



# MVP Project Disability Training<sup>®</sup>

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Disabilities Institute

MDHHS Vaccinations for Underserved Populations Grant #E20224388-00

Community Service

Education

Research

Dissemination



WAYNE STATE  
UNIVERSITY

Recorded April 20, 2022

# Learner Objectives

Participants will be able to:

- Describe the health disparities people with disabilities experience
- Identify 2 strategies to successfully communicate and engage people with disabilities
- Define person first & identify first language
- Understand and use plain language
- Identify 2 issues people with disabilities experience that may complicate their ability to follow through on medical recommendations

# Poll:

Please answer this question:

Are you a

Family member to individual with a disability

Person with a disability

Caregiver

Friend

None of the above

# Michigan Developmental Disabilities Institute (MI-DDI)

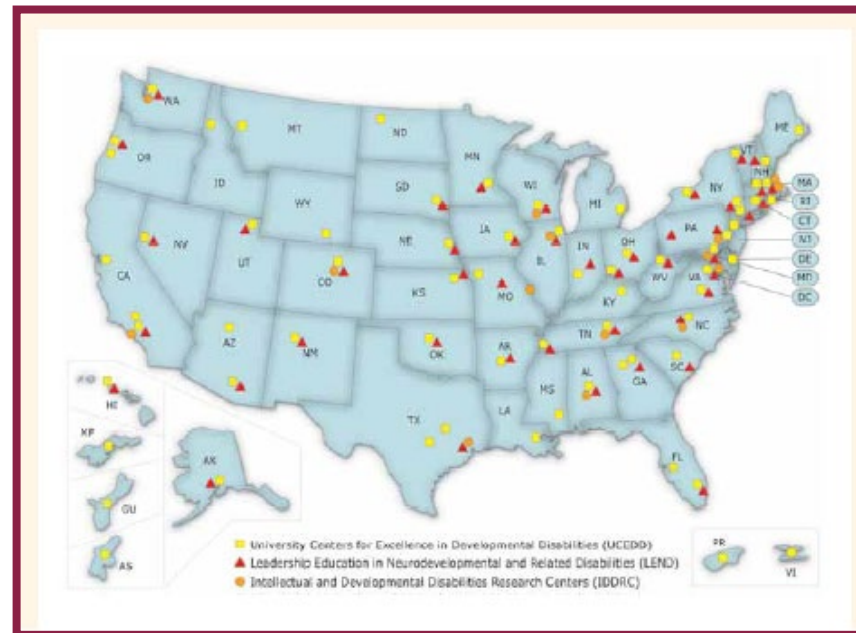
Michigan's University Center of Excellence on Developmental Disabilities (UCEDD)



# Michigan Developmental Disabilities Institute (MI-DDI)

National network of 67 UCEDDs all working to achieve a shared vision:


*all people – including individuals with disabilities – participate fully in their communities*



# Michigan Leadership Education in Neurodevelopmental & Related Disabilities (MI-LEND)

- Interdisciplinary graduate-level training
- National network of 60 LEND programs
- **Mission:** Prepare future health professionals to address the needs of families of children with autism and other neurodevelopmental disabilities



 Health Resources & Services Administration

 **HRSA**  
Maternal & Child Health



# Michigan Vaccination Partners (MVP)



- MI-DDI, AAOM, BIAMI & DRM received funding from MDHHS (COVID-19 Vaccination Supplement 4) to improve equity and access to vaccinations for people disproportionately impacted by COVID-19.



- Our organizations joined together to form Michigan Vaccination Partners (MVP) to optimize the impact of our collective funding.



# Michigan Vaccination Partners (MVP)

## **We partner because people with disabilities experience health disparities**

- People with disabilities have been disproportionately impacted by COVID-19
- People with disabilities experienced poorer health prior to the pandemic
- Lack of COVID-19 data for people with disabilities



# Michigan Vaccination Partners (MVP)

## ***Our Vision: Healthy Communities for All***

- Create a consistent vaccination and health clinic experience
  - MVP Disability Training
  - Guidelines for accessible, sensory-friendly, and scent-free environments
  - Identify and address accommodation needs of event participants
  - Collect and report disability-related data

