

Perceptions and Experience of Vaccination and Vaccination Outreach: Findings From Focus Groups With Adults With Disabilities and Caregivers in FEMA Region 5

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INTRODUCTION

The Center for Health Equity (CHE) at the Indiana Institute on Disability and Community at Indiana University Bloomington serves as a Regional Hub for the Federal Emergency Management Agency (FEMA) Region 5 (Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin), to promote vaccination among the disability community. More specifically, the Regional Hub aims to increase vaccination rates among individuals with disabilities and their caregivers through vaccination outreach, to help protect the disability community against infectious diseases including COVID-19. In an effort to effectively expand vaccination outreach in the FEMA Region 5, CHE conducted seven online focus groups between April 20 and April 25, 2023. The objectives of the focus groups included:

- Learn where people with disabilities and their caregivers receive vaccine information.
- Identify their preference for how individuals with disabilities and caregivers want to receive vaccine information.
- Learn about what motivates people with disabilities and caregivers to get vaccinated.
- Learn about barriers to vaccination for people with disabilities and caregivers.
- Identify promotional activities to encourage the disability community to get vaccines recommended by the Centers for Disease Control and Prevention (CDC).

METHOD

Participant Recruitment

Participants were primarily recruited from their participation in an online survey on vaccination outreach conducted between March 27 and April 25, 2023. At the end of the survey, participants were asked if they were interested in participating in the online focus group. In addition, CHE staff asked the members of a Vaccine Outreach Advisory Committee to promote the focus groups in their state to recruit the participants. (The Vaccine Outreach Advisory Committee consists of adults with disabilities and caregivers from the FEMA Region 5 states except for Ohio.) Additionally, CHE contacted disability organizations in the FEMA Region 5 and requested that they promote the focus group recruitment information with disability advocates and potential participants in their area. After potential participants expressed their interest, they were contacted by CHE staff to further determine their eligibility and availability. People were eligible to participate if they met the following criteria: a) were 18 years old and older; b) lived in the FEMA Region 5; and c) were either adults with disabilities or family or paid caregivers of individuals with disabilities.

Online Focus Group Protocol

The focus groups were conducted through Zoom, and their duration ranged from 30 minutes to 90 minutes. Three research associates from CHE administered the focus groups with one serving as the main facilitator and the other two research associates handling multiple roles including asking clarifying questions and recording sessions for analysis. Before recording began, participants were reminded that their participation was voluntary, that they did not have to answer any question they did not want to, and that they could leave at any time. Participants were provided with a \$50 electronic gift card as compensation after the completion of the focus group. The facilitators used a question guide (see Appendix) which included questions about the information needs of the disability community including the best ways to share information

about getting vaccinated and what other resources were available and should be shared. Participants were also asked about their opinions on vaccination and suggestions to improve the vaccination experience for people with disabilities and their caregivers.

The focus groups were recorded, and the audio of each Zoom session was transcribed verbatim. Inductive thematic analysis was used to identify themes (Braun & Clark, 2006, 2013). Research staff read the transcripts and independently identified codes and potential themes. Staff met to discuss codes, grouped related codes, and identified overarching themes and sub-themes. Afterwards, definitions of the themes and sub-themes were created.

RESULTS

Participants

CHE staff conducted seven focus groups in total: four focus groups with adults with disabilities, and three focus groups with caregivers of individuals with disabilities. For adults with disabilities, a total of 16 people participated in the four focus groups. The participants with disabilities came from the following four states: Illinois (n=2), Indiana (n=5), Michigan (n=4), and Minnesota (n= 5). The focus groups included 12 women and 4 men. For the caregivers, 12 people participated in the three focus groups (9 family caregivers and 3 paid caregivers). The caregiver participants came from five states: Illinois (n=1), Indiana (n=3), Michigan (n=5), Minnesota (n=1), and Ohio (n=2). These focus groups included 9 women and 3 men.

