Project ALIVE

Accessible Life-saving Integrated Vaccine Equity

Using a Trauma-Informed Framework for Mitigating Disability Bias

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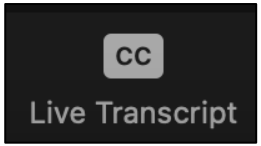

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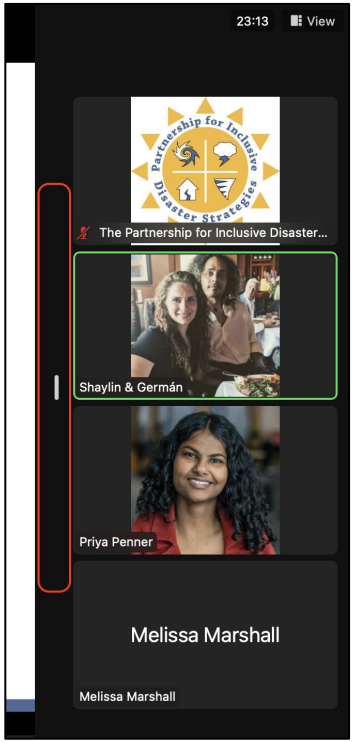

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- Please identify yourself before speaking
    - Ex. “This is Jessie, and…”
- Please avoid using acronyms

Montana Introduction

Meg Ann Traci, PhD
Montana University Rural Institute for Inclusive Communities

Information about: Montana and Aging and Disability Partners Work Together to Share COVID-19 Information

Information about Montana Centers for Independent Living here

Welcome and About Us

Welcome and Introductions

Project ALIVE (Accessible Life-saving Integrated Vaccine Equity) is a short-term (February-October 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 those wanting a vaccine and needing support, to access one.

Project ALIVE Montana Partners

Project ALIVE

Accessible Life-saving Integrated Vaccine Equity

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APRIL
Association of Programs for Rural Independent Living

THE PARTNERSHIP
FOR INCLUSIVE DISASTER STRATEGIES

SUMMIT INDEPENDENT LIVING
Building Awareness
Advocating Change

LIFTT
Living Independently for Today & Tomorrow

Population Focus of Project ALIVE

Project ALIVE's focus is on:

- People with disabilities in rural areas of Montana who desire a COVID-19 vaccine and experience barriers to access the vaccine.
- People who are hesitant but are still open to getting vaccinated.
- Strengthening relationships between Centers for Independent Living (CILs) and Public Health Departments.

Nursing Continuing Education (CE)

This nursing continuing professional development activity was approved by Montana Nurses Association, an accredited approver with distinction by the American Nurses Credentialing Center's Commission on Accreditation.

No individual with the ability to control the content of this activity has any relevant financial relationship with ineligible companies to disclose.

To earn a certificate, learners must attend this entire webinar session and complete and submit an evaluation.

This Nursing CE availability is possible thanks to the University of Montana Rural Institute for Inclusive Communities.

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.

This Presentation is an Overview

This training is an overview of disability bias and its related trauma. Many specifics have not been included here.

Objectives

For you to be able to:

- Recognize unconscious disability bias and ableism in health care.
- Interrupt disability bias during planning and service provision.
- Use most appropriate disability etiquette.
- Understand the relationship between ableism, other forms of bias and trauma.
- Design and manage an environment and process that best supports people with disabilities to receive COVID-19 vaccinations.

Ground Rules

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

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

Word Association

Words Associated with Disabled People

Many people associate negative words with disability, such as:

- Dependent
- Burden
- Suffering
- Violent (mental health conditions)

Thinking Differently

Can you think of some positive words to associate with disability?

Positive Associations

Here are some positive words you might associate with disability:

- Independent
- Thriving
- Educated
- Employed
- Entrepreneur
- Activist/Advocate
- Happy
- Fulfilled
- Health Care Providers

Positive Associations

In other words, the same associations that non-disabled people have/should have of and for themselves.

“Positive” Stereotypes

Harmful “Positive” Stereotypes

Some “positive” stereotypes that still harm disabled people are:

- Brave
- Compensatory Abilities/Senses
- Dependable

“I’m not your inspiration” - Stella Young

Discussion

Discuss a time when you were:

- Completely comfortable with a person with a disability.
- Less than comfortable or did not know what to do.

Extra points if your response is related to health care planning or service delivery.

What made the difference?

Comfort and Discomfort with Disabled People

You may be more comfortable with disabled people when you have a relationship with them as:

- Members of your family
- Friends
- Colleagues

Comfort and Discomfort with Disabled People

You may be less comfortable with disabled people when you don’t have a relationship with them because:

- You are uncomfortable with their disability
- You are afraid to ask questions
- You don’t know what to do

What Do We Mean by Bias?