# Prevalence of Disability

## Disability in the United States



**1 in 4** adults in the United States has a disability

### What is a disability?

*A disability occurs when a person's body, mind and/or emotional functions intersect with a physical or social environment that results in a limitation in activities or restrictions in full participation for the person*

### Of U.S. adults:



People with disabilities are a diverse group of individuals with a wide-range of health care and support needs

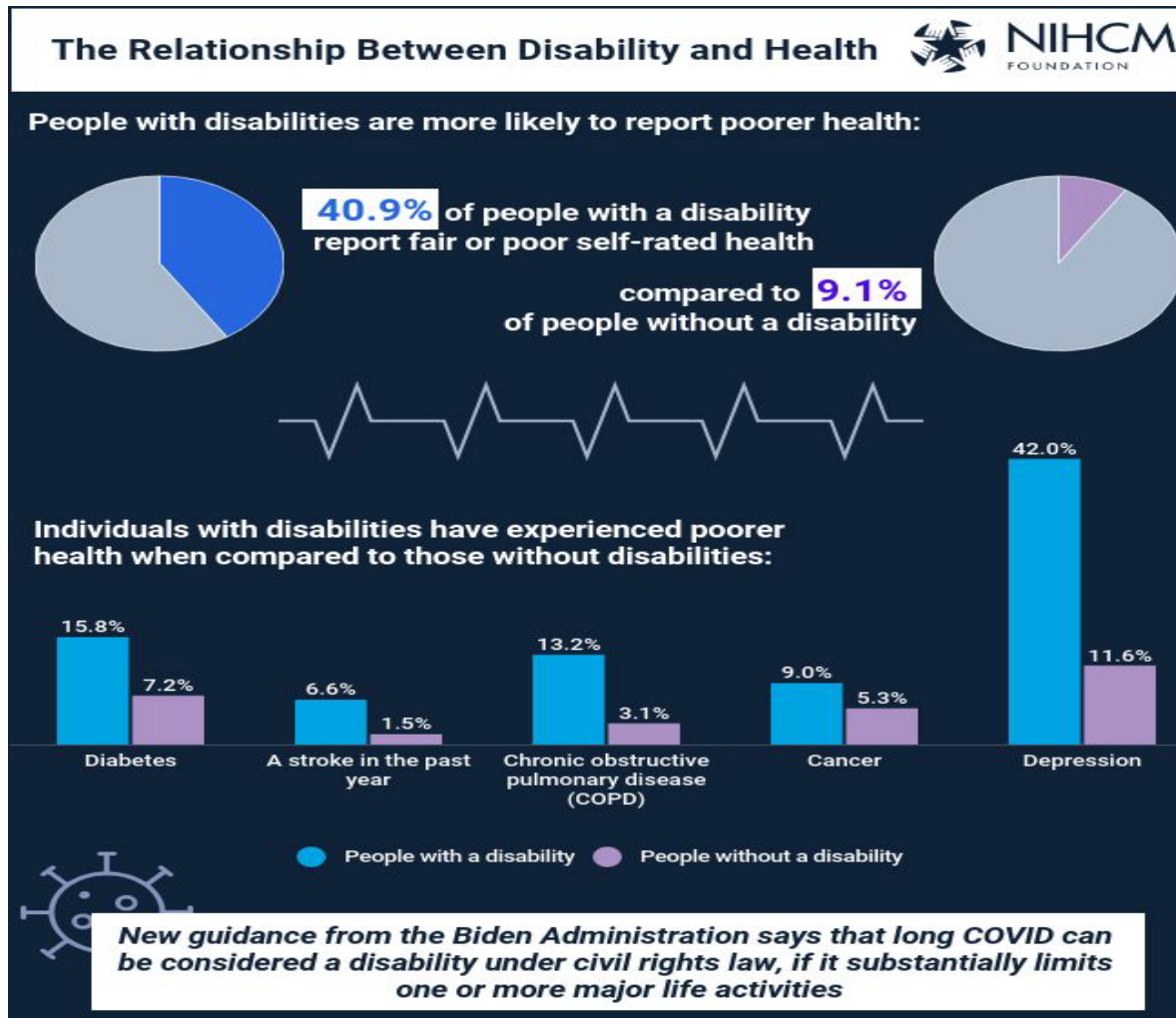


Michigan Developmental  
Disabilities Institute



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# Disability and Health



# Disability and Health Care Access

## Health Care Access Challenges



People with disabilities have less access to adequate health care due to factors such as:

