

Project ALI  E



Accessible Life-saving Integrated Vaccine Equity

Navigating Vaccine Hesitancy for Missouri Centers for Independent Living

Accessibility for this Presentation

This event is recorded and an archive will be available.

Closed Captions:

Click the button at the bottom of the screen labeled "CC" to start captions.

Accessibility for this Presentation

- To ask or respond to questions: use the “raise your hand” button OR type in chat
- For technical assistance or to alert us to an issue, type in chat/raise hand
 - Ex. “slow down please”
- If the chat is not accessible to you, please submit your questions to priya@disasterstrategies.org.

Accessibility for this Presentation

Friendly reminders:

- Please identify yourself before speaking
 - Ex. “This is Jessie, and...”
- Please keep yourself on mute when not talking
- Please keep your camera off unless you are talking
- Please avoid using acronyms

Welcome and About Us

Welcome and Introductions

Project ALIVE (Accessible Life-saving Integrated Vaccine Equity) is a short-term (February-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.

Population Focus of Project ALIVE

Project ALIVE's focus is on:

- People with disabilities in rural areas of Missouri who desire COVID-19 vaccines (primary series and booster) and experience barriers accessing them
- People with disabilities who are hesitant but are still open to getting the COVID-19 vaccines

Disclaimer

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.

Ground Rules

- Maintain confidentiality
- Ask questions
- Have fun!!!

Do you have ground rules you'd like to suggest?

Objectives

By the end of this presentation, you will be able to:

- Understand some causes of COVID-19 vaccine hesitancy and how to respond
- Identify barriers to accessing COVID-19 vaccines (primary series and booster) and know how to respond

Understanding Vaccine Hesitancy, Uncertainty, and Rejection

Understanding Vaccine Hesitancy

Definition of Hesitancy: The delay in acceptance, reluctance or refusal of vaccines despite the availability of vaccine services.

Some People Move from Hesitancy to Acceptance

A study in the Journal of Community Health found that 62.4% of people uncertain about getting vaccinated, and 30.7% of vaccine rejectors received vaccines over the one year period of the study.

Reasons for Vaccine Uncertainty and Rejection

Major reasons for uncertainty and rejection were:

- Faith-based beliefs
- Political affiliation
- Racial/ethnic identities

Reasons for Vaccine Uncertainty and Rejection

Faith-based and political beliefs and racial / ethnic identities are core and constant. It would be disrespectful and inappropriate to try to persuade one to change.

Moving from Hesitancy to Acceptance

Why and How Do People Move from Hesitancy to Acceptance?

The best educators are peers!

Identify peers based on:

- Disability
- Race / Ethnicity
- Culture / Language

CIL staff should address people's concerns about information in an open, unbiased, welcoming manner.

Why and How do 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.

Questions for You

Moving from Hesitancy to Acceptance

Does anyone have examples of people who were hesitant and moved to acceptance?

What was that like?

What can we possibly learn from it?

Reasons and Responses to Vaccine Hesitancy

Reasons for Hesitancy

Some reasons are:

- Distrust of media to provide accurate information
- Distrust of government to provide accurate information
- Distrust of medical profession based upon history of ableism, racism or other forms of bias and abuse

Reasons for Hesitancy and Ways to Respond

Issue:

A consumer knows of someone else who got the vaccine and still got COVID-19

Response:

The purpose of the vaccines is beyond not getting COVID-19. It is to reduce the chances of dying or being hospitalized.

Reasons for Hesitancy and Ways to Respond

Issue:

A consumer thinks the vaccine will make their disability worse

Response:

Seek advice from your medical provider.

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 a vaccine.

Questions and Comments

Have you heard of other reasons for hesitancy?

Do you have questions or comments?

Who is At Risk of COVID-19?

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.

