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Supporting Individualized Informed Choice: Conversations About The COVID-19 Vaccine

CPR held a series of six listening sessions in the winter of 2021. These sessions were conducted with a cross section of people with disabilities, including people with Intellectual and/or Developmental Disabilities, people with physical disabilities, and people with lived experience in the mental health system, as well as family organizations. These conversations formed the basis for this document, which is designed to facilitate a respectful discussion between people with disabilities and their supporters regarding whether or not to get the COVID-19 vaccine.



What is informed choice?

Informed choice means that someone has the information that they need to weigh the risks and benefits of a decision, that they have the opportunity to have their questions answered, and that they are allowed to make the decision for themselves -- free of any and all coercion.



Why is it important?

Informed choice is important because it ensures that people are making decisions for themselves that are carefully considered and made with all of the necessary information. This preserves peoples' autonomy, sustains their personhood, and respects their preferences. Making informed choices also helps to build individuals' confidence in their ability to be independent.

Based on our Listening Sessions This is What People with Disabilities Say Matters Most in the Conversation:

- Hearing about the vaccine from trusted sources, including medical providers, peers, family and friends
- When possible, using messengers with equal power and avoiding dynamics that may feel coercive (i.e., staff and client)
- Creating opportunities to discuss individual health conditions with medical providers
- Listening to individuals' concerns without presuming to know what is best for them
- Being attentive to individuals' past experiences with services and service systems, including past experiences of trauma and loss of autonomy
- Pointing to reliable sources of information that are readily accessible
- Providing support when requesting reasonable accommodations
- Offering assistance to overcome barriers in scheduling or transportation
- Creating plain language resources that are easily understood
- Encouraging messengers from diverse communities
- Creating a safe, judgment-free space to discuss fears
- Acknowledging and respecting hesitancy



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- Considering how culture, background, and experiences of racism may inform individual decision-making
- Treating individuals with respect, including respecting their right to decide what is best for them
- Appreciating that it may take more than one and maybe several conversations with someone before they are ready to make a decision
- Acknowledging that the vaccine is complicated, and hard to understand for everyone

Tips for Supporters, Providers, Family Members and Professionals

The suggestions below are based on feedback from individuals with disabilities, and are offered to guide conversations about the COVID-19 vaccine. They include recommendations on timing and preparation, setting expectations, structuring the discussion, providing neutral and accessible information, and identifying/resolving barriers to vaccination.

Timing and Preparation

- Do your homework—Make sure you understand some basic facts about the vaccine before you have the vaccine conversation.
- Facts about the vaccines are evolving quickly. If you don't know the answers to someone's questions, don't guess. Work together with the person to locate accurate and responsive information.
- Consider having an ombudsman or someone in a similar rights-oriented role be involved in the sharing of information.
- Ask in advance whether the person has a condition or need that requires specific modifications or accommodations in order to have an effective conversation about the vaccine. This may include selecting a particular time of day; having a trusted person present; allowing additional time; the use of communication devices; and the presentation of informational materials in an accessible format.
- Keep in mind that many individuals have experienced serious, negative side effects from psychiatric medications. As a result, they may be reluctant to trust information from mental health professionals or other health care providers.
- Consider other basic human needs, stresses, and pressures on people during the pandemic that can make the vaccine conversation emotionally distressing or loaded. For example, people might be concerned about vaccine safety, but also feel like they need to be able to see family again. This emotional stress about seeing family shouldn't be used to negate someone's fears. Instead, discuss the person's concerns and try to address each of those fears separately. Keep the desire to see family as a positive outcome and not as leverage.
- Start the conversation well before the vaccine is available to the person or at least before the appointment is made.



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Expectations

- Be clear that informed consent is always required, even in environments controlled by providers, like group homes. Although the way that a particular program/individual talks to someone about the vaccine may differ, they still need to ensure that individuals with disabilities are given the information and accommodations that they need to make and communicate a decision for themselves.
- It is important to be transparent and honest, including about potential coercion or conditions on receipt of services – without becoming part of the coercive system. Ideally, offer to help the individual address any fears or concerns regarding coercion.
- Recognize that excitement to offer the vaccine got ahead of the need to affirmatively address peoples' questions. Some people still need those questions answered before they can make an informed decision about the vaccine.
- Consider historical traumas like the Tuskegee study or the radioactive oatmeal experiments at the Fernald school. For more information on these atrocities please read:
 - https://www.mcgill.ca/oss/article/history/40-years-human-experimentation-america-tuskegee-study_
 - <https://www.smithsonianmag.com/history/spoonful-sugar-helps-radioactive-oatmeal-go-down-180962424/>
- Use a community organizing approach – establish trust and seek enthusiastic consent.
- Acknowledge that vaccination is voluntary. People have the right to say 'no.'
- Be attentive to power dynamics.
- Validate peoples' fears and respect their decisions.
- Don't assume that everyone wants – or has to get – the vaccine. They should also know that they don't have only one chance to get it. They can always change their mind and get it later.

