- Welcome, everybody.

Thanks so much for joining us

for the Partnership for  
Inclusive Disaster Strategies,

Recognizing, Interrupting and  
Deconstructing Disability Bias

in Emergency Management.

My name is Priya Penner,

and I'm with the partnership.

I use she/her pronouns,

and I'm a young brown woman  
with long, curly black hair.

Today, I'm wearing a  
multicolored gray cardigan

as well as a black shirt.

On the screen, you have a title  
slide with text that reads,

Recognizing, Interrupting and  
Deconstructing Disability Bias

in Emergency Management.

Below the title is our website,

www.disasterstrategies.org.

Above this text is the  
partnership's header logo,

which is a sun with four images within it.

In the text,

the Partnership for  
Inclusive Disaster Strategies

to the right of the logo.

The four images within  
the sun are a hurricane,

a thunderstorm cloud  
with a lightning bolt,

a house with a split down  
the middle and a tornado.

So I'm gonna go ahead and get started

with a few accessibility and  
technical support reminders,

and then we'll get started.

Most folks are already  
familiar with the accessibility

that we use for our presentations,

but just for folks who are joining us,

I do wanna remind us all  
that the training is recorded

and an archive of today's  
conversation will be available

in the coming weeks.

In addition to the recording,

you'll also receive an  
accessible slide deck

of the presentation used today.

So do be on the lookout

for these items in your  
email in the coming weeks.

We also have AI captions  
available through Otter.ai.

You can access the captions  
via the Show Captions CC button

on the bottom of the navigation  
bar and the Zoom screen.

Click the CC button once  
to show subtitles in Zoom.

You can edit the font size

and the text color via the  
Subtitle Settings button,

which is accessed via the small  
caret within the CC button.

A screenshot is on screen

that shows the Zoom Navigation bar

that sits on the bottom of our screens

with the Show Captions  
button outlined in red.

We also have

American Sign Language  
interpretation provided today.

And our ASL interpreters  
are Jessica Tenovo

and Desiree Carolyn.

Though already spotlighted for us all,

if you're not able to  
see the interpreters,

please do let us know in chat,

or you can let us know via email at Priya

P-R-I-Y-A @disasterstrategies.org.

To adjust the size of the slides

and the speakers and the interpreters,

you can drag the divider,  
which is highlighted,

outlined in red in the  
screenshot on the screen,

and you can drag that divider to the right

or left to adjust the size of speakers

and the screen.

Again, if you cannot access  
the ASL interpreters,

please do let us know as soon as possible.

To ask or respond to questions,

please either, you know,  
you can raise your hand

and use the Raise Your Hand button

at the bottom of your Zoom screen.

You can also type in chat,

or you can simply unmute yourself

and jump into the conversation  
at appropriate times.

Do raise your hand

or type in chat if you have any need

for technical assistance

or to let us know if an issue arises.

For example, please do let us know

if we're speaking too quickly

or if you have a question.

Again, if chat's not accessible to you,

please do email your questions

to Priay@disasterstrategies.org.

And then, finally, some friendly reminders

for this presentation.

Please do identify  
yourself before speaking.

An example of this would be,

this is Priya, and I have this comment.

Please don't talk over others

and keep yourself on  
mute when not talking.

This is especially helpful

for folks accessing the captioning

or the ASL interpreters to  
follow the conversation.

If you're having trouble  
with your Mute button,

we will help you mute yourself.

But please, feel free to unmute

and jump into the  
conversation at any point.

And then finally, please do  
define any acronyms you may use

just so that we're all on the same page.

And with that, I'm gonna  
turn it over to you, Melissa.

- Thank you Priya.

Welcome, everyone.

I'm Melissa Marshall,

and I'm the director  
of Policy and Planning

for the Partnership for  
Inclusive Disaster Strategies.

I'm an older gray-haired woman  
with shoulder length hair,

and today I'm a white woman.

I use she/her pronouns.

I use she/her pronouns,

and I am sorry, distracted so  
that I use she/her pronouns.

And today, I am wearing a  
multicolored pink and green

and yellow and purple cardigan.

And I have glasses.

I wanna welcome you all here today.

Next, please.

- This is Priya.

As we're moving to our next slide,

Melissa, I just wanted to let you know

your camera is not on.

- So sorry about that.

I have a list of things I have to do.

So no one could see my

multicolored sweater  
and my gray hair, okay.

And paintings in the background.

But, thank you, Priya.

So the Partnership for  
Inclusive Disaster Strategies is

the only US disability led organization

with a focus mission on equity for people

with disabilities and people with access

and functional needs throughout  
all planning programs,

services and procedures, before, during,

and after disasters and emergencies.

We are your disability and disaster hub.

And we're reviewing this for  
people who are watching this,

for people who participate  
in other presentations.

You've heard some of this before,

but we're saying it again for new people

who join us and as a refresher.

Next, please.

Again, there's ground rules.

Please maintain confidentiality.

Don't talk about specific situations

or name specific names,

but feel free to talk about  
general kinds of situations.

And anything that happens  
here, you know, stays here,

knowing that this is  
recorded for your audiences.

Ask questions.

Be the brave person to say,

"I don't understand," to  
say, "Please slow down,"

which isn't a question, it's a request,

but please feel free to do that.

"I don't get it."

"Is this right?"

"Am I wrong?"

Be that person. Ask that question.

And the third most important ground rule

that some of you are  
familiar with is to have fun.

And to facilitate y'all having fun,

I have with me a bag of  
virtual fabulous prizes.

So one could leave here with  
a new virtual fabulous car,

fabulous prize car or something else.

So just think about that.

And fabulous prizes aren't awarded

for giving the correct answer.

They're awarded for giving an answer,

or for just speaking out at all.

Just keep that in mind. Next.

So why this training,  
you might be wondering?

Recognizing and  
interrupting disability bias

and ableism as it occurs

throughout disasters can save lives.

This is literally lifesaving.

And it can protect the  
freedom of disabled people.

So it's not just mushy.

We're gonna learn about ableism.

We're gonna learn how to save

disabled people's lives

or expand your knowledge

about how to save disabled  
people's lives, I should say.

And we all have the power  
to help change outcomes

through people with  
disabilities and disasters.

And a lot of that is by interrupting

disability bias and ableism  
and for us, recognizing it,

'cause we can't interrupt  
it unless we recognize it.

Next.

And this training will draw upon

information gathered from Hurricane Ian

and will also assist

Hurricane Ian survivors with unmet needs.

Next, please.

We're gonna review key  
terms and principles.

And when Priya did the  
intersectionality training last week,

she went over many of them.

We're expanding on some  
of those a little bit

and talking less about others of those.

But this is as a review

and to make sure you've  
got the knowledge in depth,

because a lot of our material,

we call it multiple exposure material.

You kind of need to see  
and hear it a couple times.

And I know a couple of  
you who are on the call

and might not have had a chance to listen

through the recording yet.

So next, we'll look at  
key terms and principles.

First, key term, bias.

Everybody know what bias is?

Some hands raised.

I'm not gonna call on you, don't worry.

Priya, I can't see.

Can you see the...

- This is Priya.

I'm not seeing any virtual hands raised.

And that is, I see some  
reactions from Dimitra

and other folks also  
sharing their reactions.

So I think some folks are, wonderful.

I see some folks under have  
an understanding of bias.

Yes.

- And you have the answer  
for you on the screen.

Bias is prejudice in favor  
or against one thing,

person or group compared with another,

usually in a way to be considered unfair.

People pretty much know what bias is

in day-to-day conversation.

Be against a person.

I could have bias about an idea.

I could have bias against a thought.

I could have bias against a group,

I could have bias against, you know,

a set of ideas and those kinds of things.

Now, implicit bias, not  
everybody knows necessarily.

And implicit bias is

when we have attitudes toward people

or associates stereotypes

with them without our conscious knowledge.

So I know I have bias

towards people like  
pineapple on their pizza.

I have bias towards pineapple pizza.

It's not really towards the people.

It's towards pineapple pizza.

Let's just say that.

But, I might have other biases

that I don't know that I have.

I probably have other biases.

They're called implicit biases,

that I know that I don't have.

We all have implicit or unconscious bias.

That doesn't mean we're bad people.

that doesn't mean we're  
ableist people, necessarily.

It means we've learned from our culture.

And our job is to learn

about those biases and to recognize them.

Next, please.

Next term is prejudice.

