

Project ALI  E



Accessible Life-saving Integrated Vaccine Equity

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# **Navigating Vaccine Hesitancy for Missouri Centers for Independent Living**

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# **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
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# 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!

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