- [Melissa] Who knew  
you were gonna have to

listen to me again?

I'm here with Shari Myers today who's also

with The Partnership who's  
gonna introduce herself

in just a minute, but welcome  
to "Collaborate to Educate:

How Planners, Emergency  
Management, and Communities

with Access and Functional  
Needs Can Communicate."

Next slide, please.

We are still The Partnership for Inclusive

Disaster Strategies and I still look

the way I looked mostly.

Maybe a little bit worse for wear

than I was an hour and a half ago.

Would you like to introduce  
yourself, Shari Myers?

- I'm Shari Myers.

I'm the Disaster Operations Coordinator.

I just turned it on, I thought.

Am I just not close enough to it?

- Yeah.

- [Shari] Okay.

I'm Shari Myers, I'm the  
Disaster Operations Coordinator

for The Partnership.

I am a Caucasian woman  
with wild, crazy gray hair.

I am wearing a green striped shirt

and my pronouns are she/her.

- [Melissa] Okay, thank you.

Next slide, please.

And our agreements and goals are the same,

especially the having fun,  
so please keep doing that.

Next, please.

And today's goal specifically  
for this session,

what we would like your  
learning objectives as it is,

by the end of the session, we'd like you

to better understand ways to utilize

the National Planning  
Framework as a common language.

Shari's gonna talk to you about that.

Identify and interrupt  
disability bias and ableism.

I'm gonna talk about that.

Include the disability community  
in emergency management.

We're gonna both talk about that.

And how to collaborate  
across sectors to save lives.

Next, please.

Again, please avoid using acronyms,

or at least say what the abbreviations are

so we all understand, and we all do it

and it's all shop talk, but let's try

to explain it to everyone so we all know

what we're talking about.

Next, please.

First term I wanna talk about is access

and functional needs, and  
this comes under the acronyms.

And Sadie did a really good job

of talking about access  
and functional needs.

She's great.

I know she's still in the room  
today, but that was great.

And sometimes the term gets problematic.

Let's talk a little bit about that.

Sometimes it can be forgotten  
that people with disabilities

are members of a legally-protected class

with rights that other people with access

and functional needs don't have.

Now, I'm an older adult.

That will be an access  
and functional need.

I'm also not protected as an older adult.

I have legal rights as  
somebody with a disability.

So sometimes it gets lost  
that people with disabilities

have legal rights, so I want  
you all to keep that in mind.

Next, please.

And common language and understanding

is really important.

This is about collaboration.

What's the first step to collaboration?

Communication.

To communicate successfully,  
you want a common vocabulary.

You wanna know what the words  
everyone's talking about

and you want an appreciation  
of each other's needs

and priorities and see people  
through their own lens.

And today's audience is diverse.

You're from all kinds  
of sectors and agencies

and organizations that  
I just love, love, love

that you're all here  
today, so the material

might be your review for some of you,

going, "Why is she going over this?

I've known this for 20 years."

Well, other people don't and  
there might be some stuff

that other people have known  
for 20 years that you don't,

so just we all have to hear things

that we might have heard before and people

are gonna learn new stuff for everybody.

It'll be something new for everybody.

And sharing information is how we begin

to develop collaborative relationships.

Questions before we get started really?

With that, I will turn it over to Shari.

- [Shari] Thank you, Melissa.

So we're gonna talk a little bit

about the National Planning Framework,

and I know a lot of you  
are familiar with it,

but some of you won't be.

So if you already know it, you  
can help others at your table

understand it and be  
there to answer questions.

But we'll start with

a question for you.

How familiar are you with the  
National Planning Framework?

So we're gonna do a show of hands.

Not at all familiar?

Okay. Somewhat familiar?

Very good. And very familiar.

Great.

- [Melissa] Can you say  
it by how many people

are responding to each of those?

- [Shari] I'm gonna say that  
was about 10 to each one,

and I'm sorry I didn't count.

So the National Planning Frameworks

describe how the whole  
community works together

to achieve the National Preparedness Goal.

The National Preparedness Goal

is a secure and resilient nation

with the capabilities required  
across the whole community

to prevent, protect against, mitigate,

respond to, and recover from the threats

and hazards that pose the greatest risk,

and that would be the greatest  
risk within your area.

And I'm just gonna say  
at this point in time,

I think we all could experience

just about any kind of hazard.

With the changes that are happening,

you know, it gets warmer  
and warmer in the summertime

and sometimes we have  
really severe winters

and sometimes we have no winter at all.

I live in Minnesota and year before last,

winter before last, we  
had 90 inches of snow.

