again, because I'm on this little rolling chair and if I roll back a little bit, it seems like that causes a problem. So I'll try to remember to stay close. So if, yeah, if we could do the click, that brings up the response for this issue. When someone said, "Oh, my friend got the vaccine and still got COVID." You may want to let them know that the purpose of the vaccine is beyond not getting COVID. It's to reduce the chances of dying or being hospitalized. Next, please. So more reasons for hesitancy and ways to respond. A consumer thinks the vaccine will make their disability worse. What might you say to that consumer? Well, like me, I don't know, I'm not a medical provider. So I'm gonna tell them to seek advice from their medical provider because they think, think is the operative word here, or they fear the vaccine will make their disability worse. They need to check with the medical provider. Next, please. Another consideration, some people cannot be vaccinated for medical reasons or the vaccine is not effective because they are immunocompromised. Those of us who can be vaccinated can help protect others by getting the vaccine, yet, another reason to congratulate people when they get vaccinated. Next slide, please. Questions and comments. Have you heard of other reasons for hesitancy? Anybody wanna offer other reasons that people have said they don't want to get vaccinated? Don't be shy. I'm sure you have. Anyone from The Partnership heard other reasons for hesitancy or rejection?

- [Mariah] Hi Regina, this is Mariah and, often, I hear people say they do not know what's in it. And kinda, you know, piggybacking off of the last question, it's like, you can ask your medical provider exactly what's in the vaccine so then they can really tell them the ingredients and see if it's something they're allergic to.

- Yes. It's interesting. And I don't advise saying this to a hesitant consumer, but what I'm reminded of, what I think of when people say they don't know what's in it is that neither do they know what is in much of the fast food and processed food that people just run to and consume because it tastes good. Anyway, that's just my aside. Any other hesitancy reasons that people have heard?

- [Priya] This is Priya. I'm actually really curious to hear from Travis. 'Cause I believe, Travis, you had shared some hesitancy reasons last time. And I just wanted to, perhaps you could free share or maybe there are others that you wanted to add?

- [Travis] I don't recall what those were if I did, other than I remember sharing some inaccessibilities of the vaccine distribution system, but, the only hesitancy I can think of, I mean, obviously, political ideology is a big one here in Montana. But then again, some of the people who I know fall on that side of the spectrum did end up getting vaccinated much for the grandkids reason, so.

- I know that some others that I've heard of, are people fearing that the vaccine will actually do them harm, that it might have a negative effect on pregnancies or children that they're going to have, might have problems due to something in the vaccine that it was developed too quickly. And therefore, they don't have confidence in it, all the way to having heard it referred to as the mark of the beast or that it has a microchip in it, that's meant to monitor and control people. So there's, you know, everything from zero to a hundred in terms of reasons for hesitancy. Does anybody have any questions or comments at this point?

- [Melissa] This is Melissa. I just wanna add one more thing. I have yet another friend on Facebook who's from childhood. And so we don't really know each other now, but we've exchanged pleasantries from time to time. And she was saying she wasn't getting a vaccine and it just, I'm curious why. And I was trying to keep it real neutral, I'm just curious. She said, I said, "You know, I think it's real 'cause," and she said, "No, I think it's real, but it's just a flu."

- Okay.

- And she's someone works in the medical profession. She's a phlebotomist. So that was just another example. She still doesn't think it's real.

- Yes, that is another one. Yeah.

- [Melissa] And she's a medical person.

- Uh-huh.

- So just kinda let go 'cause I put out information and you know, do it what she will.

