



Webinar Transcript:
“Person-Centered Planning and Supports for Vaccine Access”

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to a small group of No-Wrong-Door state grantees*

SPEAKERS

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Alixé Bonard

Welcome to this webinar. We have a number of people joining, and as we're just starting at the top of the hour we will allow about another 15 seconds for people to come into the room before we get started, completely.

All right, we are going to get started now at this point, and again, welcome everyone to today's session entitled Person-Centered Planning and Supports for Vaccine Access. My name is Alixé Bonardi and I am co-director of the National Center on Advancing Person-Centered Practices and Systems, which is operated out of Human Services Research Institute, and funded and supported by both the Administration on Community Living, and the Centers for Medicare and Medicaid Services. Thank you for joining us everyone today.

For today's agenda, we will be starting with our welcome and introductions, and then move through a few topics, starting with a person-centered approach to vaccine confidence with our colleague Sheli Reynolds from the LifeCourse Nexus at UMKC. We will be also having some content shared with us including a video from our colleague, Liz Weintraub from AUCD and also spending time watching a



short video, which is focused on vaccinating the highest risk and hardest to reach population panel discussion will follow and we do have time we hope at the end to spend in with some questions and answers. For those of us who, for those of you who are joining this webinar live, we do have the chat function, open, and we encourage people to enter their questions into chat. We will be answering as we can in chat as well as, as, as, sharing information afterwards if people choose to reach out to the speakers, a couple of words, words about logistics. This webinar is being recorded and will be made available afterwards on the National Center on Advancing Person-Centered Practices and Systems, the NCAPPS website. I will be putting a link into chat as well as the ACL Technical Assistance website, which will also hold this webinar. This webinar is being captioned in live captions in English and Spanish, and we have live sign language interpreters. Thank you everyone for joining us and with that I would like to turn it over to Gilbert Thompson, a project officer at the Administration on Community Living.

Gilbert Thompson

Thank you Alixe. Good afternoon and welcome to today's No Wrong Door webinar on person centered planning and supports for vaccine access. Again, I am Gilbert Thompson with the Administration for Community Living ACL. Today's webinar will highlight how No Wrong Door systems are uniquely positioned to support vaccine access in a person-centered way. We understand and recognize that applying a person-centered lens is critical to providing individuals with valuable information, all while balancing what is important to and important for individuals ADRC and No Wrong Door systems play a key role in providing individuals with unbiased and in-depth information to help make informed decisions about their long-term care needs. Since the beginning of the COVID-19 public health emergency ADRC's have sprung into action to address and support COVID-19 related efforts, including recent activities around vaccine access and vaccine confidence. Your continued support and engagement, you know reminded me of part of a speech that Stuart Scott, a former sports analysts gave in that part of his speech, he noted, everything has a start date and an end date. The grant funding you receive to support COVID-19 related activities does have a project start date and an end date, and in between that project start date and



end date is usually a dash, and the most important thing is that dash and that is that dash, and to make it count. And all you have all your continued efforts throughout, you know the years you have made, you know, that dash count, and all the work that you, that you're doing. And we just wanted to say you know give a huge thank you again for making that dash count for your continued efforts and to and. And with that, I am going to pass it off to Sheli Reynolds. Thank you.

Sheli Reynolds

Thanks Gilbert, and you know, um, you know your introduction is perfect in the sense that we're here to really talk about person centered practices but we're also here to really talk about this dash that we're on. But this dash is not new to us in terms of what we do with people and so how do we build on that and use that as an opportunity to, you know, continue to offer Person Centered informed information. So, next slide, just a little bit about myself. My name is Sheli Reynolds I work at the University of Missouri Institute for Human Development, where I'm the associate director. But as you'll see from this slide, I think the thing that's the most important to note is that I have a sibling with a developmental disability so the work that I do every day, not only is what I do professionally, but it's also really thinking through, and understanding the impact on my own family, both with my brothers with and without disabilities, as well as my, my aging parents so a number of the initiatives that I'm involved in are very closely related to supporting that individual and their personhood, as well as supporting that family unit. Next slide. As Gilbert said he talked about the role of No Wrong Door and I think it's really important to just repeat that no matter what the topic is the goal and role of a No Wrong Door and ADRCs is complete, accurate information, and that we're here to help those individuals make decisions when we're talking about vaccines or safety or talking about services or support. That's what our role is and so nothing changes just because we're talking about this topic of vaccines or the pandemic or wearing masks. So I think it's important to stay grounded and what we know we know how to do. Next slide. So, as Alixe mentioned, and I'm here with the Charting the LifeCourse and so throughout this presentation I will be integrating both person-centered concepts as well as Charting the LifeCourse concepts, and when I was preparing for this presentation, I just kept going back