- Prejudice in favor of or against one thing, person, or group compared with another, usually in a way considered to be unfair.
- Often, bias is unconscious.

Unconscious Bias

Unconscious bias is a bias/prejudice of which the holder is **unaware.**

- It may not be easy to identify.
- It communicates that the person the bias is directed toward is less valuable than others.
- People toward whom unintentional bias is directed may or may not be consciously aware of its existence and its effects.

Ableism

ableism

noun

able·ism | \ ˈā-bə-ˌli-zəm \

Definition of *ableism:* discrimination or prejudice against individuals with disabilities’

- Merriam –Webster

Oppression based on physical, mental, intellectual, cognitive, sensory or other ability or perceived ability

- Melissa Marshall

Intersectionality

Intersectionality is a way to analyze the interlocking effects people with multiple marginalized identities experience.

People of Color, religious and ethnic minorities, low income and other multiply marginalized people with disabilities experience disproportionate bias, ableism, and discrimination.

Privilege

Privilege can be understood as anything from which one benefits that they did nothing to earn. We all have some types of privilege.

- It is difficult to see our privilege.
  - Fish in water don’t know that they are wet.
- Privilege can make the condition and needs of others invisible to us and lead to unconscious bias.

Effects of Privilege

People with privileges often don’t think about people without it when planning and conducting services and activities.

Acknowledging Our Privilege

It’s important to acknowledge our privilege because:

- It helps us to remember those without that privilege.
- We can use our privilege to advocate for those without our particular privilege.
- We can use our position and privilege to educate our peers.

Key Terms and Principles

"**Microaggressions** are the everyday slight, put down, indignity, or invalidation unintentionally directed toward a marginalized group."

– Dr. Derald Sue, Professor of Psychology and Education

- Microaggressions can be the result of unconscious bias or unacknowledged privilege.
- Microaggressors often do not intend any harm.
- Microaggressions may be a sign of discomfort.
- Microaggressions point out differences.

Disability Microaggressions

Examples include:

- Tone
  - Patronizing tone/words such as “honey, baby, dear”
  - Infantilizing tone

- Word choice
  - Using language that expresses bias such as “brave, courageous”

Disability Microaggressions

Examples include:

- Touching someone's wheelchair or other device without permission.
  - Is it okay for someone you don't know to touch your property while speaking to you?
- Touching a person without permission.
  - Ex. helping someone put on a jacket without asking if they need help.

Disability Microaggressions

Examples include:

- Bringing attention to differences
    - Ex. telling someone using a scooter or wheelchair that you are going to give them a speeding ticket

Key Terms and Principles

Microaggression Equation:

Microaggression + Microaggression + Microaggression =

MACRO effects of:

- Alienation
- Frustration
- Low self-esteem
- Ableism
- Discrimination
- Lower Productivity

Reducing Disability Bias

Language

Use the terms “people with disabilities” or “disabled people.”

Avoid language that presupposes the negative

- Victim of…
- Suffering from…
- Challenged

Avoid language that groups people

- The mentally ill
- The disabled

Language

Avoid “endearing” terms:

- Honey
- Sweetie
- Dear

Avoid infantilizing terms:

- Mamma
- Baby

Disability Etiquette

Disability Etiquette

The following slides address some specific types of disabilities and is not inclusive of all disabilities.

These suggestions may not work in every situation. Make sure to communicate with the disabled person and ask them what they need.

Source: Etiquette: Interacting with People with Disabilities

Resource: Disability Etiquette

Offering Help

It’s okay to offer to help someone who appears to need assistance. Respect their response.

Always ask permission *before* helping someone.

Disability Etiquette

Blind and Low Vision

- Identify yourself and others when entering the room and let the person know when you leave the room.
- Offer a tour of the facility to a new person. Assist with navigation *if asked.*
- Offer your arm if they ask to be guided. Do not take the person’s arm.

Disability Etiquette

Blind and Low Vision

- If the person has a guide dog, walk on the side opposite the dog.
- Describe the setting and any obstacles as you walk with the person.
- Narrate events as they happen during the appointment.
- Keep walkways free of obstructions. Keep doors all the way open or all the way closed.

Disability Etiquette

Blind and Low Vision

- Inform people about furniture or structural changes.
- If asked, be willing to read information or assist with completing and signing paperwork.
- Make sure websites are screen reader accessible.