- Yeah, and that reminds me of some of the mistrust of government. Not that in many instances it hasn't been earned, but I've heard people say it's not real. The numbers are being, you know, invented basically. So all these people didn't die of COVID. The infection rates aren't that bad. So yeah, there's a lot out there. A lot of discussion. Next slide, please. That brings us right to the question of, who is at risk for COVID-19? Another reason that I've heard are people feeling that, "Well, I don't need it. I'm young, I'm healthy. I don't have pre-existing conditions." So this is something to talk about. Next slide. Who is at risk? 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. And it's a good time to mention that most people don't have just one disability or condition or comorbidity. Next, please. Disabilities and risk. People with one of these disability types might be at increased risk for COVID-19 and its effect. 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. Disabilities and risk. People with one of these disability types might be at increased risk for COVID-19 and its effects. People who may not be able to communicate symptoms of illness. That seems a repeat and people in congregate settings. Next slide, please. Some medical conditions that increase risk include cancer, chronic kidney disease, chronic liver disease, chronic lung disease, cystic fibrosis, dementia or other neurological conditions, diabetes type 1 and 2, heart conditions. Next, please. Continuing on disabilities and risk with more medical conditions are cerebral palsy, congenital disabilities, developmental and intellectual disabilities, learning disabilities, spinal cord injuries, certain mental health conditions, sickle cell disease or thalassemia. Next slide, please. It's important to address all forms of risk reduction. Remember that someone who doesn't want a vaccine might be willing to practice other forms of risk reduction, such as masking, social distancing, hand washing, and isolating. Next, please. Discuss risk specific to the individual. Help individuals to do a risk benefit analysis regarding practicing risk reduction behaviors, explore risk factors, such as age, their specific disability, such as people with respiratory issues like asthma, people with diabetes and other chronic conditions. Environmental factors, such as being in close proximity to caregivers, explore requiring caregivers to use mask, gloves, et cetera. Next. We're going to talk about reasons and responses to vaccine hesitancy. Next. These are the reasons we spoke of before with suggested responses. First, we'll see what you think. And then we'll look at the suggested response. So the issue here is distrust of media to provide accurate information. What might you say to this consumer? Okay, the suggested response is to provide access to a variety of media and public health websites to allow the person to make an informed decision. We're looking at science-based sources, such as the state public health department, Centers for Disease Control, et cetera. Next. Distrust of government to provide accurate information and distrust of the medical profession based upon that history of ableism, racism and other forms of abuse that we spoke of earlier. How might you respond to consumers not trustful of government or the medical profession? The suggested response here is to respect an individual's and or community's history with government media and the medical profession. To listen respectfully to their perceptions of them. Here's a good time to remind you that your ongoing relationship with this consumer is what is the priority. So you don't want to argue and push people away or damage the relationship in any way. Next slide, please. In responding to vaccine hesitancy, here are two other issues. Uncertainty about the long term effects of the vaccine and fear that the vaccines will cause illness or infertility. Any responses from any of you before we pull up the suggested responses? Okay. Our suggestions, are to support the person in a risk versus benefits analysis and talk to them about the current risk of getting COVID versus the long term risk of getting the vaccine. And you may wish to discuss with them post-COVID condition, previously referred to as long COVID. Next. What are post-COVID conditions, PCC or long COVID? Common symptoms include fatigue, breathing difficulties, insomnia, pain, and brain fog. Post-COVID can negatively affect organs like kidneys, lungs, pancreas, and heart. Most people recover from COVID-19 within three to four weeks of getting it, yet, a significant number of people experience lingering symptoms. Next. Another issue here is fear the vaccine because it was developed so quickly. Any thoughts on how you might respond to that consumer with that concern? Okay. The Partnership suggested response is to provide education about how the vaccine was developed. And I'll talk about some of that right now, starting with that President Donald Trump championed Operation Warp Speed in order to develop and mass produce safe vaccines. Next. The development of the vaccine happened with a partnership of government science and industry, using a new model to do in nine months what would usually take five to seven years. Another important thing to tell people who were concerned about it being developed so quickly, was it wasn't really developed that quickly. Scientists had been working on this type of vaccine for over 10 years. That is, the researchers have been studying and working with mRNA vaccines for decades. Interest has grown in these vaccines because they can be developed in laboratory, using readily available materials so they can be made and produced in large quantities to be used when needed. Next. Development of vaccine continued. The federal government oversaw the process instead of the pharmaceutical companies. Steps were taken simultaneously. In doing like a parallel preparation, there was increased financial risk to manufacturers and let's face it, for pharmaceutical companies, you know, any private industry is always concerned about their bottom line. With government overseeing it, they were saying, "You're gonna take the financial risk. We're subsidizing you. And we're gonna decrease the risk for public distribution to the public. That is we're going to increase, watching out for the safety and still being able to get it to people. They did consistently testing while manufacturing with government oversight. But that government oversight meant that if they manufactured something they found to be not safe, it would just be thrown away. And government was subsidizing the cost. But even if the companies lost money so be it. It's also important for some people, you know, we talked about peers and who people identify with, some will feel better about it when you talk about President Trump's leadership, others might feel better in learning that-

- [Priya] Regina, I'm gonna interject once again. It's just you're cutting out once again.

- Oh my God. I guess I have to face this.

- Yes, yeah.

- Is it not, which way I'm looking? Okay.

- Yeah.