to what we call our, our three buckets. And the reason those are buckets is that it's about how, how do people have means in each of those buckets and how are we supporting and what I would say, filling each one of those buckets. So again, no matter what the topics are the role of the ADRCs is really to fill those three buckets are help a person get those three buckets filled. So when we start thinking about it, the role is to provide information, knowledge, skills, in a way that that best reflects how that person wants to communicate and how best reflects how they need that information. The second big bucket that we're constantly filling as a No Wrong Door ADRC is how are we connecting you to somebody else that's been there, maybe it's just ensuring you have people in your life that that are there to talk to and understand it can help you make informed decisions. Maybe you need to formally be connected to a peer support, or maybe you need to talk to a professional about that information. And so that is really kind of the role that we play right information, peer support that sort of connection part. And we typically focus our conversations around the goods and services a person needs. So the types of information they need for medical or financial housing long term services and so to me it's all three of those buckets. So no matter what topic that somebody presents with or what question we're helping them problem solve, we need to be considering those three buckets at all times. This is going to be especially true when we're talking about topics that are hard to talk about or maybe hard to understand, or maybe it just has a lot of fear wrapped around them. So not only should we be giving them information, but how are we ensuring that emotional needs to make that informed decision is happening which is that second bucket. Next slide please. This slide really just reinforces what we already know when we think about person centered practices, the tool isn't the answer right it's the way we go about doing our business and so I think that, again, this has, this is the foundation for the way you offer your support, we always think about the focus on the person they're at the center of the conversation. They're at the center of the information they're at the center of making that informed decision, and that's true when we're talking about conversations around the vaccine.



The second bullet I think is the most important vote bullet choice and self-determination. So how are we offering informed choice how are we ensuring that they have information to make the decisions about how it's going to impact their own health, their wellbeing and their life goals. The other part is community inclusion and I think that's going to come up as well. And then the last part is our availability so when we're thinking about vaccines, you know, are they available, is transportation in need are these a number of things. So the principles that ground our work are exactly hold true to talking about the vaccine. Next slide. Self determination to me is the scale right and we talked about the concept of important too and important for but it's also about dignity of risk. And I know that many of us serve many different populations so maybe it's someone who is aging, maybe it's somebody who had recently experienced a traumatic brain injury. Maybe it's a teenager with Down syndrome, we constantly need to be balancing self-determination and dignity of risk. And I think that this is really, really important for us to always remember, but especially as we're talking about the vaccine and how, how, of course many people around an individual might say, they need this for health and safety or this is a new protocol or those certain things, but how are you ensuring you're balancing that dignity of risk and that self-determination by the choice that they make. And the part, our role is though is to keep making sure that they have enough information, and the right information in a way that they understand it, so that they are balancing their own dignity of risk and health and safety. Next slide. I found this slide. When I was kind of researching and looking into this and it obviously says how do you talk to your patients, and you can remove patients with the person right and I thought that these were really quick, easy to understand, you know, lead by listening, I think more importantly, that is, that is true to everything Person Centered when we talk about person centered practices. Are we truly listening? Are we truly understanding the way that they communicate? ...which is the second bullet. I also think that that is as a provider providing Person Centered supports that providing empathy and I think No Wrong Door and ADRC's are so well positioned to follow these because this is what you do every single day. You also have to be strong about your recommendations and this was specifically related to COVID And so, you know, regardless of your own opinion, are you following the



recommendations coming from CDC or your state, and how are you offering those recommendations, and more importantly, how are you then wrapping up next steps. And so those are some of the guidance that that we think about when we start, start thinking about how, how we should actually be talking to individuals. Next slide, to actually talk about both concepts and tools, some of you use the concept of important to an important for so this might be a tool that you get out, or it might be a way that you're organizing a conversation and so really understanding what is important to that person. And then maybe also understanding both from the person's perspective and the whole support team. What is important for the person. And so, although we might think things are really important for them. If that's not important to them, we're, we need to figure out how to balance that conversation. Next slide.