Disability Etiquette

Deaf and Hard of Hearing

- Ask the person for their preferred communication mode.
- Face the person directly when speaking. Don’t block your lips.
- Be open to using alternative communication methods requested, such as writing or assistive listening devices. Don’t assume that all Deaf/hard of hearing people use sign language or read lips.

Disability Etiquette

Deaf and Hard of Hearing

- If the person uses an American Sign Language (ASL) interpreter, speak directly to the person, not the interpreter.
- Do not yell, over enunciate, eat or chew gum when talking.
- Use a customary tone of voice unless otherwise requested. Speak slowly and clearly.
- Gently tap on the person’s shoulder or wave to get their attention.

Disability Etiquette

Speech Disabilities

- Ask them to tell you how they communicate. Ask if they want to write, use a communication board or a speech generating device.
- If the person has brought someone else to help them communicate, be sure to speak directly to the person, not the person assisting them.
- Allow time for delayed responses. Don’t try to guess what the person is saying.

Disability Etiquette

Autism and Sensory Disabilities

- Eye contact may be distracting or uncomfortable, do not pursue eye contact.
- Large groups, high noise levels and harsh lighting may be overstimulating. Dim lights and minimize noise.
- Respectfully allow a person's self soothing strategies (aka stimming).

Disability Etiquette

Autism and Sensory Disabilities

- Sudden changes can be upsetting so try to be as consistent as possible. Communicate changes as soon as possible.
- Allow for longer processing time during communication.
- Be open to using alternate forms of communication, such as text-based communication and ASL interpreters.

Disability Etiquette

Mobility Device Users

People who use wheelchairs or scooters

- The wheelchair is part of their personal space. Don't touch, lean on or reach over the chair. Don't ask to put a coat or package on the person's lap.
- Ask if someone wants help. If they say yes, ask for specific instructions.
    - Do not just start helping them. This can create potentially dangerous or uncomfortable situations.

Disability Etiquette

Mobility Device Users

People who use wheelchairs or scooters

- Offer to reach items from high shelves or push out of reach buttons.
- To converse, position yourself to permit eye-contact. Pull up a chair or if standing, back up a few steps.

Mobility Device Users

People who use canes, crutches, walkers or similar devices

- Need their arms to maintain balance. Don’t grab the person’s arm.
- Give them extra space to use their equipment.
- Walk at the pace of the person you are accompanying.
- Make seating available to avoid prolonged standing. Chairs with arms and higher seats are often easier for people to use.
- Do not take their device and position it beyond their reach.

Disability Bias and Trauma

Bias and Oppression is Traumatizing

Traumatic events are those that scare us, make us feel unsafe, fearing that the negative experiences will be repeated. This is sometimes based upon experiences of repeated bias or abuse.

Generational Trauma

Generational trauma occurs when trauma is passed from one generation to the next.

This sometimes happens in the case of inherited disabilities.

Intimate Oppression

Intimate oppression occurs when a loving person, usually a parent, transfers their internalized oppression to a child, other family or community member.

Example:

A mother teaching her disabled daughter that a woman's value lies in her ability to get a husband while sending a message that no man will want to marry her because of her disability.

Internalized Oppression

Internalized oppression is when people come to believe in their own inferiority and often the stereotypes about their identity group(s).

Trauma in Health Care

People with disabilities disproportionately experience medical traumas. This is due to ableism and the fact that people with disabilities have more contact with medical providers.

Can you think of examples of traumatizing experiences of people with disabilities in health care?

Traumatic Experiences in Health Care

Some traumatic experiences include:

- Being refused services
- Not being believed
- Being spoken to in less than respectable ways (patronizing, pitying, scolding)
- Being forcibly restrained
- Being “blamed” for one’s disability or medical condition
- Services being inaccessible

A Few Examples of Trauma Symptoms

- Headaches
- Weight loss (without dieting)
- Flashbacks
- Sleep difficulties
- Anxiety attacks
- Sadness/uncontrollable crying
- Dizziness/difficulty breathing
- Passing out
- Anger management issues
- Desire to physically hurt yourself or others

Trauma Symptom Checklist - 40 (National Center for PTSD)

Trauma-Informed Care

Trauma-informed care shifts the focus from “What’s wrong with you?” to “What happened to you?”

Health care teams need to have a complete picture of a person’s life situation in order to provide trauma-informed care.

Objectives of Trauma Informed Care

Trauma Informed Care Seeks to:

- Realize widespread impact of trauma and understand paths for recovery
- Recognize the signs and symptoms of trauma in patients, families and staff
- Integrate knowledge about trauma into policies, procedures and practices
- Actively avoid re-traumatization

Benefits of Trauma-Informed Care

Many people with trauma have difficulty maintaining healthy, open relationships with a health care provider.