- I'm gonna move this so I can see my screen even better. Thank you for letting me know that. Some people may have more confidence in knowing that Kizzmekia Corbit is an African American viral immunologist who led the team that developed the Moderna vaccine. So there's, you know, just different information you give people that might make them feel better about how it was developed. Next, please. So this consumer doesn't think, or is not sure that they're in a high risk category. Oh, I'm sorry. Next slide. I didn't even say that. Here we are with the consumer who thinks that he or she or they are not in a high risk category. And our suggested response is to provide education about COVID-19 universal risk in people with disabilities, pre-existing conditions, racial, ethnic, gender, and other COVID-19 information. The truth is that everyone and anyone can get COVID-19. And unfortunately, children and young adults have gotten it and died. The majority of cases are now people between the ages of 18 and 44. Next. In continuing to respond to vaccine hesitancy. Some people have said, they think the vaccine can alter their DNA and that natural immunity is better than vaccine immunity. And we suggest responding by letting them know that there is no known substance in the vaccine that can alter DNA. And we also suggest telling them we can put up, click up the response if it'll come up. Thank you, that getting a COVID-19 vaccine is safer and a more dependable way to build immunity to COVID-19 than getting sick with COVID-19. Next, please. Some people have vaccine hesitancy as a result of barriers. Next, please. And some people may be hesitant due to barriers to accessing the vaccine, the primary series and the booster. That barrier could be actual or assumed. Next. Some barriers to vaccine access include lack of transportation, especially accessible transportation, lack of sign language interpreters, lack of spoken language interpreters, and lack of physical access for wheelchairs or other mobility devices. Next. Additional barriers include lack of sensory accommodations that is scent-free environment, low level lighting, quiet room, et cetera, no support person at the site, fear that the site won't allow a service animal to enter and fear that undocumented immigration status will be discovered. Next. Additional barriers include bad experiences with vaccines in the past, disability bias, lack of accessible information about the vaccine. People with previous negative experiences may be hesitant to seek healthcare in general due to disability bias, including accessing the vaccine. Next. Additional barriers include lack of accessible registration, such as easy read, large print font, screen reader accessible, and other formats. Also, a consumer caregiver or conservator or guardian doesn't want them to be vaccinated and won't assist them. Next. Some responses to some of these barriers is to educate the consumer on disability rights and advocacy about what is and is not legally required for the consumer and for the vaccine site, focus on the consumer's specific current concerns or fears. You can call ahead to advocate for accommodations and if possible, and if the person so desires, accompany them to the vaccine site. Next. A fear we talked about was that of undocumented immigrants, that the status would be discovered or that a person will be suspected of being undocumented, even if they are not. Our suggested response is to provide education about healthcare and immigration status law. Also, offer to accompany the person to the vaccine site. You may also want to refer them to legal aid or a similar service for further education and advocacy. Next. Equal access to COVID-19 vaccines. I think it's really important to let people know who are so concerned that the Department of Homeland Security release a statement in February, 2021, ensuring that it will cooperate with the Federal Emergency Management Agency or FEMA and will not conduct enforcement operations near or at healthcare facilities, including pop-up clinics, hospitals and other such facilities. Next. Another issue, consumer had bad experience with vaccines in the past. Respond by inquiring about the previous bad experiences. Asking questions such as, did they have a medical reaction? Was there a lack of accommodations? Next. In this case, a consumer had previous negative experience with healthcare that caused hesitancy to seek any health services, including receiving a vaccine. Please respond by listening without judgment, providing disability rights, education, and advocacy, and offer peer support at the vaccine site.

- [Priya] As we move on the next slide, I wanted to read a comment from Carlos who says we can't provide services to undocumented immigrants.

- Wow. I'd like to have a conversation with you later about that. Anybody else have a comment on that or have a similar situation? Okay.

- [Germán] This is Germán. Carlos, thank you for bringing that up. And certainly, we were part of this conversations are informing us, what are the necessary resources are needed to best educate what are people's rights? And right now, COVID-19 falling within an emergency declaration, disaster services cannot be prohibited from immigrants with no need for, to prove documentation. And if they are being denied or there are fears or concerns, there are proper channels to anonymously, make complaints on this and get it resolved. We have collaborated with CILs that you know. In Idaho, for example, LINC has worked with groups that have been vaccinated that have provided vaccinations for immigrants, farm workers, no question asked. We collaborate with community members in El Paso, Texas, right by the border where they affirmed us early on, immigrants are being offered a vaccine, no questions asked. And even then to the, if they get COVID and experience the difficulties that considering that currently, during the public health emergency is a disaster that the services that they seek medical attention should be without charge. And if there are, and there are then, additional, there may be minimal charges that would apply to anyone. But there are extravagant, there are complaint mechanisms to deal with this and happy to talk it further.