Prejudice is a preconceived  
judgment or opinion,

an adverse opinion, leaning  
without just grounds

or before sufficient knowledge

and a rational attitude

of hostility directed  
against an individual,

group, race or their  
supposed characteristic.

So it's rooted in stereotype.

It's rooted in beliefs without grounds,

and that's what prejudice is.

And let me know

if you have any questions

at any point during all this, by the way.

There'll be prizes for questions.

Yes, please.

Next, please.

Now, ableism and Priya talked  
to you about this before.

We've talked about this before.

Ableism from the dictionary  
is a noun, ableism,

and it's discrimination

or prejudice against  
individuals with disabilities.

That's what Merriam-Webster  
says in the dictionary.

But ableism is so much more than that.

And that's the dictionary definition,

And it's correct-ish, it's true-ish.

It's not wrong,

but there's just a lot  
more to it than that.

So, with that, we're gonna  
go to the next slide.

And we're gonna have a  
definition based on this person,

Melissa Marshall.

And it's pretty much not

that different than it was

when we first started defining  
it many, many decades ago.

I've always defined ableism as  
oppression based on physical,

mental, intellectual, cognitive, sensory,

or other ability or perceived ability.

And I've added to that  
definition in recent years.

It's the belief that  
not having disability is

superior to having a disability.

And also the belief that  
non-disabled people are superior

to disabled people.

Next, please.

And again, some of this  
is review from last week.

And again, let me know

if this doesn't make sense or if it does.

- Melissa?

- Yes?

- Can I ask a question?

- Of course.

- In the previous slide.

- Yes, please.

- Could we also add that ableism is,

and I think I just lost my thought.

Can we go back to the last slide?

- Sure. Priya.

- That one disability may  
be superior to another.

- Ding, ding, ding, ding, ding.

You're getting a fabulous prize.

You are getting silver and  
gold, helium filled balloons.

They're small.

It's a very small tiny bouquet,

but that's what you're getting  
is your fabulous prize.

So enjoy this.

Yes, yes. And we're gonna get to that.

There's hierarchies within disability

and we're gonna get to  
them like five minutes.

So you get ahead, you get  
the great fabulous prize.

- Okay, great. And thank you.

- Awesome.

Okay, so now we are at oppression.

And one second.

So oppression is a  
combination of prejudice

and institutional power that creates

a system that regularly

and severely discriminates

against some groups and benefits others.

So what is oppression?

It's prejudice,

but it's not just prejudice.

It's prejudice with institutional power.

So prejudice plus institutional  
power equals oppression.

So you can't oppress  
unless you have power.

And you're not gonna oppress

if you don't have the prejudice.

Those two things are necessary.

It's a two part thing.

Next, please.

And you might be wondering,

what is institutional power?

And according a Vanderbilt University,

"Institutional power is

the ability or official  
authority to decide

what is best for others."

I'm gonna decide what's best  
for you as an institution.

The ability to decide  
who will have resources.

I'm gonna give you benefits.

I'm not gonna give you benefits.

The capacity to exercise  
control over others.

I'm gonna decide if you go  
to a psychiatric institution

or maybe you go to a nursing facility,

I'm gonna decide if  
that, that kind of power.

So that's what institutional power is.

I am writing the rules.

I'm gonna decide that this Medicaid waiver

where you can go directly

from your home to a nursing facility

without going to a hospital first.

It's the power.

That's the institutional power.

It's not one person.

It's a group of people.

It's a group of people with a history,

sometimes a generational  
history that have that power.

Next, please.

Now ableism, as we were  
talking about before,

presents its ways in many ways  
that isn't always obvious.

Ableism can manifested by  
representation or perspective.

So sometimes ableism isn't that it put

a bad image of someone with a disability.

They might have put a stereotypical image

of somebody with a disability on a page.

But that's not the bigger problem.

The bigger problem tends to be

that there's no image of a person

with a disability on a page.

It's an absence of  
disability representation

or disability perspective.

Everybody knows that nobody  
needs things interpreted,

because everyone can hear.

It's the presumption of hearing,

the presumption of vision,

presumption of those kinds of things.

The presumption of  
tolerance of stimulation,

not incorporating perspective

of people with disabilities  
can lead towards our ableism.

So again, we have disability prejudice

plus institutional power,  
and that equals ableism.

Next, please.

I'm gonna give you a  
couple forms of ableism.

The first one, is sanism.

And sanism is defined as oppression

and bigotry that relates  
to a neurological trait

or variance a person has or is judged by

on a societal or an individual level.

Lots of people with labels  
of psychiatric disabilities,

labels of mental illness,

and some neurodivergent  
people look at sanism

as specific kind of ableism.

Then there's audism, A-U-D-I-S-M,

which is the notion that  
one is superior based on

one's ability to hear or  
behave in the same manner

as one who hears.

You're signing. Don't you speak English?

What's wrong with you?

When you write, it looks funny.

It doesn't look like English.

That's because it's ASL.

That's an example of audism.

Next, please.

Now, questions for you.

What are some examples of ableism

you've experienced or witnessed?

Bonus points if you've seen or experienced

or witnessed ableism  
in a disaster context.

Double bonus points, if  
you saw or experienced

examples of ableism during Hurricane Ian.

Go for it.

And I'm not having lots of visibility,

Priya, for some reason.

So if you could just let me  
know if there're hands raised.

- This is Priya.

Of course, always.

I think folks are still  
thinking of some examples.

I think I can speak to

some of my own examples  
if that is helpful.

And, just a quick example,

certainly when I think  
a good recent example,

and I think, Melissa, you know  
what I'm gonna talk about is

I was trying to buy something off of,

from someone directly  
off of a Facebook group,

and it was just some indoor plants.

And I, you know, live in a  
not very accessible building,

and I needed the person to  
deliver to a specific door,

because I don't have  
access to other doors.

And it's not easy for me  
to meet them on the street.

And they refused to bring the items to me.

Thankfully, I did not pay them yet,

so I did not have to worry  
about getting my money back.

But, they were refused to meet my,

this accommodation need that  
I need as a disabled person.

But then, there was also  
an interesting aspect

of it as well, given that  
they were saying that,

"They did not feel safe  
in my particular area,"

as a quote "single woman."

I think it's also important to note

that they are a white person  
or at least passing as white.

And so, I think this really  
showed the intersectionality

of these interlocking oppressions, right?

So this is an example of ableism,

because she, you know,  
did not work with me

on meeting this accommodation need

and completely refused  
to sell me the item,

and then also felt unsafe  
in this particular area.

And of course, I live in  
the city and it's, you know,

we all know those implications as well.

So that's one example for myself.

- And it wasn't like you're  
asking her to go down

a dark alley or anything.

It was during the day with  
a street view, you know?

- Yes. Of course.

It was just a very interesting situation.

And this happens all the time.

Certainly, you know, folks  
refusing services to people

with disabilities, delivery,  
whatnot, due to perceived

perceptions of, you know,

what that person may or may not do,

because of their disability.

I've heard other stories

where folks with mental health  
disabilities are refused

services, because people  
think that they're violent

and that the person  
delivering the service has

the preconceived notion,  
the ableist notion

that they're gonna be hurt, right?

And so, it's unfortunately all too common.

- And we've been trained  
not to recognize ableism.

"Oh, you're just exaggerating.

Why you saying that?"

Priya and I were talking  
before the training,

"You have no sense of humor.

You have no sense of humor."

And lots of relatives  
over my life told me,

"I had no sense of humor  
around women's issues

and around them making  
fun of my disability.

I just had no sense of humor."

And like, that was a way  
to mask their ableism,

racism or all those other  
intersectional things,

in my case, sexism, that they experienced.

But I think that those things  
we need to start looking for,

just looking for.

We're gonna talk about  
microaggressions again in a minute,

but just looking for the ableism,

looking for the ableism in disasters.

We've talked about some of it.

We've talked about a woman in Fort Myers

who ended up in her  
sleeping in her scooter

for was it 11 days?

It was a long time.

And because there was no bed,

and everyone knew there was no way to get

a motorized bed into a shelter,

except one could call even  
a pharmacy that had them.

But you know, there's all kinds of things

that was entrenched ableism.

So just start looking.

And I'd ask you to  
challenge yourselves from

for the rest of today,  
maybe through tomorrow

or maybe over the  
weekend, look for ableism.

Look for ableism in your  
life and conversation.

Look for ableism in media  
you consume, on social media.

Look for ableism if you watch TV.