**Costs** **26.7%** of people with a disability could not see a doctor due to cost in the past 12 months compared to **10.1%** of people without a disability

### Health care provider stereotypes about disabilities

**82.4%** of U.S. physicians reported that people with significant disability have worse quality of life than nondisabled people

Only **56.5%** strongly agreed that they welcomed patients with disability into their practices

### Lack of appropriate provider training



Only **40.7%** of physicians were very confident about their ability to provide the same quality of care to patients with a disability

### Lack of accessible medical facilities and equipment



Exam tables and chairs may not be adjustable



Scales may fail to accommodate wheelchairs or require a step up



People with visual disabilities or intellectual/developmental disabilities may not be able to access patient portals

### Communication barriers




Care after a medical visit may be hindered by materials that are not available in plain language or braille

Lack of accommodations, such as sign language interpreters



# Disability and COVID-19

## COVID-19 Disproportionately Impacted People with Disabilities



### Risk of poor outcomes from COVID-19:

*Individuals with intellectual and developmental disabilities are at a higher risk of dying from COVID-19 than those without such disabilities*

**6x**

Those with intellectual disabilities were 6x more likely to die from COVID-19 than other members of the population




**Psychological Distress**

Activity restrictions can induce mental health stress - especially among those on the autism spectrum

### Reduced access to routine health care and rehabilitation:

#### Telehealth

For some, telehealth provided opportunities to access care, for others, it posed additional challenges:

-  Blind/low vision: screen reader tools were not necessarily compatible
-  Cognitive disabilities: tools may be difficult to navigate
-  Deaf/hard of hearing: ASL interpreters or closed captioning unavailable

#### Caregivers

Individuals have experienced disrupted access to caregivers

Lack of resources available to support family caregivers

#### Interventions



Many interventions, including mental health & school-based, were not implemented due to reduced in-person work

### Adverse social impacts:

#### Unemployment

During the first months of the pandemic, nearly **one million** U.S. workers with disabilities had lost their jobs, impacting:


1 in 5 workers with a disability compared to 1 in 7 workers in the general population

#### Unmet Needs

For some, the pandemic impacted transportation options and reduced access to medications, food and other basic necessities

Home & community-based service providers did not receive the level of federal pandemic assistance made available to other providers, and at least half of states saw permanent closure of HCBS providers



# Developmental Disabilities ACT of 2000

Federal Definition of Disability:

Developmental Disability Assistance and Bill of Rights Act of 2000 Public Law No 106-402, defines Developmental and Intellectual Disabilities

# DD Act of 2000 Continued

- Is attributable to a mental or physical impairment or combination of mental and physical impairments
- Is manifested before the person is 22
- Is likely to continue indefinitely
- Results in substantial functional limitation in three or more of the areas of major life activity



# Substantial Functional Limitations

## Must meet 3/7 for Medicaid Eligibility

1. Self-Care (eating, dressing)
2. Receptive and expressive language (understanding communication & being able to communicate)
3. Learning (learning new things & being able to apply experiences to new situations)
4. Mobility (fine and gross motor skills)
5. Self-direction (ability to make decisions, protecting one's self-interest)
6. Capacity for independent living-self determination
7. Economic self-sufficiency (getting and keeping a job)



# Early Disability History: Medical Model

- Institutionalization
- Ugly Laws
- Eugenics

City of Chicago, 1881, Updated 1911

“Any person who is diseased, maimed, mutilated, or in any way deformed, so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, ... or public places in this city, shall not therein or thereon expose himself to public view...”