- Yes. And thank you Carlos for bringing that up. All right. Continuing on responding to barriers. Someone says that their caregiver, conservator, or guardian doesn't want them to be vaccinated, and won't assist them. In this case, you should refer them to Disability Rights Montana. Next. In a case where there is inaccessible information about the vaccine process, you can provide education about the process and advocate for accessible information for the vaccine site for it to be accessible at the vaccine site. Next. The issue here is inaccessible registration and the response is to provide information and education to public health about the legal requirements or materials in alternative accessible format. Have you dealt with any of these issues and have you tried some of these responses? All right. We'll soon have the transcript and everything from the legal training as a resource, as well as the checklist so that will be helpful to you. So now we're looking at some scenarios here. This is the part where you get to have fun. And let's say a consumer calls you and that after their friend got very sick from COVID, they've decided they want a vaccine, but their family is against it. They depend on their family for transportation and personal assistance. What do you need to consider and how should you respond? And if you wanna make this fun, you could volunteer with somebody who's here with you that you know to do it as a role play, you don't have to, but that might make it fun. And if not role playing, what would you need to do for this person who says, "You know, my family won't let me do it." Okay.

- [Priya] This is Priya. I'm wondering if Mariah has any thoughts on this scenario?

- [Regina] Yeah.

- [Mariah] Hello, everybody. This is Mariah from Ronan. And so I would, approach this, let them, you know, really listen to them, but I would also provide, arrange transportation. So they're able to get to the vaccine site.

- Okay, thank you. Next slide.

- [Priya] This is Priya. I just wanted to say that's a fantastic inclination in response, you know, doing whatever you can to help them get to the vaccine sites. If possible, helping them arrange transportation, perhaps, encouraging them to rely on other natural supports if they have them such as a friend who could go with them for the duration of the vaccine process. Or even if you're available, you know, perhaps you also accompany them as peer support. Carlos, I see you went off mute.

- [Carlos] Yes. This is Carlos from LIFTT. And I would recommend my community health worker to talk to the family before working with the consumer, because if the consumer might not be aware of the risks that he is exposed to allergies, reactions, or even medical advice, and the risks are too high. And even if it's trying to persuade to the family about the benefits of the vaccine.

- Thanks, Carlos. That's a good suggestion. Those are good suggestions.

- Absolutely, and-

- This is Melissa.

- [Priya] Go ahead, Melissa.

- [Melissa] Yeah, this is Melissa. I just wanna jump in and just, you know, and I know you know this Carlos, but making sure that the consumer has signed off in you talking to the family and that they agree with that. And that they're cool with that, maybe offering that as a suggestion, that they talk to the family and maybe you help persuade or talk to the family about that. It also seems like in the scenario, there might be some deeper dynamics because let's say you get transportation, which is great. You wanna do what the consumer wants to do. And the family might not provide personal assistance if they've gotten a vaccine, that suggests maybe a greater need and a deeper dynamic for personal assistance, that's independent of the family in the person's life, because there might be something that the person does later that the family also disagrees with. And you can't hide the fact that you've gotten a vaccine at very least your arm's gonna hurt. So if they're giving you that kind of intimate, personal assistance, they're gonna have to work a backup personal assistance. And it sounds like in the situation that's particularly something you wanna have anywhere. Does that make sense to people?

- [Priya] This is Priya. Yes, absolutely. That makes sense to me.

- Yes.

- [Priya] I think that's a great suggestion.

- Uh-huh. Yes, indeed. Next slide, please. Some considerations for this scenario are to think about the legal status of the family member to the consumer. Are they a legal guardian? You know, are they a caregiver without any legal status? And also to consider, and I think Melissa kinda alluded to this, what repercussions may result. There may be other interventions needed. It certainly looks like there's more than one thing going on. If you know, family says, "We don't want you to do it and we'll stand in the way of it being done." Next slide. Other responses include referring them to Disability Rights Montana and discussing that level of family resistance possible outcomes. What's the openness of the family to education? If it's feasible, provide education to family members. Next.

- [Melissa] This is Melissa. If can jump in one more time, 'cause I'm like cut.

- Oh, please

- Sorry.

- No, please do.