Disabilities and Risk

People with one of these disability types might be at increased risk for COVID-19 and its effects:

- People with limited mobility or sight who cannot avoid coming into close contact with others
- People who have trouble understanding information or practicing prevention measures like hand washing and social distancing

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
- People in congregate settings

Medical Conditions That Increase Risk

Some medical conditions include:

- Cancer
- Chronic Kidney Disease
- Chronic Liver Disease
- Chronic Lung Diseases
- Cystic Fibrosis
- Dementia or other neurological conditions
- Diabetes Type 1 or 2
- Heart Conditions

Disabilities and Risk

Some medical conditions include:

- Cerebral Palsy
- Congenital Disabilities
- Developmental and Intellectual Disabilities
- Learning Disabilities
- Spinal Cord Injuries
- Certain Mental Health Conditions
- Sickle Cell Disease or Thalassemia

Address All Forms of Risk Reduction

Remember that someone who doesn't want a vaccine may be willing to practice other forms of risk reduction, such as:

- Masking
- Social distancing
- Hand washing
- Isolating

Discuss Risks Specific to the Individual

Help the individual to do a risk / benefit analysis regarding practicing risk reduction behaviors.

Explore:

- Risk factors such as age, specific disability, 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 masks, gloves, etc.

Reasons and Responses to Vaccine Hesitancy

Responding to Vaccine Hesitancy

Issue:

Distrust of media to provide accurate information.

Response:

Provide access to variety of media and public health websites to allow the person to make an informed decision.

Responding to Vaccine Hesitancy

Issues:

- Distrust of government to provide accurate information.
- Distrust of medical profession based upon history of ableism, racism, or other forms of abuse.

Response:

Respect an individual's and/or community's history with government, media, and the medical profession and their perceptions of them.

Responding to Vaccine Hesitancy

Issues:

- Uncertainty about long-term effects of the vaccine.
- Fear that vaccines will cause illness or infertility.

Response:

- Support the person in a risk vs. benefits analysis.
- What are the current risks of getting COVID vs. the long term risks of getting the vaccine?
- You may wish to discuss Post-COVID Condition.

What are Post-COVID Conditions (PCC or Long COVID)?

Common symptoms include:

- Fatigue
- Breathing difficulties
- Insomnia
- Pain
- Brain fog

Post-COVID can negatively affect organs like kidneys, lungs, pancreas, and heart.

Responding to Vaccine Hesitancy

Issue:

Fear of vaccine because it was developed so quickly.

Response:

Provide education about how the vaccine was developed.

President Donald Trump championed “Operation Warp Speed” in order to develop and mass-produce safe vaccines.

Development of the Vaccine

- A partnership of government, science and industry used a new model to do in nine months what would usually take 5-7 years.
- It wasn't developed "quickly:" scientists had been working on this type of vaccine for over 10 years.

Development of the Vaccine

- The federal government oversaw the process instead of the pharmaceutical companies.
- Steps were taken simultaneously:
 - Increasing financial risk to manufacturers
 - Decreasing the risk for the public in distribution

Responding to Vaccine Hesitancy

Issue:

A consumer doesn't think, or is not sure that they are in a high risk category.

Response:

Provide education about COVID-19, universal risk and people with disabilities, other pre-existing conditions, racial / ethnic / gender, and other COVID-19 information.

Responding to Vaccine Hesitancy

Issues:

- The vaccine can alter the DNA.
- “Natural immunity” is better than vaccine immunity.

Response:

- There is no known substance in the vaccine that can alter the DNA.
- Getting a COVID-19 vaccine is a safer and more dependable way to build immunity to COVID-19 than getting sick with COVID-19.

Vaccine Hesitancy as a Result of Barriers

Hesitancy Due to Barriers

Some people may be hesitant due to barriers to accessing the vaccines (primary series and booster).

The barrier could be actual or assumed.

Barriers to Vaccine Access

Some barriers include:

- Lack of transportation / accessible transportation
- Lack of sign language interpreters
- Lack of spoken language interpreters
- Lack of physical access for wheelchairs and other mobility devices

Barriers to Vaccine Access

Some barriers include:

- Lack of sensory accommodations (scent-free environment, low-level lighting, quiet room, etc.)
- No support person at site
- Fear that site won't allow service animal to enter
- Fear that undocumented immigration status will be discovered

Barriers to Vaccine Access

Some barriers include:

- Bad experiences with vaccines in the past
- Disability Bias
- Lack of accessible information about the vaccine process

Barriers to Vaccine Access

Some barriers include:

- Lack of accessible registration, such as easy read, large print font, screen reader-accessible, and other formats
- Consumer's caregiver, conservator or guardian does not want them to be vaccinated and will not assist them

Responding to the Barriers

Response:

- Educate the consumer on Disability Rights and advocacy around what is and is not legally required for the consumer and for the vaccine site
 - Focus on the consumers' specific concerns or fears
- Call ahead to advocate for accommodations
- Accompany person to site if they desire / if possible

Responding to the Barriers

Issue:

Fear that undocumented immigration status will be discovered, or that person will be suspected of being undocumented, even if they are not.