By utilizing a trauma-informed approach, you will:

- Improve patient engagement
- Improve treatment adherence
- Improve health outcomes
- Help reduce unnecessary treatment and excess costs

It also may help reduce staff burnout and reduce turnover.

Principles of Trauma Informed Care

- **Safety:** Throughout the organization, patients and staff feel physically and psychologically safe.
- **Trustworthiness + Transparency:** Decisions are made with transparency and with the goal of building and maintaining trust.
- **Peer Support:** People with shared experiences are integrated into the organization and viewed as integral to service delivery.

Principles of Trauma Informed Care

- **Collaboration:** Power differences between staff and clients and among organizational staff are leveled to support shared decision making.
- **Empowerment:** Patient and staff strengths are recognized, build upon and validated.
- **Humility + Responsiveness:** Biases and stereotypes and historical trauma are recognized and addressed.

Questions and Discussion

- Where have you see examples of disability bias in health care policies and practices?
- Do you see improvement in the elimination of biases?
- Can you cite examples of trauma-informed care in your organization?

Supporting People with Disabilities During the Vaccination Process

Avoid Triggering Environments

- Vaccine sites that are crowded, noisy, unpredictable, and confusing.

Triggering Behaviors

- Using a raised voice (even it is only meant to provide instruction.)
- Expecting people to be able to move and speak quickly.

Perceived Inappropriate Behavior

What to do:

- Approach the person and calmly talk / interact with them
- Ask how you can help
- Brainstorm solutions together
- De-escalate

De-Escalation

Some **de-escalation strategies:**

1. Be Empathic and Nonjudgmental
2. Respect Personal Space
3. Use Non-threatening Nonverbals
4. Keep Your Emotional Brain in Check
5. Set Limits
6. Choose Wisely What You Insist Upon
7. Allow Silence for Reflection
8. Allow Time for Decisions

What to Do to Make the Vaccination Process More Comfortable

You should:

- Ask what the person needs.
- Invite them to the quiet low stimulation area, if needed.
- Invite them to move to the front of the line and explain what will happen next, if this is your practice.

What to Do to Make the Vaccination Process More Comfortable

Create a lower stimulation environment by:

- Asking people to speak in low tones and modeling it.
- Using incandescent lighting, where feasible.

Provide objects that are soothing, such as:

- Fidget devices
- Weighted blankets

What to Do to Make the Vaccination Process More Comfortable

Be flexible:

- Give injection in space outside of designated injection area.
- Permit people to walk or move.
- Walk or move with people if they want.

Do you have examples?

Actions to Avoid During an Incident

Do not call 911!

- Unless the person is threatening to physically hurt themselves or others

Scenarios

Scenario 1

A person in line to receive a vaccine motions for you to come to them.

As you approach, they begin talking faster and louder and becoming angry. They tell you that they cannot stand much longer, they are in pain and that there are no chairs. They say that you are violating the ADA and that if they fall or get hurt, they will sue you! They talk faster and louder, with increasing anger.

What do you do?

Scenario 2

A Deaf person is checking into your site for a vaccination. He pre-registered and requested an ASL interpreter, who is at the appointment.

Two men waiting to register start to complain loudly and rudely that this person is taking up too much time with “all those weird hand motions” and that it is “as bad as those people who don’t speak English.” Other people are visibly uncomfortable.

What do you do?

Inclusivity Suggestions

Involve People with Disabilities

- People with a wide variety of disabilities should be included in all aspects of planning and implementation.
- Without our involvement, there will not be equity.

Involve People with Disabilities

- Create a culture where it easier to include people with disabilities in planning:
  - Plan physical meetings so they are always in accessible spaces and on a bus route if your area has public transit.
  - Create accessible material inviting people to and that is disseminated during and after meetings for people who don’t read print.
  - Ensure sign language interpreters are provided as necessary.