Last year we got maybe a foot and a half

and went through some severe  
drought in the spring,

and now flooding as it  
rains and catches up.

What is whole community?

The concept of whole community is one

of the guiding principles  
of emergency preparedness.

It means two things, involving communities

in the development of local, state,

and national preparedness  
plans and guidance

and ensuring community  
stakeholders' lived experience

and subject matter expertise are reflected

in the content of the  
materials that are distributed

and the planning that's done.

The National Preparedness System outlines

an organized six-part process  
for the whole community

to move forward with their  
preparedness activities

and achieve the National  
Preparedness Goal.

The National Preparedness System,

the six components are  
identifying and assessing risk.

Two, estimating capability requirements.

Three, building and  
sustaining capabilities.

Four, planning to deliver capabilities.

Five, validating capabilities.

How well did it go?

Did we meet those capabilities?

Did we expand on them?  
Did we improve them?

And then six is reviewing and updating,

which also has a lot to do  
with continuous improvement.

What went well? What  
could be improved upon?

And some of you will be familiar

with the National Incident  
Management System,

or NIMS, N-I-M-S, guides  
all levels of government,

non-governmental organizations,  
and the private sector

to work together to  
prevent, protect against,

mitigate, respond to, and  
recover from incidents.

It also provides stakeholders  
across the whole community

with the shared vocabulary,  
systems, and processes

to successfully deliver the capabilities

described in the National  
Preparedness System.

And then we have our  
Emergency Support Functions.

And I know that Illinois has its own set

of, I believe you call them annexes,

and so these may be a  
little bit different.

I'm gonna go with the national  
ones as described by FEMA.

So the Emergency Support  
Functions, or ESFs,

provide the structure for coordinating

federal interagency support  
for a federal response

to an incident.

So when there's a declared disaster,

those are the Emergency Support  
Functions that are used.

They describe the federal  
coordinating structures

that group resources and capabilities

into functional areas  
most frequently needed

in a national response.

Excuse me one second.

The Emergency Support  
Functions, there are 15 of them,

and there will be a link  
you'll see on these slides

when you get a copy for FEMA's ESF list

and that will explain it more fully.

We're primarily going to  
concentrate on ESF six

and ESF eight.

States, as I said before,  
may have different ESFs,

and ESFs are only as good as  
each individual function's

communication with the rest.

So I'll go through these real quickly.

Emergency Support Function  
one is transportation,

ESF two is communications.

ESF three, public works and engineering.

ESF four, firefighting,

ESF five, information and planning.

ESF six, mass care, emergency assistance,

temporary housing, and human assistance.

ESF seven, logistics.

ESF eight, it's public  
health and medical services.

ESF nine, search and rescue.

ESF 10, oil and hazardous  
materials response.

ESF 11, agriculture and natural resources.

ESF 12 is energy.

ESF 13 is public safety and security.

ESF 14, cross-sector  
business and infrastructure.

And ESF 15 is external affairs,

communication with the community at large.

So Emergency Support Function six

at the state and local level  
may include mass care and...

I apologize, I haven't said  
next slide once, (laughs)

but you all are keeping up with me.

Sorry about that.

So ESF six at the state and local level

may include mass care, which is feeding,

sheltering, reunification,  
and distribution

of emergency supplies.

It may include emergency assistance,

which would be financial assistance.

Sometimes, as an example,  
you may see a program

that's instituted for  
rapid financial assistance

to help people who may just  
need a few hundred dollars

to go stay with family or  
find a temporary solution

until they're able to return home

if they have damage to their homes.

It also includes human  
services, assistance with health

and mental health needs, and the Disaster

Supplemental Nutrition Plan,  
which we refer to as D-SNAP.

Emergency Support  
Function eight may include

provision of medical  
care and human services

to those affected, disease surveillance,

environmental public health actions

to reduce the public health  
effects on the community,

and education and training to  
enhance community resilience

to respond to a disaster.

Illinois Emergency Operations Plan

is focused on addressing the  
seven community lifelines

identified by the Federal  
Emergency Management Agency:

safety and security,  
food, water, and shelter,

health and medical,  
energy, communications,

transportation, and hazardous material.

So including disabled  
people into ESF six planning

is very important to help  
ensure that needs are met

in mass care and human services.

So that would apply to  
things like accessibility

of shelters, points of distribution,

service delivery sites for recovery,

and other types of programs and services.

For ESF eight, it's important  
to focus on supporting

the rights and needs of disabled people

to live in their community.

So focusing on community  
services, not just acute care.