Response:

Provide education about health care and immigration status laws.

- Offer to accompany person to vaccine site, refer to legal aid or similar service for education and advocacy.

Equal Access to COVID-19 Vaccines

The Department of Homeland Security released a [statement in February 2021](#) ensuring that it will cooperate with the Federal Emergency Management Agency (FEMA), and will not conduct enforcement operations near or at health care facilities, including pop-up clinics, hospitals and other such facilities.

Responding to the Barriers

Issue:

The consumer had bad experiences with vaccines in the past.

Response:

Inquire about the previous bad experiences.

- Did they have a medical reaction?
- Was there lack of accommodations?

Responding to the Barriers

Issue:

A consumer had a previous negative experience with health care which caused hesitancy to seek any health services, including receiving a vaccine.

Response:

- Listen without judgment.
- Provide disability rights education and advocacy.
- Offer peer support at the vaccine site.

Responding to the Barriers

Issue:

My caregiver, conservator or guardian does not want me to be vaccinated and will not assist me.

Response:

Refer to [Missouri Protection & Advocacy Services](#).

Responding to the Barriers

Issue:

Inaccessible information about the vaccine process.

Response:

- Provide education about the process.
- Advocate for accessible information for the vaccine site.

Responding to the Barriers

Issue:

Inaccessible registration

Response:

Provide information and education to public health about legal requirements for materials in alternative accessible format.

Scenarios

Scenario 1

A consumer calls to tell you that after their friend got very sick from COVID-19, they want to get a vaccine but their family is against it. They depend upon their family for transportation and personal assistance.

- What do you need to consider?
- How should you respond?

Considerations for Scenario 1

Consider:

- What is the legal status of the family member to the consumer?
 - Legal guardian?
 - Caregiver?
- What repercussions may result?

Responses for Scenario 1

Some responses include:

- Refer to [Missouri Protection and Advocacy Services](#)
- Discuss level of family resistance, possible outcomes and openness to education
- If feasible, provide education to family members

Scenario 2

A vaccination site tells a consumer that they cannot accommodate her need for a quiet place to receive and rest after the vaccination.

Considerations and Responses for Scenario 2

- Inform consumer that the site may be required to provide place to rest but cannot assure it will be quiet.
- CIL staff might call the site to advocate for a quiet space, emphasizing that there may be a legal obligation to make a reasonable modification to a policy or a procedure.

Scenario 3

A consumer tells you that she refuses to get a vaccination because they believe the vaccine will alter their DNA.

Considerations and Responses for Scenario 3

- Do not argue, but provide factual information.
- Listen and encourage consumer to tell you more. You want to maintain and strengthen the relationship.
- The ongoing relationship with the consumer is the priority.
- Encourage other risk reduction behaviors such as masking, hand washing, distancing.



Scenario 4

A consumer tells you that his personal assistants refuse to get vaccinated. He needs personal assistance to live independently.

Considerations and Responses for Scenario 4

Consider:

- Brainstorming alternate sources of assistance with the consumer
- Pre-existing conditions of the consumer that increases risk

Considerations and Responses for Scenario 4

Response:

- Provide sources of Personal Protective Equipment (PPE) and require assistants to wear masks, wash hands, use sanitizer and gloves
- Encourage consumer to take similar precautions

Scenario 5

A consumer tells you that they cannot get vaccinated because they are afraid of needles based upon their experience being forcibly medicated in a psychiatric facility.

Considerations and Responses for Scenario 5

Consider:

- What has helped you in the past?

Some responses are:

- Support person on-site
- Meditation or breathing techniques
- Faith-based practice(s)

Your Thoughts and Experiences

What other scenarios have you experienced or do you think you may encounter?

What are some considerations and responses to these scenarios?



Thank you!

Regina Dyton, MSW

regina@disasterstrategies.org

(860) 752-8091

www.disasterstrategies.org

112 N. 8th Street, Suite 600, Philadelphia PA 19107

© 2022 *The Partnership for Inclusive Disaster Strategies*

Project ALIVE



Accessible Life-saving Integrated Vaccine Equity

Project ALIVE is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,900,000 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.