Now's where I'm going to start giving you introducing some of the Charting the LifeCourse concepts and how you can apply this to these conversations both the thinking and some of the tools and one of the sort of key concepts that we constantly talk about is truly understanding where that person wants to go. Sometimes I talk about that the vision for the future or whatever it is we're trying to accomplish. So, this is my friend Ben and, and this is just talking about his vision for a good life, these are the things that are important to him this is what I say is his North Star, and you see below that cloud, things like fire station NASCAR girlfriend tattoos, you see in the cloud underneath it are the things that he doesn't want to do. And when I'm providing information supports or I am problem solving or providing person-centered that are planning with an individual. I sometimes get this visual out, or sometimes I'm just asking the question what's important, what's important to you, what's your vision, but not only what's important to you, what don't you want help me understand what's going on. I think of no wrong doors and ADRCs as that green line that's pointing up, telling the individual you're on a trajectory you're on a life trajectory, you're making decisions and you're have life experiences. And based on those decisions sometimes your decisions might take you towards what you don't want, and sometimes those decisions take you towards what you do want, and our job as an ADRC No Wrong Door is to keep giving you information that's going to take



you towards the vision that you want. So I was applying this to the concept around vaccines. What I've been asked to talk about so if you could go to the next slide please. I know for many people that the concept of vaccines can become a very political and touchy conversation so I prefer to have those conversations talking more about health and safety. And what is your sort of during this pandemic. What is it, what's your vision, what do you want to happen to kind of break through this pandemic. And so oftentimes individuals will say things to me like I have a vision for going back to work. I want to hug my family and friends again. I want to exercise at the gym, I want to be able to go to concerts again. And so for me the conversations about safety and around the vaccine really need to start with what is personal, what is important to that person. And that's what we're seeing in the literature, we're seeing that, that the closer you can get it to that personal impact or somebody that they know or things they care about. So first is you got to ask that question, what's going on in your life both that you want. But what's going on in your life that you don't want. So when I talked to Ben. He wants to go to the gym he's tired is sitting at help. He's so scared about getting sick though, and he definitely definitely doesn't want others to get sick, and he's tired of wearing the mask right these are all things that were very common, so it's important for me to really understand that and for him to feel heard when I talk about that. So this is just actually a tool I could fill out, I could show him and help him say that this is, this is what you want but how do we make an informed decision to get you there. Next slide please. So some of the things that obviously we used to have as a vision to get there is, I always talk about things above the line, right, those are things that are going to help move you towards what you want. So if I'm having a conversation, you know, and I understand what they want, you know, we know some of the recommendations, you know, washing your hands covering, and when you cough or sneeze, Staying home when you're sick. These are not new recommendations. And so how do we actually just talk about this, you've always done these things or, you always should have done these things, but it's even more important right now, when we're going through this, this pandemic. We also know that there's recommendations to wear your mask, and other people also recommended getting vaccinated. So, those are additional things and recommendations that



can support your vision and helping the person I'm talking to understand those. Next slide please.