So whose responsibility is sheltering?

It's always local or county government.

Sometimes the state also  
has responsibilities.

Local governments may  
contract with other entities,

such as American Red Cross  
or the Salvation Army.

Sometimes county manages the shelters

and other entities like Red  
Cross Supplement Services.

So that would be a partner-managed shelter

typically is how they refer to that.

And then there are popup shelters.

So those may be faith-based organizations,

community organizations  
that will open up a shelter

specifically kind of at  
that micro-local level.

So do we have any questions?

Okay.

- Yes, my name is Libby Oxenham.

I've heard that in Florida,

they didn't have shelter  
by the American Red Cross.

It was another company  
that handled the shelters.

So the state decided

to use that company to  
set up the shelters,

and I think it's very important

for the state to check and make sure

that they're following,  
because maybe that company

or some shelters might  
not be in compliance

with all of the laws.

So I was curious about that,

if you know anything about that.

- [Shari] So in another  
life, I was the Disability

Integration Coordinator  
for the American Red Cross

and I was there during that time.

If I'm not mistaken, that  
was the county's decision.

It was Lee County specifically  
that was running this shelter

and they contracted with the group.

And Red Cross did have  
people in the shelter,

volunteers in the shelter  
who were supporting as well

for most of the time that  
that shelter was open.

There were many accessibility issues

and in after-action with  
a lot of the disability

stakeholder organizations,  
those were reported out,

recorded, documented,  
and are being addressed

in the hopes that that won't happen again.

Thank you. Great question.

Any others?

Okay, Melissa, I will turn it over to you.

- [Melissa] Thank you so much,

and we still have fabulous prizes.

- [Shari] Oh.

- [Melissa] I'm just gonna go  
off the script for one second.

I wanted to review something, and this

will be in your slides, and people,

I wanna talk a little  
bit more about access

and functional needs  
that, again, in review

from what Sadie said,  
people with disabilities

are part of access and functional needs,

but it also includes  
children, older adults,

people with limited English proficiency,

people with unmet transportation needs,

and people experiencing houselessness,

and run the language and acronyms.

We talk about AFNs and  
it's really important

we talk about people with  
access and functional needs.

I am never an AFN.

No human being is ever an AFN.

We're people with access  
and functional needs.

And I just wanted to be  
clear, I was clear about that.

Okay, so why is understanding  
ableism and bias important?

Again, why is she here? (laughs)

If we can go to the next slide, please.

Sorry.

So understanding ableism  
and bias is important

because it's critical to understand

how to communicate with disabled people

and disability-led organizations.

So if you're doing something  
that's unconsciously biased

that you don't wanna do, then  
you wanna know about that.

It also enables you to identify

and interrupt individual  
bias, individual ableism,

and it helps you work on systemic ableism.

Stuff I was talking  
about in the last session

about the 1135 waivers.

Knowing that's systemic ableism

basically helps you deal with that.

And it provides you a frame of reference

for the experience of disabled people.

So I just wanted to talk  
a little bit about why.

Next, please.

So what all is ableism?

Ableism is oppression based on physical,

mental, intellectual, cognitive, sensory,

or other ability or perceived ability.

It's the belief that  
not having a disability

is superior to having a disability

and the belief that non-disabled people

are superior to disabled people.

That's my definition.

There's a million other  
definitions out there.

I did not coin the word ableism  
in any way, shape, or form,

but I've been using it since  
the late 1970s. (laughs)

Dating myself again here.

So just wanted to make sure that everyone

had a clear understanding of that.

Bias? You probably know  
what bias is already.

Bias is prejudice and  
favor or against one thing,

person, or group compared with another,

usually in a way considered to be unfair.

Implicit bias, sometimes  
called unconscious bias,

is bias that occurs when  
we have negative attitudes

toward people or associate  
stereotypes with them.

And I don't believe that most people,

any people get up in the morning

and rub their hands together and say,

"I'm gonna be ableist to  
people with disabilities today

and I'm gonna discriminate against them

and it's gonna be so fun!"

No, we don't know what we're doing.

We don't understand it.

Okay? Next.

The next slide, it talks  
about intersectionality.

How many of you have heard  
the term intersectionality?

Okay, I see about 10 of you maybe.

Intersectionality is a coin termed

by Dr. Kimberlé Crenshaw  
and it's a framework

designed to explore the  
interlocking effects of race,

class, gender, and other  
marginalizing characteristics

like disability that  
contribute to social identity

and affect health.