- [Melissa] What I wanna say too, is just because someone has the conservator or guardian and I'm trying to recall what it is in your state. It's a different view here, conservator or guardian, but someone has that person with the legal power. If they wanna get a vaccine and the conservator or guardian says no, that's not an automatic slam dunk no. There's ways to go to probate court to get that person, their permission to get a vaccine. And the Protection and Advocacy Systems are in high alert and will red flag situations like that. So just because someone says, "I really want one and my guardian won't let me," don't just say, "Oh, they have all the legal responsibility." They might wanna go to Protection and Advocacy. They might wanna bring their guardian or their conservative probate court possibly. There might be some other things that can be done. So don't just automatically say, oh, if they say no, there's nothing we can do about it. There may be things you can do about it. Thank you, Regina.

- Oh, sure. Thank you, Melissa. That's an important piece of education for consumers because many consumers may just assume that they have no right, no pushback, no say. All right.

- [Mariah] Hi Melissa. This is Mariah. Thank you for that feedback. So that's very good to know. Thank you.

- Uh-huh.

- You're welcome, Mariah.

- All right. Let's move on to scenario two, please. A vaccination site tells a consumer they cannot accommodate someone's need for a quiet place to receive and rest after the vaccination. And what do you need to consider? How would you respond? Vaccinations said, "We can't do that." All right, let's go to the next slide and see.

- [Priya] I was actually, this is Priya. I'm actually curious to hear from John on this answer. John had some fantastic responses to the scenarios last time. And I'm just curious to hear your thoughts on this one.

- [Melissa] This Melissa and John got lost, lost in brand new virtual fabulous price cars from the last time. So I hope he's gonna join us.

- Oh, yes, indeed.

- [Priya] If John's not available, which is absolutely okay. I actually, you know, Melissa, I wanted to ask you, this, we talk a lot about, of course, the need for accommodations and recognizing not everyone has the same accommodations. The accommodation of a quiet place, I'm curious. Do you have any insight?

- [Melissa] This is Melissa. I'm gonna give you my favorite scholarly look, answer from last week, it depends. It depends on what they're doing. So if it's a reasonable modification to policy, practice or procedure, then they have to do it. If they're in a space, you know, there's a building that has many offices or separate places, yes, that's gonna be a reason for modification on policy or practice. If they're busy pharmacy, not so much, but if their busy pharmacy has a quiet area, then they might be required to do that. Does that make sense? So they might not have to do that, but they might advocate for it. So it's not always saying that you have to do this as required under the law. It's like, gee, you could really do this guy a favor by finding a quiet space. Maybe the place in back of the pharmacy. You know, that he can go that would be safe or she can go that would be safe or they can go that would be safe. Does that make sense, Priya?

- [Priya] This is Priya. That makes a ton of sense. I'm wondering, is this an issue that perhaps is arising in Montana? Is this not necessarily one of the forefront issues? Has a similar situation happened in Montana? And Carlos, I'm really, I'm actually gonna turn to you for this because I believe you shared that accommodations, you know, or ADA following the ADA in general has been tough for the state of Montana. Do you see that when disabled people are requesting accommodations in vaccine sites, is that being met? Is this not necessarily an issue? And Carlos, if you're speaking, you're on mute.

- [John] Okay. This is John. Just to let you know, Carlos just stepped down his office. I think he had to use restroom. Sorry about that.

- No worries.

- Okay. It's all right. We can certainly come back to that. Let's go to the next slide.

- [John] So if you don't mind, I think that could probably give a little light on that. So myself, Nancy, we've been going around to the counties within our law area of responsibility here. And so there are certain barriers, certain issues we're coming across. We're going to the health departments, we're going to the hospitals and they could be everything from, like for example, as a Carbon County last week, in Carbon County, I was surprised see that the wheelchair ramp going into the health department was really narrow. So that could have been a massive barrier right there. And seeing out at this point, there's not any viable vaccination plant in a lot of these counties here. Another issue running into, everything's case by case basis, some of the folks out there in the population with disabilities, for example, vision loss, they receive flyers in the mail. Obviously, they can't read them. Or lot of information is being put out by radio. A lot of these folks live the way out there in boondocks. Well, they don't get the radio signal. So those are some barriers that we're facing here in our law or in the state.

- [Melissa] This is Melissa, order, Jackson, you know, it's not accessible to radio as an accessible mechanism for them at all. And I just wanna add with the ramp it's legally required that vaccination sites within a reasonable geographic proximity be accessible when we talked about that last week. And in addition to being accessible, I could see something like that being dangerous, depending on how it's being set up. If it's too narrow, it might be too steep as well. Do you know I'm saying, John?