But I think just as important it is to kind of talk about those recommendations is also talking about the barriers, and understanding that, you know what, what are the things you know that's going to prevent me from going back to work. If I don't wash my hands if I don't cover my face if I continue to go out when I'm sick, or other people do that. And so sometimes I tell people the reason why the slide is like that is, some people would rather start with the barriers and some people would rather start with what should be happening in their lives so whatever way is that that person wants to tackle this conversation, it kind of helps me be able to guide it. The next slide please. So this was kind of puts it together and kind of just puts together both the concepts and so this is a finished document, I sometimes take this document, and use it as a way to educate it's already somewhat populated and sometimes I'll leave out the vision for what I want or what I don't want and say, Let's fill that out and this is a very concrete simple way to simplify this conversation. Again, this has to be targeted in a way that appeals to the person that you're talking to. So, if they're a visual learner, if they're an auditory learner. Maybe this is too plain language for them. So you you know best, the person that you're talking to. Next slide please. But now I want to move specifically into the vaccine and having conversations about the vaccine. You can use this exact same conversation or this exact same tool to dig in to into thinking about, You know, getting the vaccine. So if you're directly hitting it head on, you know, we know our vision is to have as many people vaccinated as possible that are able to get the vaccine, but our job too, is to really listen and listen empathetically of understanding why maybe the person you're talking to, does not want to get that vaccine. And I really think that that's really, really the key role of ADRCs and No Wrong Door, about anything that they want is really if someone's going to make an informed decision we have to understand where they're coming at it from. Next slide please. So, so when we start thinking about what some of the responses are going to be. Our job is we're going to inform a person about the vaccines and have a conversation is is we have to understand what they think the barriers are to that, you know, is it that they don't like needles,



is it there's not transportation. Is it because they don't think there's money to pay for it. There's, there's not, you know, sure where to go to get it. Maybe their family and friends are saying no, maybe there's misinformation out there so I think no matter what, whether there is a tool or a conversation, it's about digging in and understanding their fears, understanding their hesitations because in order to then counter those hesitations, you have to know what they are. And so, next slide please. We know what some of the recommendations are right, we know that people are, you know that that they have been tested and they're they're presented as safe and free we know that the chances of dying have had become have dropped to nearly zero for those that have had the vaccine. We also know it's important to protect yourself and others. But, everything I keep saying he keep hearing says, You've got to make that personal. So obviously you're going to share those messages and though that's the data you can use and the research you can use to protect to back it up, but it's also about getting personal, you know, who do they know who do they trust you know do they know somebody who maybe has gotten sick from COVID Have they themselves gotten sick from COVID and how can it benefit both them and the people around them. And I think that's really important to understanding the why, but then also helping that person say, now you have to balance your you know your, your dignity of risk you have to balance the risk of not getting it or getting, getting the vaccine. Next slide please.

So when it comes down to it, the two options when you're making an informed choice. There's risk with getting COVID and there are risks with getting the vaccine, and really talking through that right, and really talking through helping that person really weigh and then balance where those risks are and where those fears are because there's fears and risk on both sides. And so your job really is to help list those, and at the end of the day they have to weigh which one of those choices, they're going to do. Next slide please. If you're familiar with Charting the LifeCourse you know that I can't do that, do a presentation without talking about our star and the integrated support star is, is a way for me to, to think about and problem solve on different topics. So there's five points on that star, and it's ways for me as a staff person or an individual that just gets a star



out to, to push my thinking in terms of exploring answers and solutions. And so, you know the, so in the middle here it says, you know, if I'm trying to identify where a person can get information regarding the vaccine or get resources about the vaccine. The first thing I need to do is think about that person and I need to best understand the way they communicate, do they communicate using words do they want to see a video, do they want to read something, do they need to see pictures, how do they want to best communicate and learn about the vaccine. The second thing I would move over to is what is on the right is what we call relationships part of the star, who in their lives do they trust, who can they have conversations with that will help provide, you know, accurate neutral informed information, and helping them identify, you know, go talk to those individuals understand what, what, why they did or didn't get the shot and so having people in our lives that we trust. And so it might be problem solving people outside their immediate circle, you know, is there somebody else in their community do they, that they could talk to the green part of the star is remembering eligibility specific which oftentimes means government so you know the recommendations from CDC or some national doctors Association, what are the recommendations came coming out of the State Health Department's, regardless of our personal opinions right now is a No Wrong Door site it's important for us to find the trusted information that people share and then it's the information that fits within inside the current standards that are constantly changing. So where are we going to get our information, you know, who are the people that we trust to provide that information, case managers No Wrong Door ADRC staff are supposed to be providing neutral information so that should be just like they trust you for other information, they're going to trust you regarding this information. The next part of the star are thinking about the places this individual might go. Where are they getting either misinformation or where can they go to get informed information, you know, do they trust their doctors and nurses have they talked to them about it. Do they know the local pharmacist. Do they go to school and they trust their teachers and their principals, you know, do they go to a senior center so helping them think about the people in their lives who also might be messaging this to help them make that decision. The other part is technology can which can be our friend and definitely our enemy when it