And we have a graphic next  
to it, to the right of it,

of what looks like an  
asterisk with each person

with an overlapping line  
representing the following

marginalized characteristics:  
their sex, race,

ethnicity, religion, age,  
disability, gender, geography,

culture, income, sexual  
orientation, and education.

Okay? That's intersectionality.

And The Partnership always  
tries to look at things

through an intersectional lens.

Next, please?

So let's look at some  
examples of ableism bias

that happen during disasters.

Telling a disabled person they  
must go to medical facility.

Telling someone they need  
to go to the nursing home.

Telling someone they need  
to go to the hospital

when they don't have hospital needs.

Believing that disabled lives  
are less worthy of rescue.

And assuming that disabled people

don't have the ability to consent.

We're talking about guardians and stuff,

and when there's a guardian, that guardian

legally has the authority to consent,

but getting the person's  
consent whenever you can

and assuming just maybe  
someone has a speech disability

and making the jump from there.

Oh, they have a speech disability.

They must have an intellectual disability,

and if they have an  
intellectual disability,

they don't have the ability to consent.

Not necessarily the case.

Next.

This is how ableism is  
manifested in disasters.

Sometimes our assumptions, we assume

the world is as it should be and is just.

We assume that disaster  
notifications by sound are equitable

'cause we're forgetting  
that lots of people

don't hear sound or interact with sound.

The assumption that sign  
language interpreters

are readily available.

Anybody involved in planning events

probably knows that's not the case.

Assuming that physical access  
only applies to buildings.

Points of distribution, or  
PODs, must be accessible,

even when they're outdoors.

The point of distribution  
where you get your food,

you get your ice, you get  
your medical supplies,

you get those things  
are sometimes outside.

The assumption that  
transportation is accessible.

I don't know what the standard is.

Probably accessible in Chicago.  
I'm not positive of that.

In most of Illinois, you're not

gonna have accessible rideshare.

In Connecticut, I can  
never use rideshare service

like Lyft or Uber or any  
of those rideshare services

'cause they're not there.

So when you're looking  
at behavior or systems,

try to start thinking about  
is this behavior a reflection

of bias or ableism?

And if you think it is,  
what can I do to interrupt?

How can I take this colleague  
of mine that I respect

and like and they're my friend

and point out that that was an expression

of bias or ableism?

Public humiliation is never a good idea,

so you don't wanna do it publicly.

You wanna take somebody  
aside and think about

how you interrupt it, how  
you can get the person

to understand it.

Again, I have three or four  
hours I do on bias or ableism.

I could do a whole day on that,

so this is the condensed version.

So I'm gonna have you do, I want you

to think about this scenario.

Give you a few minutes to think about it.

Maybe talk about at your  
table for a few minutes.

Coworker tells you that  
while they understand

that people with  
disabilities may not wanna go

to nursing facilities, 'cause nobody wants

to go to a nursing home, they think

that people are safer  
there, especially now

that there's so much debris  
around with the disasters.

It increases people's risk of falling

with all the garbage that's around

that people can trip over.

Think about that.

Just think about that with  
yourselves for a couple minutes.

How do you respond?

This person cares, this person gets it.

They're saying they're  
better off at an institution.

What would you say?

Mic runner?

And Sadie Martinez is the mic runner!

Thank you, Sadie.

What would you say if someone said that?

Yes.

Would you say yes, that's a great idea?

Okay, okay.

Oh, sorry.

Sadie, there's someone.

Sadie, someone's speaking.

- So I guess...

Oh, my name is Kay.

I guess one way that I  
would really start out

this conversation is that  
that impacts everyone.

There is so much debris around

and it's a risk of falling for everyone,

so we should probably worry  
about cleaning that up

and making sure we have a response to that

as fast as possible  
instead of singling out

a single group of people,  
because something that helps

one group of people is gonna  
end up helping everyone

and I don't want to trip on debris either.

- [Melissa] Yes.

I mean, yes, if someone's debris...

I'm less likely to trip over  
debris because I don't walk.

You know, and there's all kinds of things.

That's a great...

You get a fabulous prize. You get a top.

Do we have a fabulous...

Oh, I'm so sorry to make you run down.

We have a fabulous prize person.

So you get a top you  
can spin at your desk.

You can spin it and play with it now.

Thank you so much.

And see me for your fabulous prize.

Okay, so what else would people say?

Sadie's running towards someone.

I guess she's...

I see the hand now.

Yay!

- My name is Lauren.

So what I would probably tell this person

is that, just go from  
a practical standpoint.

If we start overcrowding  
these nursing homes

and long-term care facilities with people

who don't necessarily need to be there,

it does not make it  
safer, because the staff

can easily get overworked and overwhelmed.