Key Findings

The following six overarching themes emerged from the analysis of the focus group data: 1) There is trust in health experts and news media; 2) Accessible information promotes engagement; 3) Vaccination programs should provide variety in vaccination options; 4) Personalize the vaccination experiences to increase empathy and importance of vaccination; 5) Mixed messages and misinformation hinder vaccinations; and 6) People have to make their own decision to vaccinate.

Theme 1: There is trust in health experts and news media.

Regarding sources of information they used for vaccinations, participants overwhelmingly had positive views about health experts and health organizations. They often cited the CDC as their primary source. With regard to local resources, participants turned to their doctors, health departments, and pharmacists to inform their decision-making process. They also relied on health experts to be the main drivers of disseminating COVID-19 information. Participants also received vaccine information from news media.

a) CDC, healthcare providers, and health departments are reliable resources.

- Participants identified the CDC, their own healthcare providers, and local health departments as the sources they trusted most for vaccination information.

I get my information mainly from our family primary care physicians. Also from absolutely reading CDC guidelines, the notices that come.

...I get the information from the local health department, and I trust that

what they are doing is in the best interest of the citizens of our county and of our state.

b) News media provides additional sources for vaccine information.

- Other than health experts, information gathered from newspapers and broadcast news were mentioned as another vital source for vaccination information.

I principally got my information from mostly news articles that I was reading, both that I got exposed to passively and actively looked into.

I've received information from my pharmacy, I get messages from them, also from like the CDC website, and also through the typical news media like, you know, like the local evening news.

Theme 2: Accessible information promotes engagement.

Although participants mostly found information about vaccines and vaccination to be understandable, they thought that it should be presented in simple and plain language for effective messaging and accessibility. Adults with disabilities recommended making information available in multiple formats (e.g., plain language, screen reader, American Sign Language (ASL), etc.) to ensure that it is accessible to different groups of people with disabilities.

a) Information has to accommodate diverse needs.

- Adults with disabilities mentioned that they were better able to comprehend information when they were provided information in accessible formats, such as screen readers and ASL.

I think the videos with the ASL interpretation and the language description below what is being actually said, along with visual diagrams and pictures, is probably the most universally accommodating for everyone.

... the importance of it being available in multiple formats and I think almost everyone benefits from a little plainer language, as long as we trust that it's still scientific and it doesn't sound like, you know, somebody just wrote it to write it.

b) Information in plain language reduces confusion.

- Medical information can be filled with jargon that many people cannot understand or are confused about. When materials are presented in simple and plain language, participants said they were more likely to engage in them.

I think that if things were explained, were in, maybe more in layman's terms, things would be a little bit simpler to understand.

It's all medical language. It's almost like a different language altogether...They would do all the medical terminology, which is great, and everything. That just means they really know their stuff...Like I tell them, "Please talk to me in English with some of the stuff."



c) Information that is available online is not accessible to all.

- Some rural areas lack high speed internet, making it difficult to access online vaccine resources. Also, there are individuals who do not have the availability of a computer to schedule appointments or receive online vaccine information from national and local health departments.

I live in a small town, we don't have Wi-Fi. Like, that's not really a thing. And I couldn't go anywhere to get the internet. So I was relying on the news and just other people explaining things and what they understood.

...persons that we work with that are on SSI, they don't have any computing devices, internet, or any way to access that type of information. And so the only information they receive is printed information or on television.

Theme 3: Vaccination programs should provide variety in vaccination options.

Participants wanted to have multiple ways of accessing vaccinations. For people with mobility or physical limitations, this is especially important. Options such as pharmacies with long hours, mobile clinics, and vaccination events give people different opportunities to engage in vaccinations. Incentives are also seen as an effective way to motivate people to vaccinate.

a) Pharmacies are alternatives to healthcare providers.

- Pharmacies are helpful for vaccinations because there tends to be more locations and have more hours for services. Healthcare providers do not always have the same level of flexibility as pharmacies for providing vaccines.

I went to Walgreens and they just had some basic like information about the process and like how to do it and like how to sign up and that sort of thing. So, that's kind of how I did it.

...most common place in my town is, of course, the pharmacies like CVS or Walgreens. You can get information there about, you know, most vaccines that you request...