# History of Michigan's Sterilization Laws

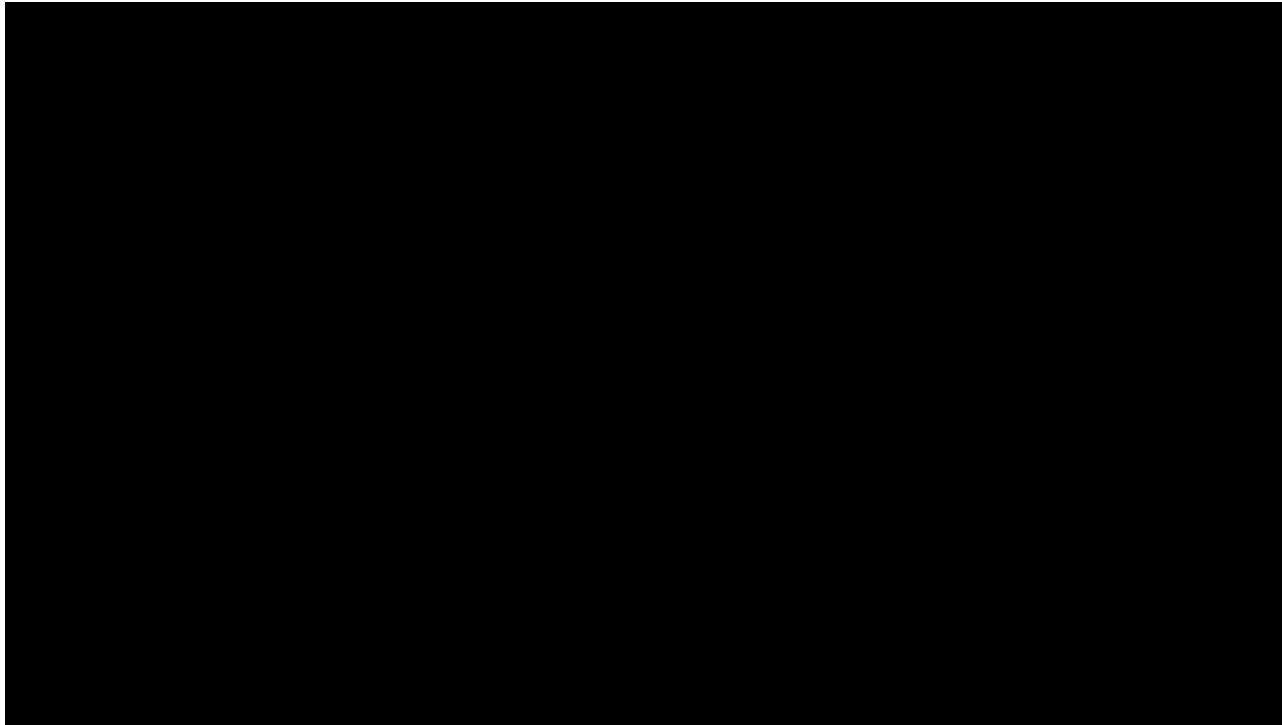
- 1897 - first state to propose eugenics legislation
- 1913 - adopted a forced sterilization policy
  - Primarily directed at the mentally defective and insane
- 1923 - expanded to include “idiots, imbeciles, and feebleminded but not the insane
- 1929 - expanded to include the “insane and epileptic persons and moral degenerates”

# Medical vs Social Model of Disability

- Medical Model:
  - The disability is part of YOU, and the solution to the disability is to fix YOU
- Social Model:
  - This disability is a function of SOCIETY, and the environment must be adapted to accommodate the individual with a disability
  - Values and Norms must change

# Engaging Individuals with Autism

Four-minute video from the Autism Alliance of Michigan



# Communication & Engagement

- In the community people with I/DD may have Direct Support Professionals (DSP), family members, or friends that go with them to events:
  - Ask who is supporting the individual
  - Introduce yourself to everyone BUT
  - When talking, address the individual with a disability directly
  - Ask if they use assistive technology



# Communication: It Takes Time

- Introduce yourself
- Identify your title
- Describe your role
- Ask how the individual wants to be addressed (full name, Ms., Mr., etc.)
- Brief explanation of what they should expect at this appointment, visit, or event



# Communication

- Discuss follow up treatments if needed
- Give the caregiver time to ask questions
- Give the individual time to ask questions
- Give RESOURCES
- Share contact information for follow up questions





# What is Person-First Language?

- Person-first language is a way of speaking, writing and referring to people with disabilities that focuses on the individual and not the disability.
- It emphasizes the person first and their disability second, if at all.