Structure

- Take some time to establish a rapport, and to put the person at ease.
- Lay out the goals of the conversation, including the intention to share information and answer questions in a respectful and neutral way, and to support individuals' ability to make a decision for themselves.
- Use simple, open-ended questions that seek to learn about the person's needs, preferences and concerns.
- Build in opportunities for questions, understanding that an individual may want or need to have more conversations down the road before making a decision.
- Do not assume a shared base of knowledge. Start by sharing the "basics" like the pros and cons for vaccination, and let the individual relate what level of detail or background information is helpful.
- Circle back during the conversation to affirm the person's understanding. Offer additional clarification as needed.



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Content

- Use and provide easily digestible information -- avoid medical jargon or abstract concepts.
- Infographics and simple materials can be helpful in breaking down the science.
- Offer information that caters to different learning styles.
- Speak in ways that are community appropriate; culturally and generationally.

Resolving Barriers

- Remember that many people need reasonable modifications to access information about the vaccine, to schedule vaccine appointments, and to navigate to or within vaccination sites. Ask about the individual's accommodation needs; and offer assistance or referrals to organizations that can help.
- Many people with disabilities, particularly those from other marginalized communities, have experienced discrimination. As a result, they may not believe that government systems will work for them. Acknowledge these experiences if raised by the person, affirm the individual's right to equitable care and treatment, and offer guidance and support in the vaccine process.
- It is important to remember that some people with disabilities have been traumatized by experiences of forced treatment. Supporting individuals' voluntary decision-making, and working together to resolve barriers, empowers people to act on their own decisions.

Model Script

Supporter: So, you will be eligible for a vaccine soon. Do you want to talk about it?

PWD: Sure.

Supporter: First you should know that it's your choice. You get to decide for yourself if you get the vaccine now or later.

PWD: OK, I like that.

Supporter: Do you know what COVID-19 is?

PWD: I think so.

Supporter: Why don't you tell me what you think it is.

PWD: I heard it is a sickness that is making a lot of people ill.

Supporter: That is right. It is a virus that has made many people sick and has killed over 500,000 people in the US alone.

Supporter: Do you know what the vaccine is?



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Model Script

PWD: I heard it's a shot that everyone has to get.

Supporter: It is a shot, but no one can make you take it. You get to decide for yourself if you get the shot or not. It does protect you from getting really sick from COVID-19, but you need to decide what is best for you and I am here to help you talk through that choice.

Supporter: So, how do you feel about getting the vaccine?

PWD: I am not sure. I have heard it can make me sick.

Supporter: Well, there can be some side effects right after the shot, but the side effects are usually mild – lasting only for a day or two – and are much less severe than the effects of getting COVID. Do you have any specific questions about the side effects?

PWD: I don't know. I just want to feel safe, and I don't want to get sick.

Supporter: The vaccine can help with that. It helps make sure you won't get really sick from COVID.

PWD: The information I've seen about the vaccines is really complicated. Is there anything you have that's easier to understand?

Supporter: Yes. There are videos, fact sheets with questions and answers, and materials written for different learning styles. First, let's talk about what kind of information you'd like to see. Then I can help you find it in a format that is more accessible to you.

PWD: Can I go back to normal life after I get the vaccine?

Supporter: You still have to wear a mask in public, but you can begin to visit other vaccinated people or low risk family members in small groups. I can provide you with more information about what is safe to do after you are vaccinated. Most vaccines take at least 2 weeks after the second shot before they are fully effective.

PWD: I'm still confused. Why is it important for me to get vaccinated?

Supporter: Getting the vaccine is an individual choice. The more people are vaccinated, the easier it will be to control the spread of the virus. In this way, getting vaccinated helps protect you and the health of others in your family and community. If you don't get it and you get COVID you stand a much greater chance of getting very sick, being hospitalized or even dying. If you do get it, there is almost no risk you will get very sick, require hospitalization or die. Most people like those odds.



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Model Script

PWD: I have other medical conditions, including allergies. Can I talk to my doctor or nurse about the vaccine?

Supporter: Of course. If you have any questions about your medical conditions and how the vaccine or COVID might affect you differently than other people, then your doctor or nurse can help answer those questions. If you'd like, I can help you arrange a time to talk with that person.

PWD: OK. So, I can take my time and think about it?

Supporter: Of course. People are here to help you and to answer your questions. We want to make sure you have all the information you need to make the best choice for you.

PWD: What happens if I don't want the vaccine right now?

Supporter: Then you can wait before making your decision. We can set up another time to talk in the near future if you think of other questions.

PWD: If I decide I want the vaccine how long will it take to get it?

Supporter: Many people are eligible for the vaccine, and wait times vary. If you are not eligible yet, but thinking about getting the vaccine, I can help you pre-register for a future appointment.

Supporter: Do you have other worries or concerns about the vaccination process?

PWD: To be honest, I'm nervous about going to a strange place by myself and getting a shot.

Supporter: That's understandable. There are different places you can be vaccinated, depending on where you are most comfortable. You are allowed to bring a friend, family member, or other supporter with you to the vaccination site. You can also bring sensory tools, or other items that help you manage stress.

PWD: What if I can't drive there?

Supporter: There are a number of options for getting to your vaccination appointment. I can work with you to make sure you have a way to get to your preferred vaccine location.

PWD: Thanks. I really appreciate you helping me learn about this so I can make my own choice.