We saw that with COVID. (chuckles)

- [Melissa] That is great!  
You get a fabulous prize!

Anyone else?

Lemme tell you a story.

I have a friend who uses  
a power chair and a vent

and she went to the shelter.

We live in the same town  
and she went to the shelter,

and we checked the shelter out for access

and the access was great 'cause they had

a lift up above four stairs.

You go into the building,  
there's a little lobby.

You have a lift up four  
stairs. It was great.

We checked this before I  
was doing disaster work.

We thought it was great.

So she went to the shelter and we had

like an eight-day power  
outage, and they said to her,

keep in mind she uses a  
vent and a power chair,

and they said to her,  
"The lift wouldn't work."

She's like, "Well, why  
doesn't the lift work?"

The generator won't power the lift

and nobody had checked that.

So that shelter was not  
physically accessible

to anyone who couldn't  
walk up five stairs.

And she said, "Well, what should I do?"

"Well, it's not a problem!"

"Good, why isn't it a problem?"

"You can just go to the  
nursing home down the street."

What I didn't tell you about my friend

is she's also an attorney who  
uses a vent and a power chair

and she's like, "No,  
we're not having that,"

and she filed a complaint, but  
it would've been easy for her

to just go down the street  
and get really sick,

and a nursing home is a dangerous facility

for somebody using a vent.

And she had the privilege to say no.

She had the resources to say no.

She had the education, she  
had all of those things,

but if she didn't know the difference

and she wasn't comfortable  
standing up to authority,

it might've been very, very different.

So you wanna support people in...

It was really easy to say she needs

to be in a nursing facility.

Well, that day she was  
living in her house.

And I think that might  
be one of the strategies.

Where were they living the day before?

Just something to think about, okay?

Makes sense?

Any other ideas, thoughts?  
Things you could say?

It's hard to explain to  
colleagues why nursing facilities,

particularly if they work in them,

aren't good places for people  
and how people get sick

and people get sicker and  
people can die, so thank you!

Next, please.

So ableism is manifested  
whenever there is non-compliance

with disability-rights laws.

So when you're not in  
compliance with the ADA and 504,

you're being systemically ableist.

That's not to say you're an ableist person

or you're a bad person  
or you should be punished

or anything like that.

It's saying some bigger  
system did something

without consciously being aware of it.

And that looks like  
people refusing to admit

a service animal to a disaster shelter

because we don't want animals here.

Now, more and more shelters admit pets

and that's changing,  
which is a good thing.

Not providing paper or  
electronic materials

in accessible format.

It's a manifestation of ableism.

And again, it's no person  
saying, "I'm gonna be ableist

and oppressed people."

Not providing sign language interpreters

or video remote interpreting, VRI,

and using inaccessible  
spaces for disaster shelters,

disaster recovery centers,  
and points of distribution.

Ableism's also steeped in  
systems of disaster preparedness

in response and recovery.

It's reflected in institutional bias

like we talked about before,  
practices and policies

that make it easier for us  
to be institutionalized,

such as the 1135 waiver.

You don't have segregated  
shelters in Illinois.

In some states, Florida is one of them

and there's like three other states.

Florida is one where it's  
statutorily mandated.

They have segregated, air  
quotes, special needs.

People with disabilities are not special.

It's whether something's  
equitable or integrated or not.

And there's shelters  
that aren't integrated.

That's a reflection of systemic ableism.

I'm gonna talk about the  
next subject very briefly,

and I think she's out  
of the room right now.

June Kailes, who spoke to you earlier,

is an expert in why disaster  
registries are a bad thing.

They presume everyone's at home.

They presume that everyone  
can be accounted for.

They are not effective and they give

people with disabilities a false  
sense of hope and security.

Just know the disaster registries are bad.

And I promised her I'd called her.

Maybe that's why she's not here.

Oh, you are here. Where are you?

What's that? Ah, she's way  
in the back of the room.

So June is the person if  
you have other questions

about that, you can just ask her. (laughs)

How do you interrupt systemic ableism?

How do you change a law or policy

when you're just one  
person doing one thing,

working on your thing?

What you wanna do is work and plan

before the disaster like always.

You wanna review the emergency  
operations plan, or EOP,

with disability stakeholders and partners.

You wanna create and implement a plan

to address the systemic ableism,

what you're gonna do to  
address systemic ableism.

And you wanna support activities

and initiatives that will help  
dismantle systemic ableism.

Next.

And just wanted to give a word  
to you here about language.