# Examples of Person-First Language

Yes	No
<ul style="list-style-type: none"><li>• People with disabilities</li><li>• Children with developmental disabilities</li><li>• Paul has autism</li><li>• Sally has Down syndrome</li></ul> 	<ul style="list-style-type: none"><li>• Handicapped</li><li>• Crippled</li><li>• Wheelchair bound</li><li>• Mentally challenged</li><li>• Special Needs</li></ul> 

# Identity-First Language

- Individuals may have a strong preference for **identity-first language** over person-first language
- Listen to how they refer to themselves and follow their example
- Identity-first language focuses on the disability as an **identity**, embracing and emphasizing it as a positive characteristic
  - Autistic person, for example
- Other examples include:
  - “I am a disabled person.”
  - “I am an Autistic person.”



# Barb: What she wants you to know

- Introduction
- Barb will share her challenges accessing health care services
- What Barb wants you to learn and share
- Discussion Questions: What can you apply to practice?
  
- About Barb:
  - Graduate of Saginaw Valley State University
  - Master Degree in Public Policy
  - MI-UCP employed 9 years, works as a public policy specialist
  - Successful reduction in guardianship applications

# Barb: What she wants you to know

- Don't make assumptions about people
- Barb's Hospital Experience
  - Nurses assumed she needed a guardian
  - Presumed she needed nursing care at a facility
  - Didn't think she should live independently
- Everyone needs some support
  - What do you do when you need help?
- Just because we need some help doesn't mean we can't live our best life.
- Presume Competence!

# Meet Julia and Oscar Hernandez

- Introduction
- Julia will share what her challenges have been as a parent to a young man with I/DD as they navigate the health care system.
- What are the lessons learned? Discussion
- How can you apply them to practice?
- Hispanic/Latino cultural considerations



# Julia: What she wants you to know

- Introduction
- Julia will share what her challenges have been as a parent to a young man with I/DD as they navigate the health care system



# Julia wants you to know:

- Pregnancy
- Oscar's Medical History
  - Toxoplasmosis
  - Hydrocephalus
  - Microcephalic
  - Blindness
  - CP
- Challenges
  - Language
  - Cultural beliefs
  - Absent father
  - Vaccinations and medical test
- Lessons learned in the advocacy field
  - Families
  - Hospitals and Clinics
  - Social Media
- Conclusion

# Honoring Culture

- Use translators.
- Don't use the children, family, or friends without prior permission.
- Identify the contact person in the family.

Recognize alternative treatments & their value to families.

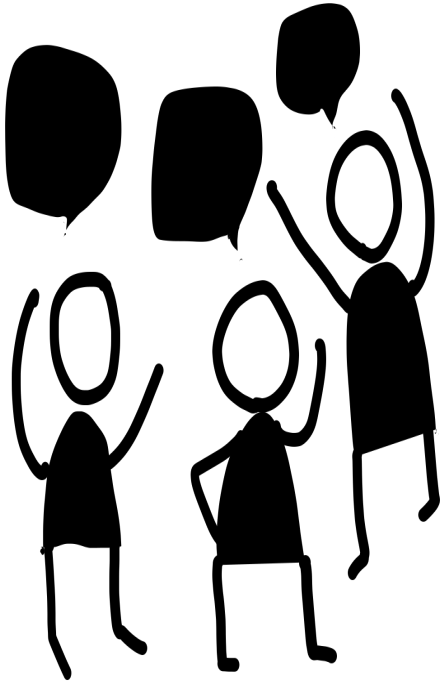


# Communication Techniques

- Always assume people understand at least part of what you are saying.
- If you know you talk fast...slow down.
- Meeting new people in new environments can be upsetting and affect an individual's ability to communicate.












# Communication Techniques



- People may gesture or point to objects or take you to what they want.
- Take time to let them communicate.
- It is very frustrating to not be understood.
- People get labeled as “behavior problems” when in reality they are simply frustrated.

# Communication Techniques: Social Stories

**Getting the COVID-19 Vaccine  
Pt. 2**

 <p>I may need to wait to make sure I am safe and healthy to go home.</p>	 <p>After the nurse tells me it's OK, I am done for today. Now I can go home.</p>	 <p>I need 2 COVID-19 vaccine shots to stay healthy.</p>
 <p>I will come back in 3-4 weeks to get the second shot.</p>	 <p>When I come back, I will go through the same steps to get my second shot.</p>	 <p>After the shots, my arm may be sore. I may have a headache or feel tired.</p>
 <p>I will feel fine after a couple of days.</p>	 <p>I will still need to wear a mask for awhile.</p>	 <p>I did my part to stay safe and keep others healthy!</p>

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CENTRE FOR EQUITY FOR PEOPLE WITH DISABILITIES

# Plain Language

- Makes information more accessible for everyone
- Uses clear, straightforward communication.
- Only uses necessary words.
- Explains ideas and concepts in detail.
- Images or pictures can help understanding.