I think it's really important to have the availability through pharmacies, because they have hours outside of the regular nine to five....

b) Mobile clinics help people with physical disabilities to access vaccines.

- Mobile clinics are necessary especially in rural areas and when physical and mobility issues are a primary concern for people with disabilities. It is also helpful because people could drive up and receive vaccines without leaving their vehicles.

Here we had drive up clinics, they wouldn't even let you get out. So everyone [drove] up in their car and that's how we got the shot.

I'm from Michigan and I live in a small town in, I was in the apartment building for people over 55. And so, when it came time to get the vaccines,

the first two times our drug store came to the building and all you had to do was be outside your apartment door and they came to you.

So we had our, the nurse that came from the health department she went out to the cars, to the vans, and administered the vaccination shots to the people in the vans. We had a privacy screen for anybody who wanted privacy during their shots and we had plenty of room to keep social distancing.

c) Promote vaccinations at community events and meetings.

- Participants spoke highly of in-person events that created safe opportunities for people to get vaccinated. Also, there are some minority communities who may not trust information coming from medical professionals. It would be helpful to have trusted local community members visit with people in their communities to share resources about vaccinations and answer questions.

What if the organizers of events hold more vaccine drops where people can have a good time while getting vaccinated....

I think maybe like human connection, like connecting it to the community, or connecting it to people that they might know, you know, to kind of, you know, provide that human connection, you know, might sway them one way or the other.

d) Incentives can be used to encourage vaccinations.

- When asked about ideas to encourage people to get vaccinated, multiple participants explained that providing incentives (e.g., gift cards) should be utilized. It does not always have to be monetary. Allowing people time to get vaccinated without letting it affect their work can be a positive incentive.

I think incentive is a good tool...we got gift cards that we passed out with each shot that was given. So, I think incentivizing them would be a great way for people to get out and get their shot.

Target/CVS will always get me there with that \$5 gift card. It's not going to make or break my day. It's not going to, you know, help me meet my budget or anything like that, it's just an incentive and I have always just gotten my shot at Target/CVS because they do the \$5 gift card. I don't know if they did it this year, but yeah. That always works for me.

I think one of the most helpful incentives, not a gift card, but giving them release time so they could do it.

Theme 4: Personalize the vaccination experiences to increase empathy and importance of vaccination.

The primary goal of vaccinations is to keep people safe from the risks of infections. The findings

reveal that it is important to maintain the human aspect of vaccinations and virus prevention. It is advantageous to share personal experiences, discuss motivations for vaccinations, and emphasize the importance of protecting friends and family because it helps to explain the reasons why vaccination is important.

a) Sharing personal experience increases relatability.

- Participants felt that making a personal connection with people in the community and sharing vaccine experiences was a very effective way of encouraging people to get vaccinated. Participants mentioned they enjoy hearing personal stories on why people decide to get vaccinated.

I think testimonials and that kind of advertising could be really effective, the benefits for people -- caregivers getting vaccinated, how you protect the people that you're in contact with and stuff like that.

I tend to try to encourage people by using personal stories that I feel like show why it's important to get vaccinated. That's probably the biggest tool.

b) The concern about getting sick is a strong motivator to get vaccinated.

- Participants indicated that their primary motivation for getting vaccinated is because they did not want to get sick. Some individuals had health conditions that made them vulnerable to diseases. They did not want to take risks.

I had a really bad bout of the flu. And I ended up in the hospital with the flu. So when COVID came around and everybody was getting really sick and people were dying from it and I already knew what it was like to end up in the hospital with the flu.

I have also an underlying condition heart issue. And so I'm exceptionally vulnerable. I would be exceptionally vulnerable if I had gotten COVID, which in fact, I did, and had to go on anti-virals, but that's another story. Anyways, so yeah, it's mostly having an underlying condition.

c) Protecting others, like family, influences people to get vaccinated.

- The motivation to get vaccinated was focused on protecting self and family from illness and maintaining their overall health and wellness goals. Some mentioned their own personal stories about friends and families who had gotten severely sick or died from viruses or at-risk for viruses.