Language evolves and morphs and changes.

It's okay to use person-first language

like person with a disability.

It's also okay to use  
identity-first language

like disabled person.

More and more people right now

are claiming identity-first language.

I'm old enough that the  
correct way of speaking

was identity-first.

I call myself a disabled  
person, and someone said

people with intellectual  
disabilities fought really hard

for us to be called  
people with disabilities,

so I changed it to  
people with disabilities,

and now it's going back to identity-first,

to disabled people.

So it's not a set-in-stone thing,

but either of those things is correct.

You wanna avoid euphemisms  
like differently-abled.

First time I heard that, I was sitting

next to a wheelchair user  
and she went, (gasps)

"Makes it sound like we can fly." (laughs)

We can't. I don't have  
any different abilities.

There's some abilities I don't have,

but I really don't have  
different abilities.

Euphemisms, like I  
said, differently -bled.

Dated terms like handicapped.

Handicapped isn't a slur as I see it,

but what it says to me  
is you're not keeping up

with the times and what's going on.

It dates you.

Terms that may viewed as patronizing.

"Hi, baby, sweetie. How are you today?"

It has a tone that goes  
with a lot of the time.

You've heard it.

Also avoid language that presupposes

a negative, like victim of.

I'm not a victim of my wheelchair.

My family is often a victim of my scooter

when I roll over their toes.

They are wheelchair victims. I am not.

Suffering from.

I'm not suffering from cerebral palsy.

That's my disability.

I might be suffering  
from the heat or the cold

or the weather or the climate or you know,

whatever's going on,  
or being in an airport,

all of those kinds of things.

I might be suffering from those  
but not from my disability.

You wanna avoid language  
that groups people.

The mentally ill.

Mentally ill is problematic  
for lots of people,

but you don't wanna group people either.

The disabled.

And as I was saying before, the AFNs.

You don't wanna group  
people by your language.

And next, please, you wanna  
take an anti-ableist approach,

so how do you do that?

How do you start?

You learn to identify  
ableism and bias, what it is.

You learn to mitigate it and interrupt

disability bias and ableism.

You understand the legal  
obligations of your organization

to disabled people.

You prioritize hiring us.

The best way to develop  
an anti-ableist approach

is to hire people with disabilities.

That does more than all  
the training in the world.

You want to have us there.

You want people with  
disabilities to feel safe,

'cause most disabilities  
or many disabilities

are not visible.

They're not apparent, those disabilities.

You wanna have people  
feel safe in identifying

that they have a disability  
and what their needs

for reasonable accommodation  
are if they need it.

You wanna include subject matter experts

and disability-led  
organization in all aspects

of planning and implementation.

You got that?

We gotta be at all your  
tables all the time.

Questions!

Questions?

We need to get our blood sugar up.

There should've been more  
sugar out there. (laughs)

So I'm gonna turn it  
back over to Shari now.

Is that correct?

- [Shari] So now we're  
gonna talk about including

the disability community, and  
we have an activity for you.

So our scenario is you're told

that you need to have representatives

of the disability community  
at your next meeting,

so our questions for you  
are who do you invite?

How do you get people to attend?

What steps do you take to  
make the process accessible?

And so you can maybe talk  
for a couple of minutes

at your table, or you know,  
you can raise your hand

and give us some ideas.

- So my name is Toni and we don't really

have answers to this.

We just talked about how  
when you do it incorrectly,

sometimes it doesn't feel good

when you feel like  
you're targeting someone

who visually looks like they are disabled.

And I aligned this to if you are trying

to bring together a  
diverse group of people

and you're targeting  
someone because, well,

I know that person's  
Latino, so lemme go ask them

to come be on this committee.

So we didn't have really great answers,

but we just kinda went  
down that rabbit hole

of boy, we could really offend some people

if we don't do it the right way.

- [Shari] And I would say to that you look

for stakeholder organizations,  
people that already identify

as, you know, having a  
disability, who are eager

to bring their subject matter expertise

and lived experience to the table.

Oh, fabulous prize.

You get a Rubik's Cube.

I don't do this as often as you do.

- Yeah.  
- Next table, over here.

- The general discussion -

My name's Mike.

The general discussion was more about

how do we get people to attend?

We pretty well have a good  
idea, a grasp of who to invite

and possibly the steps to take,

and maybe the example is here even.

How do you get people to attend?

We know what the issues are.

You know, we know that  
you can change the hours,

you can offer food, you can offer prizes.

You know, we talked about using Zoom

or something equivalent.

How do you get the public or those people

that need to attend these  
meetings to help you to come?