# Plain Language

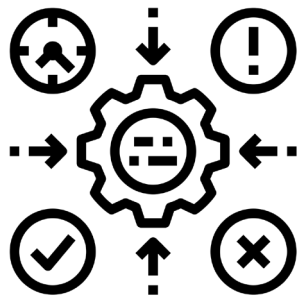
- Use Active Voice
  - Avoid past tense
  - Put the subject first in the sentence
- Other Considerations
  - Eight-word sentences
  - Use bulleted lists
  - Have a person with a disability review your work

Plain language Resources:

<https://www.plainlanguage.gov/>

# Communication Summary

Assess



Address



Success



# Activity: Assess, Address for Success

- The following examples describe possible encounters you may have with a person with in an intellectual and/or developmental disability in a health care setting. Consider what you have learned from the training about effective communication techniques. Identify at least 3 techniques that you may use to improve the outcome of your meeting.

# Activity: Assess, Address for Success

- A young man in a wheelchair approaches you for his temperature check. He appears to be alone. He has his paperwork completed and his signature is on the form.
- **Question(s):**
- Introduce yourself:
  - What questions will you ask him?



# Activity: Assess, Address for Success

- A young lady is waiting for her vaccination. She is with another person, who appears to be helping her. The young lady looks anxious and is rocking in her seat. The person with her is calmly talking to her and periodically takes her for short walks. She has an iPad with her that is playing music. You call her name and they both approach you.

## Question(s):

- What can you do to help make this a successful interaction for this young lady?

# Activity: Assess, Address for Success

- There are several adults with disabilities at an event. They have Direct Support Professionals assisting them. A few of the people have walkers and wheelchairs. It appears they came together to the event.

## Question(s):

- What can you do to ensure each individual's privacy?
- What can you do if a room or venue is not completely accessible?
- Will you introduce yourself to the group? Or will you individually introduce yourself? Or both?

# Urban Issues: Poverty and Disability

- Direct correlation between poverty and disability:
  - Family income, assets and educational attainment have a direct impact on a child's development.
- 30.6% of Detroit's families live below the federal poverty level.
- 19% of Michigan's children live in families with incomes below the federal poverty level.
- 13.7% of Michigan's children experience food insecurity.

# Poverty and Disability

## Definition of Federal Poverty level:

- In 2019, a family of two adults and two children fell in the “poverty” category if their annual income was below \$25,962.
- In Detroit 71,000 families and 45% of children –17 and younger live in poverty.
- Nationally 17% of families live in poverty (12 M).

- ❖ The Annie E. Casey Foundation Children in Poverty Kids Count Data Center
- ❖ APSE-Assistant Secretary for Planning and Evaluation



# Parent with Disabilities

- 4.1 million, or 6.2%, of parents in the United States have a disability, parenting children under the age of 18.

Source: <http://achancetoparent.net>



# A Special Thank You to AAoM



## AutismAlliance of Michigan

# Resources

- NADSP COVID-19 Vaccine Frequently Asked Questions (scroll to bottom)
  - [NADSP Statement on Vaccine Hesitancy and FAQ](#)
- NADSP Vaccine Hesitancy PSAs
  - [NADSP COVID-19 Vaccine Hesitancy PSAs](#)
- Association of University Centers on Disabilities
  - [Get Vaccinated - Let's Do What We Have to Do](#)
- Autism Alliance of Michigan
  - [COVID-19 Vaccination Considerations for Individuals with Autism](#)
- Centers for Disease Control & Prevention
  - [COVID-19 Materials for People with Intellectual and Developmental Disabilities and Care Providers](#)
- Michigan Developmental Disabilities Institute
  - [COVID-19 Resources](#)
- National Women's Law Center
  - [Forced Sterilization of Disabled People in the United States](#)

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# Thank you!

Thank you for viewing this MVP Project training resource. If you have questions or would like to contact the speaker, please send an email to:

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Or visit the MVP Project webpage at:

<https://ddi.wayne.edu/middi-mvp>