Look for ableism in there's  
any media that you listen to.

And sometimes ableism  
isn't just discrimination

against people with disabilities.

It's not having representation  
of people with disabilities.

So look for when we're not here.

And that's really important.

And one of the things I've noticed is

that the maximum demographic appeal ads

where they try to have one of everybody,

when there's a person with  
a disability represented

in an ad, usually for fast food chains,

they're oftentimes a white  
spinal cord injured man

with the least amount of  
intersectionality implicated there.

Next slide, Priya.

Now, this is Michael Hickson.

And if anyone knows about Michael Hickson,

please raise your hands  
and I will be thrilled.

Michael Hickson is, and say his name.

Michael Hickson died on June,

I wanna say ninth on June 11th in 2020.

And Michael Hickson was a man

who had a spinal cord  
injury and a brain injury.

And against his wife's, he lived in Texas.

And against his wife's wishes,

he was forced to go to a nursing facility.

Long story about what Texas does

around conservatorship and guardianship,

and how even someone who's  
a wife doesn't always have

final say when other relatives  
wants something different,

but was forced to go to a nursing facility

against his wife's will.

And he was comatose at the time,

but this is, he was not comatose,  
obviously in this picture.

In the nursing facility,  
Mr. Hickson, guess what,

contracted COVID,

which is still really common  
in nursing facilities.

Was way, way more common then.

They sent him to a hospital,

and the hospital decided

that he was in a persistent  
vegetative state.

And there are things that,

there are interventions they could do

that his wife didn't want them to do,

but she was asking for them  
to do some interventions,

you know, support him, at least feed him.

And the doctor said,

and she taped this on her phone,

Melissa Hickson, he said,  
"He has no quality of life."

As somebody with a disability,  
he had no quality of life.

As someone who had quadriplegia,  
he had no quality of life.

This is a man. You can  
see in this picture.

This is a picture of a  
man in a hospital robe

in a hospital gown in hospital bed,

surrounded by his five teenage children,

and everyone is smiling brightly.

It's really clear that  
Mr. Hickson, A is loved,

and B, can love and does love.

And he is learning how to do word games

and things were changing  
around his brain injury.

Not that that matters at all,

but that was just the fact.

He was put into in hospital hospice

where he died of air  
quotes, "natural causes,"

which often happens when you're deprived

of food and hydration for six days.

So that's the tragic  
story of Michael Hickson.

Like everyone to say his  
name, Michael Hickson.

And notice that he is a black man,

a black man with a disability,

black man with multiple disabilities

who had family advocating  
for him and it didn't matter.

And that is a prime example  
of intersectionality

that Priya talked about yesterday.

So caption above it says,

"Bias and ableism can lead to death,"

because sadly, Mr. Hickson died.

And this photo is credited

to his wife, Melissa Hickson.

Next, please.

Internalized ableism.

"Internalized ableism  
refers to a phenomenon

of disabled people believing  
prejudices about themselves

that become internalized

by living daily in an ableist society."

That's a quote from Ashley Harris Whaley.

Next, please.

We all internalize ableism.

We internalize it against ourselves.

Sometimes we internalize  
it against other people,

which someone put it out earlier.

We're getting closer to that slide.

Internalized oppression and ableism is not

the cause of our mistreatment,

it's the result of our mistreatment.

It would not exist without  
the real external oppression

that forms the social  
climate in which we exist.

Once oppression or ableism  
has been internalized,

little force is needed  
to keep us submissive.

Next slide, please.

We harbor inside ourselves the pain

and the memories, the  
fears and the confusions,

the negative self images,

the low expectations,  
turning 'em into weapons

with which we reinjure ourselves  
every day of our lives.

And those are really powerful statements,

a really powerful statement of what we do

around internalized ableism.

How we take societal ableism,

embrace it, and turn it on ourselves

and turn it on other disabled  
people, not consciously,

not 'cause we're bad people,

but because we live in this society.

We need to learn to recognize it.

Yes, please. Next please, I'm sorry,

Internalized ableism and  
can manifest in many ways.

It can look like not asking  
for that accommodation

or turning down an accommodation,

because it's too expensive.

Or maybe you could just do  
it if you just sucked it up

and did it better and easier.

Masking, and masking is hiding aspects

of your disability is a coin used

mostly in the neurodivergent community,

but lots of other people with  
disabilities do that as well.

I've masked a physical disability.

I've masked a psychiatric disability.

My generalized anxiety disorder,

I've masked all kinds of disabilities.

So it doesn't, just  
beyond neurodivergence.

And believing that you're not disabled

enough to have rights  
or get accommodations.

Do you count as someone with a disability

if your disability is not visual?

We internalize that ableism.

Also, anytime we feel ashamed

or embarrassed about our disabilities,

we're manifesting internalized ableism.

Next, please.

So more ways internalized  
ableism can manifest,

separating or distinguishing  
yourself from people

with your disability

or people with disabilities in general.

I'm not one of them.

And this is what we were  
talking about earlier.

I'm not one of those  
people with disabilities.

They're bad, and I'm good.

I'll prove that I'm more able-bodied,

like, or I'm more able than they are.

Needing to prove yourself

as a someone with a disability,

being the super person with a disability.

And then, again, what we're talking

about earlier is being an agent of ableism

toward people with your own  
or different disabilities.

Being ableist against each  
other in this hierarchies.

Well, I'm not someone  
with a spinal cord injury.

I'm not like one of those  
people with cerebral palsy.

Well, I'm someone with cerebral palsy.

I'm not like someone with  
an intellectual disability.

Well, I'm somebody with an  
intellectual disability,

but, I'm not like those people

with psychiatric disabilities.

All of those things.

We establish hierarchies.

Who's better than others,  
and we oppress each other.

Or, do we really need to do  
this for those blind people?

Or, do you really need  
to do this accommodation

for those people's sensory disabilities?

Or this meeting's about people  
with mobility disabilities.

We don't need a sign language interpreter.

Or, this meeting's about people

with psychiatric disabilities

or mental health conditions,

and we don't need to  
have it be accessible.

These are all real things I've seen

and heard over the course of my lifetime.

None of those are made up.

So that's us being an agent of ableism

towards people with different disabilities

or even our own disabilities.

Does that make sense?

Ciawanda, does that make sense

with what you're talking about before?

Did I miss something?

- No, that's absolutely  
what I was talking about.

You know, you see it often

in the mental health community, you know-

- How so?

- Where, you know, you hear people say,

"Well, at least I'm sane, you know,"

or you know, where you're  
talking about sanism

where "At least I can, you  
know, think for myself.

You know, I don't have  
to worry about taking

that medicine kind of a thing."

So yeah, you see it all the time

in the mental health community.

- At least I still have all my marbles,

whatever that means.

- Yeah, exactly.

- I've seen people with  
physical disabilities say

that I used to, and I've  
said in these trainings

before, I used to run

a consumer-led mental health  
advocacy organization,

which didn't understand  
why we need to meet

in accessible places.

So it goes both ways. It goes both ways.

And the struggle continues. Yes.

Next, please.

Now let's look at individualized  
interpersonal ableism.

Individualized interpersonal ableism.

First to ableism,

targeting an individual that's experienced

on a personal basis.

So when it's about you  
on a personal basis.

Priya experienced interpersonal ableism

or individualized ableism,

because it was about her.

It wasn't any system doing this to her.

It was this one person saying,

"No, I won't bring this  
to the accessible entrance

of your home, even though  
it will take me, you know,

20 seconds.

I won't do that."

That's individualized ableism.

When someone says, "No, you can't come

to this disaster shelter,

because you have a service dog."

That's individualized  
interpersonal ableism.

One-on-one ableism.

Next, we call cross disability ableism.

And again, this reflects  
what we said before,

and it occurs when  
disabled people are agents

of ableism towards other disabilities.

And this happens, especially

because we work in able systems.

We're struggling with our  
own internalized ableism,

and we live in ableist society.

So that's where that comes from.

Next, please.

Now we talked about this

like some of these other things last week,

but I wanna make sure everybody gets it,

because it's a challenging  
concept for some people to get.

And I just wanna go  
into it a little deeper

and a little more just to make sure

you've wrapped your arms around it.

So microaggressions,

according to Dr. Derald Sue,

who's a professor of  
Psychology and Education is

"the everyday slight put down, indignity

or invalidation, unintentionally directed

towards a marginalized group."

Originally this was defined around race,

but it impacts people  
around racism, ableism,

ageism, all of the forms of oppression.