It's a common problem we see, you know,

both in employment and in volunteering.

- [Shari] Mm-hmm. That's a good point.

And I will share an example  
from a group in Maui

working recovery that a lot of them

are younger women with  
children and they provide

food and childcare as  
often as they're able

when they're setting up a meeting,

and it's working out very well for them.

They have a lot higher participation.

But great points, thank you.

- [Melissa] Any prize?  
- [Shari] Yes.

Give him a dinosaur.

You get a dinosaur.

Next.

- Hi, my name's Sue.

Everything that everybody  
said obviously is fantastic,

but I think just taking the first step

and making that phone call  
to see if there's, you know,

the people that you  
know in your community.

Maybe those people might  
know other individuals

and it could cascade to where  
you might have more people

than you bargained for.

- [Shari] Mm-hmm. Good point.

And you get a star Slinky.

We probably have time for one more group.

- (inaudible)  
- [Shari] Yes.

You all were having a great discussion.

I was eavesdropping.

- I feel highly intense today,

so there's gonna be a lot to say.

Just wait. (laughs)

I think that since our goal here

is to just kinda tap into  
that lived experience

of people in the disability community.

Depending on the size  
of your organization,

let's say you work at like a hospital

or like a larger long-term care facility

or a school or, you  
know, an entire district,

sending out maybe like a flyer

just to everybody, you know, all inclusive

that says, "We are looking for people

to join these committees  
that have lived experience.

If you have lived  
experience in these areas,"

maybe give some examples,  
'cause some people,

they might have a disability  
but might not know

that yeah, that is  
considered a disability.

And there's a lot of  
situations where, you know,

I come into contact with  
people and you know,

even I used to work in mental health

and they were like, "I  
don't have a disability."

Well, that's considered a disability,

but you know, let's change the language,

since that's not what  
you want it to be called.

- [Melissa] Right.  
- Okay?

So maybe you don't use  
the word disability.

Maybe just use lived experience.

And then you may have an  
increased number of participants,

volunteers to step up and help you out

with that committee that  
you're putting together.

- [Shari] That's kind  
of that same cascading

effect that you're-

- Yeah.  
- [Shari] -talking about too.

Yeah. Great, thank you.

And you get a whistle,  
but you have to promise

not to use it during  
the conference. (laughs)

Okay, so let's move on to talk

about making your meeting accessible.

So you need to ensure that invitations

are in accessible formats.

Request information on any  
accommodations required

for full participation in the meeting.

And these also, you  
know, can just be listed

as, "Is there anything you need

to fully participate in this meeting

and get as much out of it as possible?"

And that kind of broadens  
your audience a little bit.

Book language-access providers,

such as sign language  
interpreters or CART captions,

and provide print and electronic materials

in accessible formats.

But when you're sending out  
those invitations by email,

just be sure that, you  
know, if you're including

any kind of infographics or, you know,

pictures or anything like that,  
that you are describing them

and making certain that  
someone who's using

like a screen reader will know everything

that's in the content of that email.

You should also assess  
your venue for access

by a trained access  
auditor, someone who knows

what to look for in that venue.

And then during the meeting,  
you wanna maintain access.

A lot of times when  
we're doing conferences,

people don't always push chairs  
all the way in at the table,

and so some of our paths  
of travel become blocked

and you have to kind of reset things.

And so just being aware of those things

and making them part of your  
housekeeping at the beginning

when you're telling people, you know,

kinda the rules of the road.

Ensure that the venue is on a bus route

and that there is an  
accessible path of travel

to the venue from the bus route

and verify that the venue  
has ample accessible parking.

Invite disability-led organizations.

Disability-led organizations  
are those organizations

where the majority of board  
and staff are disabled people,

and disability-led organizations  
may be single disability

or cross-disability  
focused and it's important

to invite both types.

Inclusive disaster planning strategies.

Connect with the disability community

by contacting Centers  
for Independent Living,

which a lot of you are familiar with,

the Statewide Independent Living Council,

which creates the Statewide  
Independent Living Plan

for your state, and other  
disability-led groups.

And we are available to talk with you

about what some of those other  
groups might look like too.

And a lot depends too  
on what your focus is,

but those are all good places to start.

So I'm gonna stop there and  
turn it over to Melissa.

- [Melissa] Okay.

Centers for Independent Living.

The good news is you have the State

Independent Living Council  
with a booth across the hall

and they might be in this room.

And the Centers for Independent  
Living are here in this room

and across the hall here today.

So for those of you wondering  
who do I reach out to?