comes to this. So understanding maybe where they're getting their information that might help you be able to have that conversation, are there, are they getting their information from a website, or somebody who's providing misinformation, you know, are they seeing a lot of their fears come out in blogs or social media. So how are we helping them get connected to credible websites, blogs and social media to help them balance the information that they are receiving. Next slide please.

This is just an example of a star with a colleague and friend of mine named Candace and so this is the star she uses when she thinks about healthy living, and again it's not specific to the shot, but it's a specific to a conversation we had during the pandemic. And so, you know, for her. We needed to really understand the things that she, her strengths and her, her assets and she's feels really strong about her ability to speak up when she doesn't feel good, not everybody has that, you know she understands she needs to take time take her medicine she needs to know herself. So when I'm sitting down with her to discuss different decisions she needs to make about staying safe, it's really important to, to understand where she's coming from. I also know that she has friends and families in her life, she has a church family so these might be places that she can go to continue to gather more information to make her decision. I also see that she goes out in the community, she does Pilates she has a job, doctors offices, these are other places that she's both going to get good information and misinformation so helping her work through that is really important. And as you see she utilizes technology and utilizes some paid services. So those are some other places as well. Next slide please. I'm not telling you anything you probably don't already know, I hope that I'm reaffirming for you and validating for you that that providing Person Centered information is what you do, you, you are a trusted source in your community. And so how do we remember that and just remember this is just a different topic we're providing that we should always provide evidence based information, neutral information. But this is something I ran across specifically related to vaccine hesitancy and I really like this, this Twitter thread is just keep your expectations modest, you're setting an achievable goal, such as just opening the topic, you and your conversations are not necessarily



meant to completely change their mind, and it's not going to happen in one place. And so, you know the other thing I keep saying, again, these are all things you already know. You know you're coming from a place of concern not hostility, you listen, you understand. I really like the third bullet, So maybe they decide not to get vaccinated, but they're wearing their masks, they're washing their hands, they're their social distancing, how can you celebrate those safety measures and say, you know, those are important too, we can't make this all about one solution, it's got to be all of those solutions. Again, it's not about talking to them isn't about about debating with them, and it's not about a winner or a loser. No matter what side you stand on regarding this, but it's about all of us really working together to stay safe. So again, I appreciate your time and the opportunity, those different tools are on our website, you can always call or email me. Next slide please. And it's at LifeCourseTools.com. The next slide has my contact information which is in the slide deck that is that you can access as well. And again if you have any questions let me know but I'm Liz and I will have an opportunity to be on a panel so I will look forward to any chats with you then. But with that I'm going to pass it over to Liz Weintraub who's going to introduce herself.

Liz Weintraub

Thanks, Sheli, and as Sheli said, my name is Liz Weintraub. I'm the Senior Advocacy Specialist, as well as the host of Tuesdays with Liz, at the Association of University Center on Disabilities, we're the network of UCEDDs, IDDRCs, well as the land. So, here is my information if you're interested in keeping in touch. Next slide. Why, why did I care about taking a COVID shot. I wanted to be safe. Oh, that's the number one reason why I took on, like, the, the COVID shot. Um, I also wanted my family and friends to be safe, and there's a picture of me and my sisters. So, I could go and visit my family who live. Some live in Texas some live here in the Washington area I wanted to be safe and I wanted my family and friends to be safe. I want to get back to normal life. I'm dying to. I don't mean to say, dying, but I'm very anxious to get back to normal life. And I put normal on quotes because I'm not sure that we'll ever get back to a normal life, but I wanted to get back to a Life somewhat normal, that I saw night before March, 20th of March, 20 of 2020 and 2020. I want to see people in person, and dying. I'm so



excited to see people in person. I know I see, Sheli and everyone moves on webinars, but to me, I want to hug... Um, and I also wanted to get out of this dark, dark tunnel. And ever since this started 16 months ago, whenever it was I kept on thinking to myself that this is a dark, dark tunnel, and that really scares me so I wanted to get out of this tunnel. Next slide. In March, I think it was March. My husband and I were invited to be part of the Maryland public facts seemed campaign, and I would like to share that video with you. And one of the, I think he's the star of the video. Um, and the, um, the quote that he like that I would like to share with you is on the symptoms of the virus is much, much, much more severe than the side effects of the vaccine, so enjoy the video. [Video starts]