Yes, please.

- I like the definition.

I almost questioned, oh, this is Ciawanda.

I almost question if it  
is unintentional, though.

Sometimes I think it's intentional.

- Well then, if it's intentional,

then it's an intentional act.

If it's, "Oh, I did that  
accidentally on purpose."

No, that's straight out ableism,

but it's when it's unintentional.

And let's take a look at that,

because I don't think you  
heard last week Ciawanda.

Let's go to the next slide.

And we have what I call the  
microaggression equation.

It says microaggression  
plus microaggression plus

microaggression equals  
alienation, frustration,

can contribute to low self-esteem,

supports disability bias,

supports and feeds into ableism,

supports and feeds into  
internalized ableism

and can even potentially lead to death

once there's enough microaggressions.

And what I say to people is people say,

"Oh, that was just one little thing.

It didn't matter."

And it's like, but it  
might be the 50000th time

that person has heard that  
expression of that thing.

Let's go to the next slide.

We'll play with it a little more.

- This is Priya.

I also just want to, you know,

really speak to your comment directly,

Ciawanda around, you know,

whether it's indirect or direct, right?

Microaggressions, you know, we often say,

and that definition does say  
right, that it is indirect,

potentially not intended,

and that therefore it is  
not necessarily ableism

or racism or whatever, right?

I first wanna say right,  
that it is, right,

even if it's a microaggression,

it's still rooted in ableism.

It's still rooted in racism.

It's still a form of that  
interpersonal oppression

and ableism, right?

And so want to acknowledge that

and also say that it,

I think for the terms of the  
purposes of our conversation,

we're saying unintended  
because we're focusing

on, you know, the implications, right?

There's certainly room

for intention within microaggression,

but for today's conversation,

I think we're focusing on unintended,

because we're sort of  
using it to delineate

how it's slightly different  
than interpersonal ableism.

So not saying that it can't be,

but that for our purposes,  
that for today that

we're sort of trying to  
make this delineated.

- And microaggressions,

I believe are instances of ableism.

There's a subset of ableism.

So it's not that it's not ableist.

- Right.

- Okay, so let's look at  
these examples a little bit.

So some microaggressions  
could be pulling back slightly

when a mental health  
condition is disclosed

at a disaster recovery center.

That person says they have  
bipolar and someone pulls back,

or they have or they have schizophrenia

and the person just pulls back slightly.

They don't even know  
they pulls back slightly,

but they have ableism that is internalized

about that disability.

It's about fear.

It's about we're afraid

for some reason of people's  
psychiatric disabilities

and mental health  
conditions in our society.

Pulling back.

Next one is touching someone's  
durable medical equipment

or assistive technology  
without their permission

at emergency shelter.

"I'm just gonna take  
your," you're in your bed.

"I'm just gonna take your  
chair and move it over here."

No, no, no, no.

First of all,

you don't take someone's  
equipment away, ever.

"I'm just gonna put my  
arm around your chair."

Not unless you put your arm,

or "I'm just gonna put my  
feet on your footrest."

Not unless you have the  
relationship with me

you put your arm around me,

or you put your feet on my lap

or something like that.

People don't know that's  
necessarily ableist.

They're doing the act intentionally,

but it's a microaggression.

Other examples are inaccessible shelters

at an emergency shelter.

First of all, that's a  
violation of the law.

It's ableist, but it's a microaggression.

Patronizing tones, when  
you talk to someone,

they're calling for disaster assistance.

"How can I help you with that dear?"

And all of those kinds

of things are included  
in microaggressions.

And I think they're subtle  
things. People do them.

The person who built the  
inaccessible building

by and large didn't sit down,  
rub their hands together

and say, "I'm gonna  
discriminate against this person

50 years later when they  
come in the wheelchair

and they can't get in."

Or likewise, in a shelter,  
sometimes people don't say,

"Oh, I'm just gonna have  
inaccessible bathrooms."

It's that they didn't use a checklist.

They didn't go through it.

They didn't do what they needed to do.

So it's a combination  
of people not knowing.

And it's okay to have  
an inaccessible shelter

as long as you have an accessible one too.

You know, you have to  
have the same amount.

You, you have to have parity  
in those kinds of things.

So I wanna move to the next  
slide where I wanna talk more,

and I wanna ask you  
folks about some examples

where you've seen or  
experienced microaggressions,

especially during disasters,

or just your work at the CIL.

- This is Ciawanda.

Like you said, the more common one is

the moving of the equipment  
or assistive technology

without regard for, you  
know, the person's space

and use of it, the person  
period really, right?

- And some yes, absolutely.

And Ciawanda, you get one of  
those little plastic puzzles

where you can make words out of it.

It's blue, like from a kid's game,

those little flat blue  
puzzles kinds of things.

Do you know what I'm talking about?

- Yes, I do. Thank you.

- Okay, you got that. Oh cool.

So it's so great.

So, so I can't wait to  
meet you guys in person

and be in Florida.

You know, the weather  
here isn't wonderful today

or in December generally.

But anyway, so and sometimes  
microaggressions are

just people being air quotes, "nice."

Some people are trying  
to do the right thing,

or they're uncomfortable.

So you say to someone who's  
going by in a power chair,

"You're gonna get a speeding  
ticket if you don't slow down."

Yeah. And that is  
harmless in and of itself.

And if one person said that to me,

I probably wouldn't have noticed it.

It is the 50000th person who says it to me

that I might lose it, because  
I've heard that 50,000 times.

And what I'll say to people is, you know,

and it's a way of filling space.

It's a way of making small talk,

particularly like on an elevator,

people do stuff like that.

But slow down and people  
don't know what to say

and don't know what to do.

And I'll say, "Make small talk with me.

Talk to me about the weather

like you talk to anybody else about."

but you're gonna get a speeding ticket.

In New England I get,

"You have snow tires for that thing?"

Seriously?

And you know, it's people  
trying to be funny,

and there's nothing inherently  
wrong with that comment,

except what it does is it  
highlights your disability.

It brings out your disability.

It brings out what's different about you

and makes that different.

And sometimes I have the experience,

and this is not disaster related,

but I worked briefly for a state agency.

And I use a scooter.

All of you know what scooters sound like?

They're not loud vehicles.

They're scooters.

It's not like driving a  
truck or car or motorcycle

or moped or anything like that.

And people will say, "Heard you coming.

You can never sneak up on anybody."

And we're commenting on the fact

that my scooter made sound,

which led me to respond,

"I guess you don't hire lots of people

who use power mobility devices here?"

That was true. There was one other person.

But, you know, anything  
that brings attention

to someone's different and  
makes the person feel different,

I think internalizes it.

Even in a disaster shelter,

trying to make someone feel good.

"Oh, look how you get  
around on that thing.

Look how you get around on  
that thing all by yourself.

Look how you get around  
this whole school just

by pressing a button on a joystick.

Isn't that wonderful?"

Well, no, it's not wonderful.

It's a pretty easy thing.

It doesn't say a lot about  
the person's other abilities.

What other kinds of  
microaggressions have you seen?

Because, like I said, it's a  
nuanced kind of subtle thing.

- This is Ciawanda.

This one probably rubs me the  
wrong way more than anything.

But, when you see one person,

a lady, or see someone  
you know in passing,

and they grab their purse a  
little bit tighter, you know,

it's that-

- Yes.

- That one probably rubs  
me the wrong way the most.

- That is racist.

Just saying that is racist. Yes, yes, yes.

When people do that in an elevator.

People do that walking by.

Yes, absolutely. Thank you, Ciawanda.

Other instances of microaggressions?

Or ableism or any other  
intersectional points?

And it doesn't matter whether  
people are aware of it,

that they're doing it or not,  
is is the other piece of it.

They're still doing it, and  
they're doing it to you.

And that's individualized  
ableism or individualized racism.

Anybody else think of other  
examples of microaggressions?

I spend time with it sometimes,

'cause I once developed  
a training with someone

who had a degree in psychology  
who was a smart person.

And for some reason it took  
her a long time to wrap

her head around this,

and she chose to do this  
part of the training

'cause she wanted to get it so badly.

But, it just took a little while

and takes a little while  
for some people to get.

And she's like, "Well, if  
they didn't do it on purpose?"

It's like, "No, it doesn't matter.

You can be aggressive even  
if you're not intentional."

And it counts.

And it's not that one thing

that's going to hurt  
someone's self-esteem.