- [Regina] Yeah.

- [John] Yes, Ma'am.

- Way out of compliance. Thank you for that input though, for that information. Some things to consider in this scenario is to inform the consumer that the site may be required to provide a place to rest, but can't assure it'll be quiet, but you may call the site to advocate for a quiet space, emphasizing to the site that there may be a legal obligation to make a reasonable accommodation to a policy or a procedure. And that's something that Melissa talked about.

- And this is Melissa-

- Yeah, come on back.

- [Melissa] And this is Melissa. just says, if it works through the consumer, finding out what times of day are least busy. One of the things that my daughter did, when she lived here during the pandemic, is first of all, this when we're first getting vaccines is she found the vaccine where they had a ramp entrance in the back closest to the pharmacy and she thought that would be great. And then she also found, looked up the time is when they're busiest and least busy. So that's something you can support a consumer in doing too. they're leas busy at 7:30 at night. So let's go then if you can get them transportation at that point or they're least busy at 10 in the morning, whatever that time is, finding when they're least busy. Think about things like, well, you have to go through the whole store because again, and that was when everyone wasn't vaccinated. So she set it up so we just had to walk, go in as far as the pharmacy. And so just looking up those things with the consumer and that's something we all have out to access to because pharmacies have websites. If they're going to a pharmacy and other places, you can just kinda call them and ask them say, "Hey, when do you tend to be most busy?"

- Okay. Thanks. Any other questions on that scenario or comments before we go to scenario three? Okay. Scenario three, a consumer tells you she refuses to get a vaccination because she believes that the vaccine will alter her DNA. Now, how might you respond and what do you need to consider in a case like this? Okay. Let's move to the next slide.

- [Priya] As we do so. Nancy, I'm curious, did you have any considerations for this scenario? Things that we might need to think about when responding? Nancy might have stepped away. That's okay.

- [Regina] Okay.

- [Priya] I just wanted to ask.

- But yes. Thanks for inviting the input. So considerations and responses for this scenario, scenario three is don't argue, but provide factual information. Reminding the consumer, there is no known substance in the vaccine that alters DNA. Listen and encourage the consumer to tell you more. You want to maintain and strengthen the relationship. You already know how important it is to listen. The ongoing relationship with a consumer is the priority. They may not want a vaccine today as they trust and continue their relationship with you. They may want one later. Encourage other risk reduction behaviors, such as masking, hand washing and distancing. Okay, next.

- [Melissa] This is Melissa. I just wanna add that consider empathy again. And it's real easy to get caught up and they should get a vaccine or they should get a vaccine or what your opinions are about that. But what it must feel one to be someone who thinks that the government or someone is out there and wants to alter your DNA, or someone wants to give you a vaccine, that's going to harm you or kill you. That's gonna be really scary. That's gonna be really hard for that person and try to empathize and connect with that person on that level. 'Cause it's really, 'cause imagine what that feels like.

- Yes. Yeah, that is really important in all of these situations to bring forth our empathy. Indeed. Next slide, please. In our fourth scenario, a consumer tells you that his personal assistance refused to be vaccinated. He needs the personal assistance to live independently. What are your considerations and thoughts on responding to this person?

- [Carlos] Well, the personal care assistant is preventing him and is stealing his self-determination. We needed to replace his assistant.

- Thank you, Carlos.

- [Melissa] This is Melissa. Is that realistic in Montana?

- Hello, this is Mariah.

- What's that?

- [Mariah] Oh, sorry. Carlos, go ahead.

- [Carlos] Oh, I was going to tell Melissa that if she asked the question, the captions did not pick it up.

- [Melissa] Oh, I was just asking if that's realistic in Montana. And the reason I asked that question is I live in Connecticut and lots of my friends are having trouble getting personal assistant that have vaccinated. Does that go through with the captioning?

- [Susan] Yes. It's hard to get assistance-

- [Carlos] Yeah. Now the captions pick it up. I don't know about the other centers, but at LIFTT we emphasize a lot, the need of self-determination to be independent, to live independently. So the consumers normally go through the training, living well in community and receiving soft skills training. And they participate in other activities that educate them about the principles of living independently. So they know they are entitled to an opinion to make their own decisions. We encourage them to do that. And it also covers any issues related to the vaccine. So they will not submit to the family decisions or to the decisions made by the PCA. These people that surround the consumer might try to persuade him and sometimes they succeed, but the consumers are reminded daily that they are in charge.