[Liz:] It's very important for people with disability to get vaccination, because the research is saying that five times higher for people with disability to get this disease die of it, that's really scary. And I want people to live. I want people to, to have a wonderful life like I do. [Liz's husband:] we both got the vaccine together, and it just basically just were just like any other vaccine just a shot in the arm. All I felt like, each to each dose it just, just, just sort of pain where this where the shot went in and then it just went away a couple days later.

[Liz:] I think all Marylanders should get the vaccine, because that's how we can get out of this dark, dark tunnel. This pandemic won't go away unless all people in Maryland can get a vaccine.

36:57

[Liz's husband:] It is very important that people take the vaccine because of its very important way because of COVID facts the disability community, listen to science don't believe those myths you hear over social media. If you have any medical concerns, talk to your doctor, and also understand before the vaccine went on market went it went through a review by a group of scientists at the FDA to be sure it has all the safeguards it has before allowing to go on the market so they know that it is safe, and, and it'll get us out of this mess.



[Liz:] Once everyone gets their vaccine, My wish is that everyone can be not behind the closed walls. We can all be part of the community that will be the nicest day. I'm free, I'm free, go vax, let's end COVID, Maryland. [Video ends]

Um, this video was played, um, played on TV in Maryland. I know in DC, and I think in Virginia. Next slide. In my value, as I think I mentioned I am also the host of Tuesdays with Liz Disability Policy for All, it's a series that AUCD puts out you can find it on YouTube channel Tuesdays with Liz, um but we, um, we just ended a vaccine campaign, call for a fun way for people to talk about why getting vaccine is so important. As a kid, cuz I'm probably 13 year, 12 or 13 talking about why he has gotten the vaccine. We asked stories from the AUCD and the disability community. We have shared on our website and our, our social media, and platform like federal partner like the CDC, I am not showing you the contest because it's the contest is over. And we'll be picking the winner next week. In connection to the ADA anniversary. Next slide. One of the thing that was really confusing to me when the pandemic started, was that there were so many rules this pandemic. How long, how many people can you be away from, people when can you see people and when you can't. Everything wasn't in plain language. What plain language is for those of you who don't know, is using only words that are needed, that everyone can understand. Everything was, um, in words that I would not be able to understand, and my friends would not understand them, and it made me feel really sad and it made me feel like I wasn't safe. And I wanted to be safe. Just Sheli could help me understand what's rule about this or CDC might be able to help me, but I wanted to understand them myself. And so therefore we have a bunch of plain language materials on our website as well as the Prepare for All website, and the link is right there if you are interested. As well as talking points. and I feel safe now. And then next slide, um, these are some resources that I thought that you might be interested in, um, we are at the top, Tuesdays, with Liz, with the National Center on Disability and Public Health which is part of the prepare for all website, and we haven't on public health team. ASAN, which is a national self-advocacy organization



It stands for Autistic Self Advocacy Network, and they have a lot of videos and fact sheets in plain language. And then Green Mountain Self-Advocates in Vermont also have a wonderful booklet about COVID. And they're all in plain language so I hope you will check them out, and that might be help to you or anyone you know. So thank you.