It's 100,000 of them, 100,000  
combined microaggressions.

Or, 100,000 of the same  
microaggressions is

what really erodes people

and diminishes people's self-esteem

and alienates people and frustrates people

and does all of those things.

Next, please.

Now institutional bias.

Institutional bias is the unconscious

or conscious belief that people

with disabilities belong or  
are better off in institutions,

including nursing facilities.

Ageism is often, but not always a factor.

Has anyone seen examples  
of institutional bias?

- Absolutely.

- What are some of these  
examples, Ciawanda?

- That doing shelter transition

at, gosh, various shelters,

at least two hurricanes for sure.

It's the automatic assumption that,

"Oh, you are older,

so you've just gotta go, you  
know, your house was destroyed.

You've gotta go to a nursing home,

because we don't have  
anywhere for you to live."

- Right.

And you were living fine  
independently the day before.

- Mm-hmm (affirmative).

- Not that all people can't live with

us supports in the community.

So that is a great example, Ciawanda.

And Ciawanda, you get a  
purple plastic dinosaur,

one of the ones with the long necks.

I forget what they're called.

It's a small, tiny one.

It's about the length of your thumb,

but that's what you get Ciawanda.

Next, please.

And we justify things in  
people's age all the time.

Next slide, please.

Systemic ableism.

Systemically ableism occurs  
when systems, regulations,

laws, rules, practices

and societal norms  
oppress disabled people.

This may or may not be intentional.

Systemic ableism may be less apparent

than individualized ableism,

because it's the way things always were,

and there's nothing you can do about it

if it's the way things always were.

For example, next slide, please.

Actually, we have systems

where everybody knows in  
order to get Medicaid,

if you earn too much money,  
you lose your Medicaid.

Well, that's a rule someone made up.

That's made up, and that can be changed.

All these things can be changed.

We just need to have a  
little vision around them.

Next slide, please.

And I'm going to, this is a slide

that Priya showed you last week,

and I'm going to describe it.

And it talks about intersectionality

and how intersectionality  
was a coined term

by Dr. Kimberle Crenshaw in 1989.

And it's a framework. It's a lens.

And so what we have here is

intersectionality is designed to explore

the interlocking effects  
of race, class, gender,

and other marginalized  
characteristics that affect health.

And what we have here is an asterisk

and has colored sections of the asterisk.

And it has religion, and so  
there'll be a section that goes

through religion on one side,  
income on the other, age,

sexual orientation,  
disability, expectation,

geography, race, culture,  
ethnicity, geography, race.

Religion and income, I think I said.

So it's, and in the middle  
where all of those things meet.

And we talked a lot about that yesterday,

but I just wanted to give  
people a reminder of that.

And Priya, if there's  
anything you'd like to add

to that description, feel free.

- This is Ciawanda.

You know, I really love intersectionality,

because I don't think  
people look at this term

enough in my opinion.

Because, when you look at it, you realize

that almost everyone in  
this world falls into this

in some manner, right?

We don't all have an overabundance

or have and don't have,

or, you know, something to that effect.

So everybody just falls into that.

And I don't think many people take

an introspective look at  
the term intersectionality

and reflect on how they  
play a role into that world.

But I think more should do that,

because I think we would all realize

that we fit into these  
marginalized communities

more than we realize.

- And especially around disability.

If you live the long lifespan  
that we all hope to live,

you're probably gonna have a disability.

Statistically, it's very, very likely

you'll have a disability at some point

during your life.

Age, again, if you live  
a long life expectancy,

you're gonna get to be an old person,

and it'll happen sooner than you think.

So you're gonna get to be an  
old person, experience ageism.

You're gonna be get to be a young person

and experience ageism.

And then, you get to be an  
old person experience ageism.

And I was saying to a friend  
of mine or colleague of mine,

at one point, "This is  
about a 15 minute period

in the middle where you  
don't experience it as much,

but it's not very long."

Next, please, Priya,

- This is Priya.

As we move on to the next  
slide, I just also wanna note

to your point, Ciawanda, right,

these are talking absolutely  
about marginalized identities,

but it's also really,  
really important to note

that, you know, we all  
have privileged identities

as well, right?

And so, intersectionality,  
you know, really helps us look

at the ways that our privileged identities

and our marginalized identities impact

how we are perceived

and how we then perceive the world, right?

And so, certainly, I absolutely agree.

It's absolutely needed that

for more folks to really  
bring this framework

into their work and into  
their personal lives.

- Right.

As a whole framework, it's  
not just a definition.

And looking at intersectional practices,

we can create educational materials

or trainings that  
prioritize the experience

of multiply marginalized  
people throughout them.

Have representation of  
multiple marginalized people.

Ensure materials and  
trainings are available

in multiple languages and formats.

It's ASL interpreted. It's  
screen reader accessible.

It's in large print or braille.

It's in languages other than English.

It's in sign languages other than ASL.

And then creating or  
supporting legislation

that specifically helps

multiply marginalized disabled people.

Really important. That's  
things we can do about it.

And when you're at the table,

you're sitting around the  
table thinking, who's here?

Glad they're here, glad they're  
here, glad they're here.

Thinking, who isn't here?

Or maybe asking,

who isn't here that we  
should have included?

Not necessarily to beat  
yourself up about it

or blame yourself, but go, who isn't here?

And how can we better invite them?

Maybe we invited 'em,  
and they didn't come.

Oh, we invited 'em, they didn't come.

Check that box. It's done.

Why didn't they come?

Was it because we weren't accessible?

Was it because we have acted in ways

that were offensive to them in the past?

Was it because we just weren't welcoming?

Was this something we  
said and how we said it,

and asked the community,  
"Hey, why didn't you come?"

Maybe they couldn't make it that Thursday,

but if they're not making it

every Thursday, then  
maybe there's a reason.

Next, please.

And the 10 principles of  
disability justice was

Priya talked about last week.

I'm just gonna read them,  
read from highlights of them.

And disability justice comes respective

that everyone needs to be included

and that legal is just  
the beginning of it.

Disability justice extends  
way, way, way beyond that.

And talks about the leadership

of those most in leadership must be from

the people most impacted,

a commitment to cross  
disability solidarity,

recognition and commitment to independence

and commitment to the  
collective liberation.

So if I'm just gonna get ahead

for people with my disability

that happen to have cerebral palsy,

that's not the collective liberation.

That's the liberation of me,

and that only does one person good,

and doesn't really do me

that much good at all to begin with.

Next, please.

- As we move on to the next slide,

when we're talking about addressing bias,

addressing any, really any form of bias,

racism, ableism, oppression  
in general, right?

One key note that I made

when we did the Addressing  
Racism presentation training was

that these are key, key  
practices to address racism,

to address ableism, to address,

you know, both internalized  
and external interpersonal

and or systemic oppression, right?

This is disability justice really looks

at the interlocking effects of the,

just like we're saying  
about intersectionality,

the interlocking effects of oppression.

And these are some of the solutions.

And we'll talk more about  
other solutions as well.

- Thank you, Priya.

Now, we're talking about ableism

and action during disasters,  
what all it looks like.

Let's go to the next slide.

I'm gonna give you some examples

of interpersonal ableism during disasters.

Telling a disabled person  
in a patronizing tone

that, "They just must go  
to special need shelter.

Just go there.

You'll be taken care of at  
the special needs shelter."

Believing that disabled lives  
are less worthy of rescue.

I was in a training, it's  
one of the few live trainings

I've done since the pandemic.

And someone virtually asked

the person I was training with, not me.

"Well, if I can go into an area

and rescue 20 non-disabled people,

and it takes longer to rescue

the disabled person,

why shouldn't I just rescue  
the non-disabled people?"

So believing that our lives are

literally less worthy of rescue.

And the person answered,  
and I helped 'em out

because it was one of  
those questions where you,

it's just you're not sure  
what and what not to say.

Also, another example is assuming  
disabled people don't have

the ability to consent.

You're registering.

Someone has a speech disability,

and there's a personal assistant

with them or family  
member with the person.

"Oh, can you sign for them?"

No, they sign for themselves.

They consent for themselves.

That's really important.

So those are examples.

In shelters and disaster recovery centers

all of those kinds of  
things sometimes happen.

Next, please.

Biased or ableist assumptions

that disaster notification  
by sound are equitable.

"What do you mean we didn't notify people?

We had sirens going off.

We knocked on everyone's door.

How could you not hear that?"