My motivation is just my own health, but also the health of others. I worked in a pretty big hospital system...and they went so far as to put little ribbons on your lanyards to designate that you had gotten a flu shot during flu season. So it's the whole - it's not just about me, it's about everybody. So yeah, that's my motivation.

I live in an apartment building, so we're all over 55 and that's when people can get really sick. So, we have like 90% of the residents getting the

vaccine, and so, we're doing it to protect ourselves from each other.

Theme 5: Mixed messages and misinformation hinder vaccinations.

The changing information about vaccines, lack of clarity in information, and the spread of misinformation about vaccines hindered efforts to improve vaccination rates. Participants sometimes found it hard to know what information to trust. Anti-vaccination rhetoric often worked to discourage any attempts to get vaccinated.

a) Inconsistent and confusing information made it hard to understand vaccine benefits.

- Participants stated information was not always consistent, and that not every source for information said the same thing. When information was confusing or conflicting, it was sometimes difficult to ascertain how to use the information to help benefit the participants.

I think that sometimes the information is confusing and maybe not very well presented. And I think that was particularly true when we're talking about COVID vaccines when maybe a lot wasn't known. So there was a lot of conflicting information.

...a lot of those type of information pushes were a little confusing at times, just because the CDC was still sorting out a lot. Like the latest commercial about vaccinations from the CDC I found confusing because it didn't feel like it was very clear as to whether or not, you know, it was recommending a booster for those who had already gotten the Omicron booster.

b) Detractors used exaggerated claims to discourage vaccinations.

- Participants discussed how people, including family members, would go to great lengths to try to convince them not to go through with getting vaccinated. Detractors would make exaggerated and misinformed claims that were not based on scientific data.

They all think that it's the Antichrist or it's, you know, the devil or something so. Because we had talked, my parents into getting it. It caused really family tension and it caused separation already within the family.

I think some of the concerns I did hear were some of the myths that were out there or the false information of, you know, "It's the government. It's putting a tracking device in you," or "It's going to give you COVID," or, you know, people that were having mild reactions to the vaccine were kind of blowing that out of proportion and maybe sharing false information or making it worse.

Theme 6: People have to make their own decision to vaccinate.

None of the participants indicated that they were not vaccinated. They generally supported the idea of vaccinations. Despite this fact, some acknowledged that vaccinations are personal choices. You can encourage others by explaining the benefits of vaccinations, but there is only so

much you can do.

a) There are limits to persuading others to get vaccinated.

- Some participants have encouraged others to receive vaccines by explaining the benefits of vaccines, but they acknowledge that each individual will have to make their own decision.

At the beginning we tried to talk people into why they should get the vaccine, but the topic became so polarized, I don't think there's anything you can do. It was very few people that we were able to persuade to get the vaccine and that was only after something drastic happened. Like they knew a friend that died or it hit home personally. So, we eventually stop fighting that battle because, just felt like it couldn't be won.

People will have their own choice to make. So the best thing we could do is provide the information that's out there. But leave it up to those people to either accept the information that we are providing or continue to stick to what they believe in, knowing that there's a cause and sequence to both.

Limitations

The findings of the focus groups must be considered in the context of several limitations. First, a potential concern is that the pool of possible participants was limited to individuals who had internet access to participate in the online focus groups. Additionally, although recruitment of participants was open to those with various viewpoints about vaccines, all focus group participants expressed the same view in support of vaccinations. Also, even though the recruitment of participants was focused on the FEMA Region 5 states (Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin), not all states were represented. There were no representatives from Ohio and Wisconsin in the focus groups for adults with disabilities, and none from Wisconsin in the caregiver groups. Lastly, we did not collect demographic data such as race/ethnicity, age, and geographic location other than state.

Despite these limitations, our findings can provide important information about how to better promote CDC-recommended vaccines among the disability populations in the FEMA Region 5. Participants highlighted barriers to accessing vaccines. Throughout the discussions, participants also shared suggestions on how to make vaccines more accessible to everyone.

RECOMMENDATIONS

Several insights were gained from the focus groups regarding vaccination outreach to people with disabilities and their caregivers in the Region 5 states.