Alixé Bonardi

Thank you very much. Well, Liz, thank you for your most recent remarks, for sharing your video for sharing the video contest and information about the video contest, and some very good guidance about how important plain language materials are in, in giving people the information they need to feel safe, and in control of their, their own decisions. Additionally, I wanted to thank you, Sheli for, for sharing, for sharing the tools you shared and also some very tangible ways that those tools can be used. This has been a terrific set of resources that you all have shared at this point. At this point I wanted to turn us to one other resource, which I think is in the the slide deck Connor, which is a video which we have selected from Dr. Louise Aronson, who is geriatrician and this is a short video that that describes, providing providing vaccines to again, harder to reach populations, particularly elders and people with physical disabilities. This is Part of a video series and once the video gets gets rolling, I will put this into chat. I'll put a longer. A longer version of the video which is also available for, for folks if they're interested. Could we, could we go to that video I'd like to just share that and then we hopefully we'll have a few, a few minutes to chat and answer some questions.

[Video Plays]

Dr. Louise Aronson

It's not just that the older you are, and which community and what part of the state you live in, that makes a difference. It actually turns out that healthier older people are more likely to get vaccinated, than less healthy older people, even though the less healthy people are the people most likely to get serious illness to require hospitalization and to die, so in this pandemic, for instance, about 4% of



American old people live in facilities, nursing homes, assisted living facilities, but they accounted for across the country, 34% of deaths. Now you might say they are the oldest and the frailest. But what is also true is that in many states, they took old people who lived in the community who got COVID most old people 96% Of all people live in our communities. Those people got sick and they, they were so sick that they couldn't go home. So, what did they do, they sent them to nursing homes and assisted living facilities with their COVID. So, they took people with COVID and put them in the facilities with the people at highest risk. At the same time they did not provide those facilities with the ability to test, or with the equipment to protect the people who worked and lived there, that also meant that the sort of people who work in those facilities, took the disease back to their communities, usually low income communities of color. So, what can you all do. Make sure you have accurate information. We've also had some trouble collecting information, maybe within your communities, you could help to collect and collect stories that enables the government to put more resources. They put resources in places where there's noise, where there's action where there's need and this is a population that by definition doesn't make too much noise. So, think about answering people's questions. What are their concerns I've heard from patients, different things such as they're going to put a chip in me. That's going to track my every movement, which if you come from certain countries. Well, I think if you come from any country, you're not going to want that but from certain countries, you'll be more worried a lot of my patients who have illnesses, think that's a reason not to get the vaccine, whereas in fact, the opposite is true, and if you can get that one message across. That would be a huge help. The older you are, the more medical problems you have. If you are disabled. These are the three best reasons to get a vaccination, contact your health department.

Alixé Bonardi

Thank you. Thank you for sharing that Connor. And that was the last piece of content that, that we all want that we wanted to share. At this point we have a few minutes remaining, And, and I want to turn to our two presenters, Sheli and Liz, who we can hopefully can unmute and turn your cameras on, and we have one question I'd like to pose to you from the audience, but first I want to start with



a question. You all have shared a number of different strategies but as you think about the work that you've been doing, what do you see as the most effective way, or ways to build vaccine confidence, and I'll start with you, Liz.

Liz Weintraub

Thanks. Thanks for that question out with Alixe. Um, and thank you for inviting me I should have said that. Um, but, um, I think the biggest way is just to share my story to share why I'm why I am getting it. i i I love to write answers to media, so I talk about why I have taken it. Why do I want to get out of the dark, dark tunnel as I like to call it. Why am I taking it. And then, because I think everything start with you, and hopefully people can see that I am a trustworthy person. I hope I am. And I can. And we can have a conversation.

Alixé Bonardi

So giving people, your story is, is certainly a great start and I know you've, you've got a great social media presence so reaching out to your community of people who trust you, right, is, is a great way. I'd like to turn that the same question to you, Sheli, what do you see as the most effective ways to build vaccine confidence.

Sheli Reynolds

You know, I think all of these public awareness campaigns are really really important but I think really when it comes down to it, it's the one on one conversations that you're going to see the biggest change. And I think that you know the more we keep talking about it, you know, the more we keep talking about any issue in our community and, and really understanding going back to Liz's point the why, you know, why are people getting it or not getting it and the, the responses really vary right there's not a particular, you know, we're all struggling to figure out what are the major reasons and can we tell if this person chose this reason or that reason and ultimately, I think it's about understanding that and I, I think that, you know, we're all walking around in this very altered state over the last 15 months of the pandemic that we don't even like, it's just there's so much coming at us all the time, right, there's new rules there's wear



your masters don't marry masters get a shot don't get a shot, there's, there's this tension in our country about a lot of things happening right now and I, I think that it's important to have conversations and, you know for me it's about talking to people when they keep talking about the shot and, you know, they, they forget that they've taken other shots in their life and they didn't even think about them as much and so, you know, helping them to understand there's a lot of stuff they've done in their own life experiences that under less stressful situation, have, have, they've made different decisions so again it's just I think it's about the why and talking to people and that nobody has a glass ball right we're all just trying to figure this stuff together.