Questions and Comments

Resources

Resources

Local Centers for Independent Living (CIL)

- Summit Independent Living (Summit)
- Living Independently for Today & Tomorrow (LIFTT)
- Montana Independent Living Project (mILp)
- North Central Independent Living Services (NCILS)

CILs Coverage in Montana

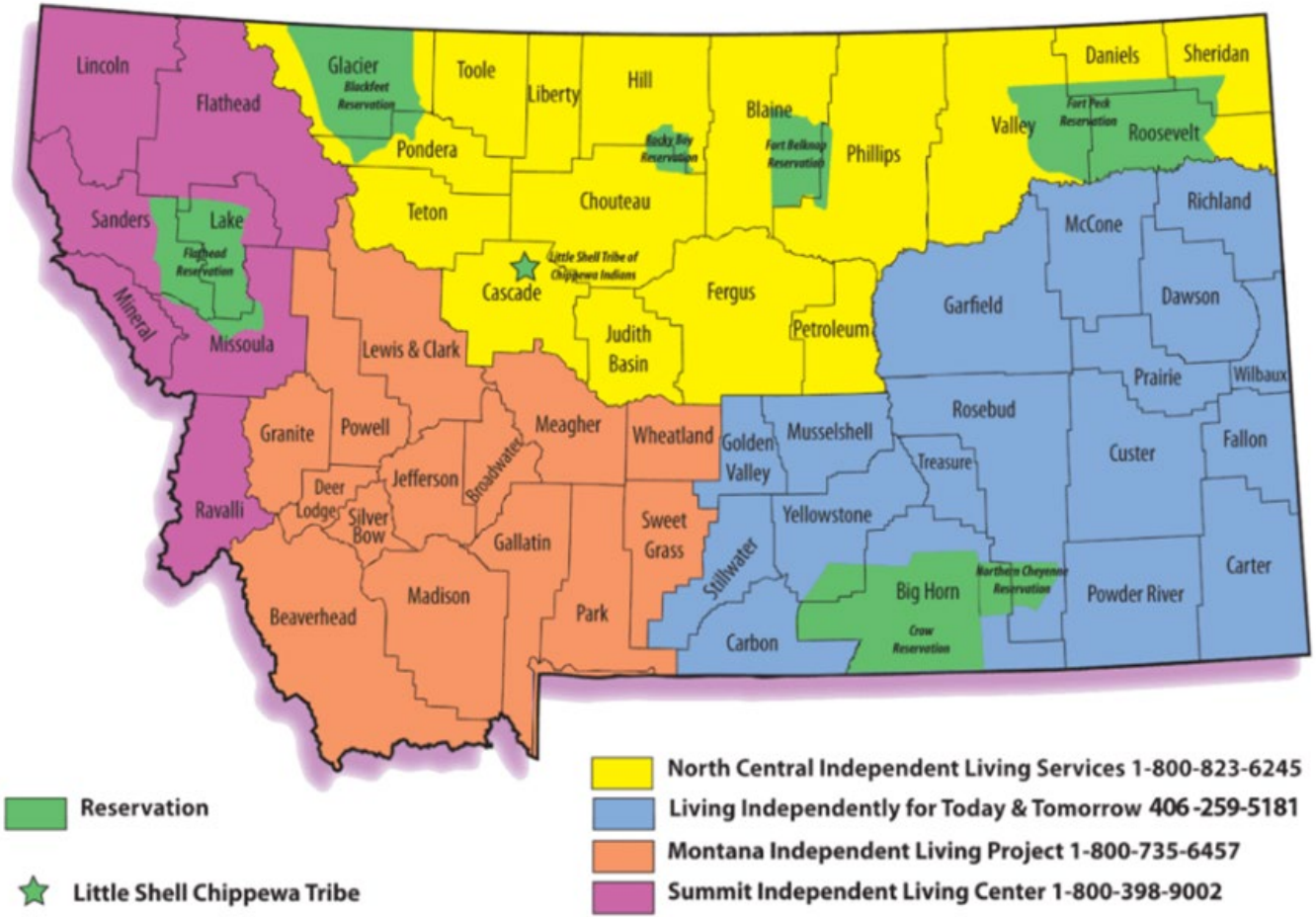

Image courtesy of LIFTT

Resources

Plain Language

- **Self Advocacy Resource and Technical Assistance Center (SARTAC):** COVID-19 Vaccine Information in Plain Language
- **Autistic Self Advocacy Network (ASAN):** COVID-19 Vaccine Fact Sheet in Plain Language
- **Association of University Centers on Disabilities (AUCD):** Tools for Using Plain Language and Easy Read
- **CDC's National Center for Health Marketing:** Plain language thesaurus for health communications

Resources

Montana and Aging and Disability Partners Work Together to Share COVID-19 Information

Peer support

- Montana Peer Network

Vaccines

- **CDC:** Prevaccination Checklist for COVID-19 Vaccines
- **Immunization Action Coalition:** Screening Checklist for Contraindications to Vaccines for Adults

Nursing Continuing Education Credit

Thank you to

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Project ALIVE

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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.

Project ALIVE

Accessible Life-saving Integrated Vaccine Equity

Thank you!

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