- [Mariah] Hi, this is Mariah from the Ronan office. And often we see this issue, however, mask wearing and washing hands frequently. When the, you know, as soon as the caregiver enters the home to wash their hands, they are to mask up. And so that's just kind of some strategies. Maybe it's not the best, but there are some PCAs who have no problem being vaccinated. And then there are others who, you know, who just refuse to get the vaccine all together. And so those are just some of the protocols that I've provided people. Sometimes it's really hard to find another trusted person. And so to just go through another PCA, you could find yourself in the same scenario too. So that's kind of like a solution we've come up with.

- [Carlos] We have to remember that this is a matter of context. So the consumer tended to blend into the context that his family and his personal caregiver belonged to. They eat at the same table. They watch the same television shows. They read the same newspapers. So most of the time he consumes the same information and his decision is shaped by that context.

- Yeah. Let's see what the next slide suggests. Pretty much what we talked about is to consider brainstorming alternate sources of assistance with the consumer and just to plan it on the place and the time other assistance may be available in terms of someone who's vaccinated. And it may not be. Also, it's important to then take into consideration the pre-existing conditions of the consumer that increase risk. Next slide, please. Try to provide sources of personal protective equipment or PPE and require the assistance to wear mask, wash their hands, use sanitizer, gloves to, you know, certainly the employer in this case can require that the assistance do those things. You can't make them get vaccinated, but you can certainly require them to mask, wash their hands, use sanitizer and gloves and encourage your consumer to take similar precautions. Next. Here's the final scenario. A consumer tells you they cannot get vaccinated because they're afraid of needles, based upon their experience of being forcibly medicated in a psychiatric facility. Other words, "They tied me down and stuck needles in me." What do you need to consider and how might you respond in this case? This is kind of a tough one. Any thoughts?

- [John] Sure, this is John. I'll give it a shot.

- Okay.

- So, I think this one here, we have to understand and recognize everybody's dear friend, everybody's got their own belief, everybody's got their own, everything about them. So if this is what this individual has in the back of his or her mind, then obviously, it's what they believe. So that right there is something that I would not push this issue on, 'cause obviously, it is the individual choice and I wouldn't wanna try to put my free will on it one way or another. So that's the way, that's how I'd consider the situation where if they're dead set, they don't want it. You might argue, but we're not gonna try to push the issue.

- [Mariah] She knows she can check this out. No. No.

- Okay. Thank you, John. Anybody else?

- [Mariah] Hi, this is Mariah from Montana and I would recommend that this individual maybe take an individual or maybe an object to the site with them to help kinda alleviate that stress. Also just kinda, again, talking about accommodations, maybe coming up with some solutions with some of the medical providers there as well. And just, you know, surrounding this particular issue, there's been really great solutions we've been able to come up with, but yeah, usually an object or a good support person, comes in handy in these scenarios.

- Thank you. Yes, because-

- This is-

- Go ahead, Melissa.

- Go ahead, Regina.

- I was just gonna say that, you know, obviously, they have a lot of anxiety and it's trauma, it sounds like PTSD based upon a past experience. So they may not actually think that somebody's gonna tie them down to give her the COVID-19 vaccination. But they're just saying, "I can't do needles because of my past experience." Melissa?

- [Melissa] This Melissa, I've couple of examples. One is someone who's participated in partnership calls and has been kind enough to share her story where she knew she was going to have a panic attack. You know, she knew it was just really scary for her. It was really hard for, she wanted the vaccine. She didn't believe the vaccine was bad, but she had bad experiences. I don't know what they were, what they're around or anything like that. But what she did was she had a really cooperative medical person. And she's saying to the doctor, "I'm going to die." "No, you're not gonna die Your heart is beating at a rate of dust and such." "I can't breathe. I'm getting no air." "No, your oxygen is really at 95%. We've got your pulse up. So actually not breathing, you're getting oxygen and you're not dying," and kind of talk her through that, which was just excellent that she had that kind of relationship with her provider. And that was just really fantastic. And I have another friend who was in fact locked in a psychiatric institution as a child and her fear wasn't so much needles for injections as blood draws, but the same kind of thing. And she also wanted a vaccine. She really wanted to get the vaccine and she brought her friend who's this gentleman who's like six foot, two or three and 250 pounds. And this big guy and she's little and petite. And she just kinda folded herself into him. And at one point they said, "You can't be in here." And he just kind of stood there. He didn't know what to do, 'cause he is not an advocate and she is, and she kind of doesn't stay here. So he just stayed there and stood there and she's like, "Give me the shot now and get it over with." And he was just there and just, she was kinda absorbed her. So he wasn't playing the role of the advocate. She was still in control. She's very much the advocate, but she wanted him there as her support person. And he's a roommate and they're close friends. And that was just a nice again, like Mariah said, having that support person there and he wasn't per se a trained support person, but he kind of knew what to do. And he knew the important thing, which was how to be her friend. And being part of being her friend was to do what she asked him to. And she got her vaccine and she got the second shot and she got a booster.