Alixé Bonardi

That's, that's very insightful as well and something we've talked about certainly is understanding that choices that people are making you started saying this earlier too Sheli, people make their own choices. There is a certain amount of dignity of risk that that everybody wants and expects in their life. So I want to turn a little bit to to the conversation about what about choice well as as people use this to reflect well this, This is a choice that I make, how might we think about talking with someone who, as you said, may make a choice may say that they've got a reason. But how might you address that to help move someone in the direction of vaccine confidence if they're at a place where they're making a choice that they do not want that. And I'll start with you this time Sheli.

Sheli Reynolds

Okay, yeah, so probably not gonna answer your response, specifically but or your question but you know the thing for me is that, you know, you know, we have we make these statements that you know from a collective it's really important to get that and and I think people, people comprehend that to a degree, but I, I also think that, you know, the reality is is that many of the populations that I work with specifically you know my brother with a disability people for many years have been making choices on his behalf. And some of them have come from, from, you know people that were supposedly trusted sources so I also think it's really important that that we really understand that some of these fears are,



were, were real fears based on history, and. And so to me, again it's going back to the why and for individuals, whether it's a person of color, whether it's because they have a disability, you know so many people have this sort of power over conversation with them and that they just you know say it's the right thing for you, you should do it and they've been led astray and I think that that's why I just want to keep stressing and that no matter what it's really about informed choice, and even knowing that people maybe by their server circumstances really need to get it. It's really understanding where they're coming from, from why they're not doing that. And there might be times that you can't, you're not going to change their mind. And so I think it's that empathy I think it's the personal stories, I think when people start hearing like Liz said, I can go see people again or unfortunately what we're seeing is people are getting the shot because they had a close family member die. And I think it's a wake up call for them and for many that's come too late. And I think helping them understand those stories, is the best way to have the conversation.

Liz Weintraub

I also wanted to jump in because I have struggled with the fact that I'm a self-determined person. Self-advocacy is built on self-determination I take pride in my self-determination skills. I want to get this, I want to do that. And who are you, but somebody reminded me last night that we, if, if you're in a car, we, we put down our seat belts, to keep us safe. And, and we do that, just because we want to keep ourselves safe and, and this is the same way. We're keeping ourselves in safe and if you can take the polio shot. When we were kids or other shots, why can't we take this shot for other reasons. This shouldn't be a political reason, and this should be for health.

Alixé Bonardi

Well said Liz. and I think you what you were saying, answers a little bit in what Sheli was saying answers a little bit, a question that just came in to chat about some people who were saying that they, they're not as concerned about getting the virus, either because they've had it and didn't think it was so bad, or have other fears. To me this, this, this seems like something that would be part of the



conversation that could be, you could use one of the tools that Sheli shared about thinking about what you want and what you don't want to have happen, and then thinking about some of the stories as you've mentioned Sheli sometimes when a close family member is, is someone who is significantly, you know, sick or or dies, is when it becomes too late for people to take some of this seriously. Using this tool can also a tool such as that can also help spur some of those conversations. This has been a tremendously rich conversation, and as we know this is just part of the conversation that is happening on a national and global level. This has been a moment for us to turn to a particularly important population, people with disabilities and aging and with disabilities to really as an area of focus for the vaccine. I hope that participants are able to access some of the resources and tools that we've shared. And with that I would like to thank the administration for community living and CMS for, for providing us this platform to you Sheli and to you, Liz for your participation as well. And, and with that, thank you all.

Liz Weintraub

Thank you.

Alixé Bonardi

Be well everyone.