1. **Encourage people to consult trusted health resources, such as medical doctors and health departments, for updated information on vaccines.** Participants reported a high level of trust in the information and recommendations they receive from their medical doctors, health departments, and the CDC. Many rely on medical experts to help them understand many of the confusing information, such as medical terminologies.

2. **Present materials in simple and plain language.** Participants reported that information from health and medical professionals can be confusing. When material is presented in layperson's terms, people are more likely to understand and pay attention to the information.
3. **Provide materials in multiple formats to accommodate diverse needs and potential accessibility barriers among the disability community.** Participants were receptive to materials in different formats (e.g., plain language, screen reader, ASL) to accommodate various needs of the disability community. Messages in different formats (e.g., print, online, webinars, etc.) were also welcome as people learn and communicate in different ways. These different formats ensured a higher likelihood of engagement with information.
4. **Use testimonials and personal stories to encourage vaccinations.** Participants thought that sharing personal vaccination experiences was an effective method to motivate people to get vaccinated, especially if one shared their reason for getting vaccinated (fear of getting sick or protecting others). It humanized the vaccination experience and presented information that was easier to relate to.
5. **Increase the places that vaccinations (including promotions) can be accessed, such as pharmacies and community events.** Participants indicated pharmacies were a great option for getting vaccines. They offer more hours of service compared to a doctor's office. They also liked the idea of community events and meetings because it was a good way for them to speak with advocates about their vaccination questions.
6. **There is still value in using incentives for vaccinations.** Incentives, such as gift cards, were common during the early stages of vaccinations for COVID-19. This could still be a valuable tool to encourage vaccinations for other types of viruses. Incentives do not always have to be monetary. They could include food. If people were allowed to get vaccinated without it affecting their work, that could be also seen as a positive incentive.

References

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Appendix: Question Guides for Focus Groups

The facilitators used a question guide for each focus group. The first part of the guide was used for the focus groups of both the adults with disabilities and the caregivers. The second part of the guide had some small differences depending on whether the group was for adults with disabilities or caregivers.

Information Needs

- Where do you or where have you gotten information about the vaccines?
- Did you feel you could trust those sources for information about vaccines and getting vaccinated?
- Were you able to understand the information you received about vaccinations? please explain why or why not.
- What ideas do you have to make vaccine information understandable?
- What methods do you prefer to receive information about vaccines? For example, social media, television, radio, online newsletter, webinar, vaccine resource website, etc.
- What are the best ways to reach people with disabilities, their family members, and direct care workers in your community about recommended vaccinations?
- What resources does your community (not including medical providers) have about vaccines and how to get vaccinated?
- What resources would you like to see available in your community to help you be better informed about vaccines?

Opinions on Getting Vaccinated: Adults with Disabilities

- What factors motivate you to get vaccinated? Or what factors motivate you to not get vaccinated?
- What concerns do you have or have you heard that others in your community have about getting CDC-recommended vaccines?
- For those who want to get vaccinated, what barriers are there in your community that keep you or others from getting vaccinated?
- If you got vaccines for COVID-19, flu, and other viruses, have you encouraged others to get vaccinated?
- What promotional activities do you think would help others to get their recommended vaccinations?
- What promotional activities do you think we should avoid when promoting vaccinations?
- If you got vaccinated for the flu but not for COVID, what influenced your decision?

Opinions on Getting Vaccinated: Caregivers

- What factors motivate you to get vaccinated? Or what factors motivate you to not get vaccinated?
- As a caregiver, what concerns do you have or have you heard that others in your community have about getting CDC-recommended vaccines?
- What barriers have you experienced in getting vaccinated or getting your family members (or clients for paid caregivers) vaccinated?

- What recommendations do you have to help family members (or clients for paid caregivers) be comfortable with getting vaccinated?
- What promotional activities do you think would help caregivers get their recommended vaccinations?
- What promotional activities do you think we should avoid when promoting vaccinations?
- If you got vaccinated for the flu but not for COVID, what influenced your decision?