- That's a great story. Thanks for that, Melissa. Yeah, it reminds me of an old saying, "Use what you got to get what you need." Be it a friend, teddy bear, whatever you need. Yes, indeed.

- [Melissa] Or a friend who is a teddy bear.

- Indeed. That's right. That's right. That's right. All right, next slide. That you might wanna ask the person with the fear of needles, what's helped them in the past, you know, with their anxiety. And support person on site. Meditation or breathing techniques might be helpful. If they have a particular faith, they may wanna call their faith-based practices into effect to help them get through this. All right, next slide. Your thoughts and experiences. What other scenarios have you experienced or you think you might encounter and what are some considerations and responses to them?

- [Mariah] Hi, this is Mariah from Montana.

- [Susan] Just say you're on Montana, did you-

- [Mariah] Oh my gosh. Yeah, one of the scenarios I've encountered. Last week, I had a family come in and, you know, they were asking just about vaccines. And it was just good to have, 'cause they were, like in some ways they were challenging, they were just really misinformed. And so I just let them, just really listen to them. But I also gave a lot of positive reinforcement and scientific information to them and they were able to come up with solutions in keeping their family safe. Unfortunately, they lost many members of their family and so they just felt really misguided and misdirected by some medical professionals. And so I was at least able to offer solutions and good information, but just really empowering the family unit, you know, and just giving them an informed choice is a lot what I see when you empower the family, you kinda have this really nice holistic way of a, you know, getting people like, Hey, I'm okay with this going forward and actually getting vaccinated. So that's just one scenario in my mind.

- Thanks. That was good work on your part. Any others? All right.

- [Mariah] Hi, this is Mariah from Montana again. I was gonna also say that undocumented immigrants are allowed to go and get services because they do, majority of the time they do work in our agriculture sector, so they are working, however, they are undocumented. And mostly what Carlos has outlined is, you know, a lot of attitudinal barriers, but there is no, I kinda have trouble with that because in a lot of instances, people are not refused service just because of that status. And I believe that it's illegal to do that. I work, previously, I used to work for Montana Migrant Council. On the yearly clinic that they would run here at Lake County. And so I do believe that's more of an attitudinal barrier than it is actually a policy.

- Yeah, I know that you are not allowed to withhold healthcare from anyone based upon their immigration status. And we'll talk to Carlos one to one on that, because I don't know, you know, exactly what's going on in that situation to have some kind of prohibition in place, but we will talk about that. Yeah. Okay.

- [Carlos] It's a contractual provision and I think all centers are subjected to it, but I agree that in the case of the vaccine, there should not be any restrictions because of the state of emergency.

- Right. Yeah. We will discuss that more. I guess I wanna take this time. I know we're at about 5:30 here to just get final input, comments from anybody, Anything from the CILs or anything from people from The Partnership before saying this thank you and ending this session.

- [Shaylin] This is Shaylin. And before we close up, just wanna say thank you all. Certainly, echoing Regina's remarks and thank you, Regina. And certainly, thanks to our accessibility team for ASL and CART being provided. Also wanna note, we put in the chat, a brief survey, similar to the one you saw last week around your feedback during today's training. We appreciate it as we continue to strengthen and grow. And we'll also send that out via email as well for anyone that may need it and following. And we'll also be sending probably, the beginning of next week, the accessible slides, the slide deck and the transcript as well. And as Priya mentioned at the beginning, the post production of the trainings will be available in the weeks to come and we'll be staying in touch. So please don't hesitate to reach out. You have all of our contacts and we are here to support you also. Thank you all for all you do. Any other last thoughts folks may have? And again, thank you all so much. We can hold if anyone has any additional questions around the project. Otherwise, thank you so much for joining us and have a safe rest of your week.

- Yup. Thanks everyone. Bye-bye now.

- [Mariah] Thank you everybody for information and everybody's input.

- [Susan] Bye-bye.