The ableist assumption behind that is,

of course, everyone hears sound,

and we know that everyone doesn't.

Or assumptions that  
physical access applies

only to buildings.

We gotta think about things

like the points of distribution center.

The PODs need to be accessible

even when they're outdoors.

That means they're not up a curb.

That means they're not down a rocky street

where the pavement isn't  
level and is broken.

That means the people can get to them.

There was a situation in Florida

in one of the hurricanes

where people in their high-rise  
building were delivered ice.

There was no power.

So obviously the elevator wasn't working

and the ice was delivered to  
the lobby of the building,

which worked if you  
could walk down stairs.

Didn't work so well for  
people that couldn't,

which was very many of the people.

They brought the ice,

but hey didn't think  
through the ramifications

of what access meant for people.

Or, the assumption of  
transportation is accessible.

Rideshare services typically  
are not accessible.

Every time someone says  
to me, "Just take Uber,

you know, just take Lyft, just  
take a rideshare service,"

I cringe, 'cause I can't.

In some cities there's accessible  
rideshare, but not many,

and you have to notify it ahead of time.

And it's not at all comparable

to what everyone is used to using.

So just that presumption.

So that's ableism how it's  
manifested in disaster.

Well, those people can get there,

'cause they can take an Uber.

"We're giving people  
Uber or Lyft gift cards."

Well that's a wonderful thing

if you have the privilege

of being able to take Uber.

And that does help a lot of people.

And, that helps a lot of disabled people

that can get into cars,  
but not disabled people

that need accessible transportation.

Next, please.

So talk about all this  
ableism in disasters.

And now, we need to look at  
what all can we do about it?

'Cause as we say, admiring  
the problem isn't good enough.

We can look at the problem.

We can look at the problem.

We can see it's reflection.

We can look at the  
dimensions of the problem,

the aspects of the problem.

You know, what color it's wearing,

you know what shoe size it is.

You know, all all the nice  
things about the problem.

But ask yourself, is that behavior

a reflection of bias or ableism?

And what can I do or  
say to interrupt this?

Doesn't mean you have to do it right away.

First, is that ableism?

Probably, you're asking  
yourself if is it ableism?

It is, probably, but we  
don't know that for sure.

What can I do or say to interrupt this?

So start thinking in those terms.

What can I do about this?

Next, please.

I'm gonna look at some more ableism.

And again, be thinking, is it ableist?

Well, we're talking about as ableism.

What could you do to interrupt this?

Ableism is manifested also  
when there's no compliance

with disability rights laws.

Not complying with  
disability rights laws is

inherently ableism in my opinion.

And this could include refusing to admit

a service animal to a disaster shelter,

not providing paper and  
electronic materials

in accessible format,

not having sign language interpreters,

not having VRI video relay  
interpreting is an option,

using inaccessible spaces  
for disaster shelters,

disaster recovery centers,  
and points of distribution.

We've talked about that.

So that's violating the law, number one.

And it's ableist.

So just think of it as those two things.

It's not just a legal violation.

It's a manifestation of ableism.

Next, please.

Ableism is also steeped  
in the very systems

of disaster preparedness  
response and recovery.

And we've talked about  
some of these things.

We've talked about institutional bias.

Those people just belong in  
nursing facilities anyway.

Segregated special needs shelters.

Now, we talked about this last week.

Florida has special needs shelters

and, or the week before that.

Florida special needs shelters,

the partnership's position is,

does not support special  
need shelters and disasters.

Disaster registries.

Again, you have registries

and the partnership has a position

that registries aren't a  
good option for people.

To register is not a  
way of keeping us safe.

And you also have policies

and practices that make it easier

for us to be institutionalized,  
such as the 1135 Waiver.

Do you folks know what the 1135 Waiver is?

Have we talked about it  
or do you know about it?

- No, I don't think so.

- Okay. It's built into our system.

We're gonna have a slide on it, next.

Let's just go to the next  
slide, Priya, so I can-

- Oh, before you go on, Melissa,

do you mind if I ask a quick question?

- Never. Never, never.

- Okay.

Because you were talking  
about the service animals

and not being, and I wanted  
to ask your opinion of

when individuals decide  
to pet a service animal.

Do you see that as a form of ableism?

- Yeah. Yeah.

It's not respectful to the  
person with disability.

And it's ableism. It's a microaggression.

It's yes, patting a service animal,

it's not a good thing to do.

- Yeah, I always felt that way,

but what I just wondered,  
what you all's take was on it,

what your take is on it.

- What blind people

and also anyone who uses people

who use service animals say is,

"You shouldn't pet the animal

without the owner's permission."

Now if say the animal's a dog,

if they're off-harness  
and they're not working

and they know they can be petted.

Because you can't have a  
dog that's never petted,

but that's only when  
the dog is not working.

So to be safe, you should  
ask the owner's permission.

The handler's permission, I should say.

Okay?

- Thank you.

- You are welcome.

Now, let's go to slide 43, Priya.

Recognizing systemic ableism in disasters

in the practice around the 1135 Waiver.

I was on the wrong slide myself.

I've got another slide open.

Sorry about that. Okay.

There are policies and practices

that make it easier for us  
to be institutionalized.

And the 1135 Waiver is one of them.

The 1135 Waiver is a  
waiver to the CMS policy,

among other things.

There's good things the 1135 Waiver does.

So it's not all things  
about the 1135 Waiver bad,

but the 1135 Waiver waives

the three day hospitalization stay.

So typically, if I wanna be admitted

to a nursing home or someone  
wants me to be admitted

to a nursing home, I  
have to stay in hospital

for three days so they can determine

I'm sick and discharge  
me to a nursing home,

make a nursing home recommendation.

Now, people go to nursing facilities

when they shouldn't go there,

and they don't belong there all the time.

But, I have to be there three days,

have a chance to get out  
and do something different.

I have a chance for a  
different discharge plan.

The 1135 Waiver waives that.

So you maybe think good.

People don't have to be in hospitals.

Well, let's look at what  
can happen sometimes.

Let's say your personal  
assistant doesn't show up.

You can't get outta bed, and you call 911.

Instead of going to hospital,

a hospital's just gonna send you back.

A hospital's gonna send  
you somewhere else.

But instead of that, you could go directly

to a nursing facility from calling 911.

Or, I'm in an emergency room,

because I'm sick after disaster.

And they can say, "Oh,  
you're not that sick.

We think you should just  
go to a nursing home."

They can send to go directly  
to a nursing facility

without going to a  
hospital for three days.

Or, if having nothing  
to do with your health,

they decide that someone  
else needs a bed more,

you can be bumped directly  
to a nursing facility.

Now we all know once you get  
into that nursing facility,

it can be really hard, if  
not impossible to get out.

And people get sick, get sicker

and die in nursing facilities.

So that's die more early  
in nursing facilities.

And that's something to think about.

So that's how that waiver,

and the waiver has been introduced  
in every single disaster

probably last since Katrina, I wanna say.

So it happens kind of automatically

that during a disaster  
there's the 1135 Waiver.

That makes some things  
easier, like telehealth

and other things like that.

During the public health  
emergency for COVID,

it was enacted

and the three day  
hospitalization stay was waived,

but also enabled telehealth  
and some other things

that are beneficial to the community.

So it's not to say the  
entire 1135 Waiver is bad,

but waiving the three  
day hospital stay is bad.

Does that make sense? It's complicated.

- This is Ciawanda. It makes sense.

Is the 1135 Waiver a  
state based waiver or-

- Federal.

Well, what they do is it typically,

if it's issued under a typical waiver,

a state has to apply for it.

But, during the public  
health emergency for COVID,

it was a blanket waiver to  
every state and territory.

And what they tend to do  
is issue blank waivers

to an entire region or entire state.

So it could be to everyone  
affected by the hurricane

to the entire state of Florida.

- This is Ciawanda. It's  
known as 1135 Waiver?

- Yes. That's what it's known as.

- Okay, thank you.

- And there's stuff on  
our website about it.

I can send you a link to it  
that actually I wrote is,

the reason I can speak  
about the 1135 Waiver is

I had to write stuff on it.

So I had to learn the ins and outs

and spent way more time than  
I should have taken learning

about the 1135 Waiver,

'cause like I say, it's (indistinct),

and there's a lot to it.

Next, please.

Any questions about this?

And if it doesn't make  
sense now, it's okay.

You're gonna get the slides,  
and you can ask about it.

Next, please.

I'm gonna look at ways to interrupt

systemic ableism during disasters.

Document areas of systemic ableism

that were recognized during Hurricane Ian.

Ask disabled Ian survivors to document

their systemic ableism in retrospect,

bring systemic ableism to the attention

of local state legislators,

local, state emergency management,  
and local public health.

Next, please.

Work with your legislators  
in emergency management

and public health departments to develop

strategies to dismantle the ableism

that you saw, those  
identified in the Ian response

and other disaster responses.

Create and implement plans  
to address this ableism.

Like, what can we do  
about the 1135 Waiver?

What can we do about people  
automatically getting sent

to nursing facilities?

Support legislation and other initiatives

that will help dismantle ableism

identified in the Ian response.

And you do this with public health

and with emergency management.

Does anyone have any questions?

Next slide, Priya, sorry.

I don't see any questions right now.

And I wanna take us through a  
history of disability rights.

- This is Priya. Ciawanda,  
I see you've come off mute.

Do you have a question or a comment?

- Yeah, I do have a comment.

Thank you for noticing, Priya,

'cause I usually do have one.

- Always.

I can't see you Ciawanda, so.

- No, no worries, no worries.

So, you kind of talked about, you know,

bringing this to the attention

of the local emergency management.

And I can say that as Centers  
for Independent Living,

you know, we try and do  
that here in Florida.

One of the things that I don't think

that we have tried to address yet,

because it's gonna take, you know,

a mountain to make this change,

and that's the special needs shelters.

- Yes.

- I think it's gonna take a lot more work

than we've built ourselves up for.

But I do think that it's something

we need to address,

because I think that  
what I can say is this,

I had the pleasure of being

at the governor's Hurricane Conference

this past this 2023 year.

And they were open to allowing us to host

a training session on  
access and functional needs.

And we had a lot of state  
emergency managers there,

and a lot of local  
emergency management there.

And so I think that individuals  
are starting to recognize

the importance of this conversation.

And so I feel like in Florida,

we're trying to get it right.

Like I said, I think we  
have way more work to do

when it comes to that  
special needs shelter.

But I do wanna just kind of throw in there

that we're trying to figure out

how to get this, you know, figured out.

- And work with other centers  
and work with yourself.

Because, Florida is the only state

that has a special needs  
shelters mandated by law.

- Right.

- It's not just a policy change

where we say to someone,  
"Hey, do this differently."

And the answer's, "Oh,  
we're public health,

so we're gonna do this differently.

Whoever's doing this, so we're  
gonna do it differently."

It's you've got to educate people.

And the first step

to educating people's  
documenting instances.

And by the way, the person who was

in the special needs  
shelter that was safer

for people with disabilities,

that person who used  
the scooter for mobility

and slept in for all those days was

in a special needs shelter.

And so documenting things that  
is really, really important.

Bonding with the other  
centers, bonding with yourself,

talking about them, sharing stories

without violating people's  
confidentiality of course,

but sharing instances and  
then going to legislature

and saying, "We need to make some changes,

and this is why this isn't helping us.

- Right.

- 'Cause intuitively a  
special needs shelter sounds

better to a lot of people.

And registries sound  
better to a lot of people,

and registries don't work.

So it's a matter of sitting down

with other centers and doing it.

So thank you, Ciawanda.

- Absolutely. Hi, this is Tomora.

I've got a question,

and I'm not sure if you have the answer,

but I'm gonna ask.

- It's okay.

- Do we know why the state of Florida is

the only one that has  
a special needs shelter

during a, you know, a  
state of an emergency?

- What I will say is, I don't  
know how that came to be,

but perhaps it was the only state

or territory that thought it  
was an important enough idea

and a good enough idea to put into law.

And that's not, you know, it's just,

or it had legislative force.

It had impetus.

And Tomora, you get a teeny,  
tiny white teddy bear.

- Ooh, thank you.

- So don't know, so.

Beth Myers at the CIL  
could probably answer

that question, or she's certainly  
better equipped to answer

it than I am.

Next, please.

I'm gonna run through a brief history

of the disability that social movements,

and I could spend a day on this,

but we're just gonna  
go through it briefly.

Much of what you probably know,

and some of it you might not.

Next, please.

Now why is she teaching  
teachings about history

and social justice movements

and disability social justice movements?

Disability social justice  
movements identify

systemic and individualized bias ableism.

And they've successfully  
interrupted many types

of systemic individualized  
bias and ableism.

And in order to identify

and interrupt ableism, look  
towards these movements.

So I'm gonna quickly go  
go through some of them,

just so you know about them.

Next, please.

The Independent Living Movement,

which is literally why we're here.

Do you know about this?

Raise your hands if  
you do and let me know.

Priya, we're seeing lots of hands?

Ed Roberts is a man with quadriplegia,

and he founded the Rolling  
Quads at UC, Berkeley.

He got to go to college,  
was one of the first people

that level of injury and disability

that got go to college.

And in 1972, the Berkeley  
Center for Independent Living,

the CIL was started by Ed Roberts

and just quickly joined by Judy Heumann.

Right after that, CILs were started

in Champaign-Urbana, Illinois and Boston.

And the first Rural Independent  
Living Center was started

in western Massachusetts by  
my good friend Chris Palamas.

Anyway, so 1974 Atlantis  
Community was founded

by Wade Blank and 19 people

he helped free from the institution.

And in 1978, ADAPT had its first action,

which was the group that Wade Blank

and the Gang of 19 founded,

and made its first action  
in Denver, Colorado.

Next, please.

And we're just jumping through this,

just so you know it's there.

Next is psychiatric survivors  
are the Madness Movement.

There's Madness Network News

and Madness Network News in NARPA,

which we're gonna talk about in a minute,

rejected the term mental illness.

They did not believe that  
psychiatric survivors had

any particular illness  
or mental impairment

other than emotional and  
physical damage created

by brain damaging tranquilizers,

electro shock, poverty,  
institutionalization,

oppressive family situations,

and or stigma against people

who have been in psychiatric institutions.

Next, please.

"On Our Own:  
Patient-Controlled Alternatives

to Mental Health System," it's written

by a woman named Judi Chamberlin,

who is the founder of the  
Psychiatric Survivor's Movement.

And then that book led to  
the founding of that movement

of the Psychiatric  
Survivor's Movement in 1977.

Next, please.

And I mentioned NARPA,

that stands for National  
Association of Rights Protection

and Advocacy was founded in 1984.

And NARPA's mission statement is

"To support people with  
psychiatric diagnoses,

to exercise their legal and  
human rights with the goals

of abolishing forced treatment  
and ensuring autonomy

and dignity of choice."

And the partnership was privileged to be

a presenter at the NARPA Conference

this year, earlier in October.

Next, please.

The Deaf Movement,

in 1817 American School  
for the Deaf was founded

in West Hartford, Connecticut.

And guess what?

In the chair I'm in,

I'm sitting in West Hartford, Connecticut

and my street is the  
intersection of Gallaudet Drive,

I kid you not.

And 1864 Gallaudet University,

the first university for  
deaf people was founded,

led by deaf people.

They had a big movement, a Deaf  
President Now move in 1988,

because they had appointed, hired

non-deaf presidents and that was not okay.

And they started the Deaf Pride  
Movement through Gallaudet.

National Association of the  
Deaf was founded in 1890.

And the National Black Deaf

Advocates Association was founded in 1982.

Really important to know  
that people were recognizing

intersectionality issues in 1982.

And it went back as far as 1982,

but it's been going on for  
a lot longer than that.

Next, please.

Deaf culture is a term denoting membership

in a cultural community  
comprised of deaf individuals

who utilize American Sign Language, ASL

as their primary form of communication.

Like other cultural gaps,  
unique social norms,

acculturation processes

and stages of identity  
development are present

within deaf culture.

Next, please.

The organized blind movement  
began in 1832 that we know of.

And Schools for the Blind  
were open in Boston, Mass,

New York, New York, and  
Philadelphia, Pennsylvania.

Then in 1834, Dr. Newel Perry

and Dr. Jacobus tenBroek founded

the California Council for the Blind

an organization that enabled

that blind people bring the concerns

to the state legislature,

because Dr. tenBroek went to UC, Berkeley.

So many people with disabilities going to

UC, Berkeley, even before people

with physical disabilities  
and before Ed Roberts.

In 1835, the Federal Social  
Security Act was passed,

containing a provision that funds

state grants to aid the blind.

Next, please.

1936, Congress passes the  
Randolph-Sheppard Act granting

blind people the exclusive privilege

of operating vending  
stands on federal property.

And in 1940, delegates  
from seven states gathered

in Wilkes-Barre, Pennsylvania to fund

a National Organization of Blind People

and The National Federation of the Blind.

Dr. Jacobus tenBroek  
was its first president.

Next, please.

And neurodiversity and  
artistic rights movements.

In the 1990s, autistic  
self-advocacy became organized.

And in 2006, ASAN,

or the Autistic Self-Advocacy  
Network was founded

in response to the lack of representation

of autistic voices in the  
national dialogue on autism.

Next, please.

Self-advocacy Movement.

The People First Movement began

on January 8th, 1974  
and October 8th, 1974.

The first People First  
convention was held in Oregon,

560 people with intellectual disabilities

that identify as self-advocates attended.

Within five years, Oregon had  
1000 People First members.

Nebraska, Washington, Kansas  
had growing memberships.

People from 42 other states were asking

for assistance to start their  
own People First groups.

Next, please.

And Self-Advocacy Movement,

which is part of what  
People First came from is

in September, 1991,  
Self-Advocates Becoming Empowered

or SABE was formed.

People First led to the creation

of the National Organization

for People with Developmental  
and Intellectual Disabilities.

And there's a link for that.

Questions?

That was a lot of history  
in just a few minutes,

but I wanted to get it as much  
of it in there as possible.

And you'll have the slides.

Did you know of the history  
of independent living?

- This is Ciawanda.

Yes, I'm glad there's no test though,

because retaining.

- I'll tell you a secret.

I don't believe in tests.

I have really different  
beliefs about education,

how people learn.

So I don't believe in tests,

so don't worry about it.

- I probably agree with  
you on that belief, so.

- Now, does anybody  
want to try a scenario?

You don't have to try this scenario.

I'm gonna throw a scenario  
for all of you to think about.

We're only gonna get to but probably one,

maybe two of these, but just  
wanted you to play with it.

So Joe is a black man

whose home was destroyed in a hurricane.

Let's say it's Hurricane Ian.

He disclosed his mental health condition

when checking in at the shelter.

This information is  
overheard by a volunteer.

You are working on site,

and you overhear a coworker say,

"They don't feel comfortable  
working with Joe,

because he might get violent.

You never know, he might get violent."

What do you do and how  
might ableism be in play?

- One of the things, this is Ciawanda.

One of the things you can do is have

a conversation with the  
person about ableism.

And because ableism absolutely  
exists in this sense

in that you can have the  
conversation about, you know,

some of the things that happen

and do not happen with individuals

who have mental health conditions.

And, so.

- Yep.

And I am fond of saying  
to people that, you know,

people with the intersection

between people with  
mental health conditions

and violence is the more likely to be

victims of violence than other people.

And they're far less likely to  
be violent than other people.

So I think there's ableism at play here.

I also think there's  
probably racism at play here.

- This is Priya.

I see Deidre's hand up.

- Deidre.

- Hi this is Deidre.

I think the issue also is

everybody just expects  
having a mental health issue

as someone being crazy.

So, they're just not educated

on the different types  
of mental health things

that there are.

- Right?

Well I meant people

with mental health conditions are really

unlikely to be violent and in a stress.

You know, it's people might act out,

but that doesn't mean  
they're gonna be violent.

And its just because someone's doing

something kind of ableist to them.

Absolutely right.

And you get a pink striped zebra,

a small plastic pink striped zebra.

- Okay, thank you.

- As your fabulous prize.

Never given one of those away before.

- Oh special.

- You are.

Okay, so I wanna talk about this scenario,

and we probably won't get through it.

Priya, if you go to the next scenario?

'Cause this is our complex one.

A consumer with a mobility  
disability volunteers to be

part of a county disaster planning group.

When she learns that the  
meeting place is not accessible,

she asks 'em to move to an  
accessible meeting place.

They tell her, "It's too late  
to change the meeting site,

and she really doesn't need  
to be on the committee,

because Florida has special  
needs shelters to make sure

disabled people's needs are met."

She contacts you at the  
center and ask you what to do.

What do you tell her and how  
might ableism be in play?

So I'm on the phone with you right now.

You get to tell me something.

- Yeah, this is Ciawanda.

I'm hoping my staff will answer this.

- Is there ableism in play?

If I say I'm not gonna  
move the meeting site?

- Hi, this is Dimitra.

Yes, there is ableism there.

- Right.

And it doesn't say what,

she might be calling 'em the night,

before and they say they  
can't move the meeting site,

then they should be having  
it an accessible space.

But yeah, it's ableist. Yes.

It's not thinking about her. It's ableist.

Okay, so great.

Ableism is in place. Let's check that box.

So what do you tell her?

She doesn't need to be on the committee,

'cause you all get special  
needs shelters in Florida.

We take care of our people in Florida,

our disabled people.

Hint, whenever someone calls you our

or addresses you as one of theirs,

as it implies that they own you,

that's not indicative of  
a rights bearing attitude.

Our disabled people,

meant lots of times with affection,

but can be really patronizing as well.

The special needs shelters  
take care of everybody

with a disability in Florida well?

- This is Dimitra.

I don't think that they do,

just from hearing of the situations

that have happened over  
the last few hurricanes.

I do feel like maybe there should be

a person with disabilities on a committee.

They're saying that, "She  
shouldn't be on the committee."

However she can put her input in

as she or he can put their input in

as a disabilities person in the committee,

Because some people don't understand

or are ignorant to the fact  
of people being disabled.

- And I think whenever they tell me,

"They don't need me,

there is a person with  
disability," guess what?

That's the best way to  
get me to go to a meeting.

If you're a meeting you really

that you don't think I wanna go to,

tell me I shouldn't be there.

I don't belong there.

That's against people. Yeah.

We need to be really cautious

when they say people with  
disabilities don't belong there

or shouldn't be there.

- Yeah.

- And again, Ciawanda go ahead.

- No, no, no. I was gonna say, you know,

we're being mindful that  
this is a volunteer group,

so there's no expectation

of someone in particular being there.

Right?

There is an expectation  
that anyone who wants to be

a part of the process  
is allowed to be there.

So, I mean the first thing

that I'm gonna tell her to do is put

the request for the  
accommodation in writing

and send that to the group.

That's gonna be the very first thing

I'm gonna tell her to do,

because you know, to get  
the meeting site changed,

she has to at least request

that accommodation in a timely manner

which it sounds like she may  
not have been able to do that.

And so, that's the very first thing

I'm going to tell her to do.

- For all we know is she did it

three months ahead of  
time, though we didn't say.

- Well that's true.

- But yeah.

- But I agree,

but the questions is, you know,

did she put it in writing?

You know?

- I agree. Yeah, I totally agree.

- But you know, it helps.

- Hi, this is Tomora.

I guess one of the other things

that I would try to see if  
it was available is to do

a Zoom call so that she  
would be able to participate

even if she wasn't able to get there.

- Yay.

Tomora, you get a little  
spinning purple top,

little tiny one.

- Winner. Thank you.

- So yeah, participate virtually.

It's not the same,

but it's least some kind of participation.

Anything else?

- Hi this is Dimitra.

I didn't get my prize.

- Dimitra. Dimitra,

Dimitra, I owe you a prize.

Do you have any general idea

what you'd like best for?

Dimitra, do you know what your prize is?

You get a silver sports car.

It's a Lamborghini.

- Oh, ooh, ah.

- That's what you get to  
take home with you today.

- Thank you.

- You are welcome.

I'm sorry I forgot to give you your prize.

- This is, that's fabulous.

I am so sorry to cut you off, Melissa.

I just wanted to note that

that was a fabulous exchange.

Thank you.

- So I wanna thank all of you

for participating in this training.

And those of you that have  
listened to the series,

I wanna thank everyone for coming today,

and I wish you all a happy almost weekend.

Any final questions?

And we have our contact  
information on the slide,

and my contact information  
is on the slide.

Feel free to email me at any time.

Ciawanda, you know how to call  
me, how to reach me, anytime.

Please feel free.

Working on lots of other stuff,

and there'll be another training coming up

in January on your Continuity  
of Operations plan.

And I think we have the date set,

but I didn't put a slide on it.

I forgot, I apologize.

But enjoy the holiday season everybody,

and have a very good one.

So thank you as always.

- Be well.  
- Thank you.

- Have a good holiday.  
- Bye bye.

- Bye.