They're here, so that is  
really, really exciting

and I'm thrilled about that.

Can you tell I'm a former Center director?

I love Centers for Independent Living.

CILs are disability-led, cross-disability.

That means it's people with all different

kinds of disabilities.

They're locally-administered.

They're run locally. Very, very locally.

And they're not-for-profit organizations.

They're not state agencies.

They're not beholden to  
the federal government.

That's where they get their funding,

but they're not state agencies.

They're not federal agencies.

And CILs provide advocacy and support

to assist people with  
disabilities of all ages

to live independently and fully integrated

in their communities.

People will sometimes say,  
"Well, how many people

live at this Center for  
Independent Living?"

No, the goal is so that people  
can live in the community.

And I get why it's confusing language,

so just know that about CILs.

Next slide, please.

Independent Living philosophy,  
and this is just a thumbnail

and I'm leaving lots out, but this is just

to whet your appetite for it.

Independent Living philosophy  
accepts what's called

the social model of  
disability, which means

that disabilities don't  
need to be fixed or cured,

rather society needs  
to remove the barriers

and create inclusive,  
non-ableist environments,

that ableism and disability  
bias need to be mitigated,

and that disabled people  
has should have the right

to self-determination, equal opportunity,

and full participation and equity.

Next, please.

Disabled subject matter experts.

And I talked about this  
a little bit before.

While everybody with a disability

is an expert in their own experience,

absolutely, positively. Not  
everybody with a disability

is or should be expected to  
be a subject matter expert.

That's a lot to put on someone.

What if I wanna be an astrophysicist?

I wouldn't be an otherwise  
qualified person with disability.

That couldn't happen.

What if I said I knew nothing  
about Independent Living

or disability rights?

I'm just someone who  
happened to use a scooter.

Or what if I didn't wanna work?

Or what if I'm a stay-at-home parent?

You know, all of those kinds of things.

So you wanna ask about an  
individual's qualifications

when technical expertise is needed.

So you just say, "Jane uses a wheelchair.

They must know all about what  
an accessible bathroom is,

and probably they know about  
sign language interpreters

and what blind people need too."

Ask if they're qualified,  
and if they are qualified,

understand it's not something  
that's easily learned.

You have to study and develop expertise

and you need to compensate  
people for their time.

A lot of work has gone  
into them learning that

and you wanna be respectful of people

and pay them for their time and expertise,

'cause nobody trains us  
as a disabled person.

We don't get a manual when we're born,

so you know, we have to go  
figure it out on our own.

You wanna plan and partner

with disability-led organizations.

Include disability-led  
organizations, or DLOs,

in all, and this is in all  
caps, aspects of planning.

Not just access and functional needs,

but all your aspects of planning.

So you don't wanna have a group  
that deals with disability.

When my state dealt with COVID,

I was put on the communication committee

that did public relations  
and nothing else.

There needed to be someone  
with disability stakeholders

in every aspect of it.

You wanna include people back and forth.

And you wanna include organizations  
which represent people

with all types of disabilities.

Try to create opportunities  
for partners to convene

and lead planning meetings,  
preparedness events,

and exercises and drills.

So you want those  
disability organizations?

Maybe they take the lead.

Conferences.

Invite people with disabilities  
to your conferences as well.

When you have events,

invite the Centers for Independent Living.

Invite the State  
Independent Living Council.

Ask the State Independent Living  
Council across the corridor

to send out flyers and brochures.

So the electronic material  
might be appealing.

They might overlook  
something you sent them,

but if the Independent Living  
Council send it to them,

the Statewide Independent  
Living Council sent it,

it might get more attention.

Go, "Oh, this is something  
pertaining to us."

So just remember that. Remember that.

Go to disability community tables.

Invite yourself.

They're not shy. Don't you be shy either.

Ask to come.

Start and continue to build relationships.

Like I said, go to their  
annual picnic or whatever.

Build relationships with them  
in blue-sky times if you can.

Get on their mailing lists.

So what works?

Disability community informed planning

for preparedness response and recovery.

Disability community informed training

for emergency responders and managers.

That's really important.

Real time, real people  
drills and exercises

and acknowledgement of  
individual and community agency,

mutual aid efforts, and resilience.

That's really important.

Questions!

We definitely need more  
blood sugar bits. (laughs)

But there's still more fabulous prizes

and I'm gonna turn it back over to Shari.

- [Shari] Thank you.

So now let's talk about  
how we can work together

to save lives.

First I'm gonna tell you a story.

In a disaster not too long ago,

a person had to sit and sleep  
in their mobility device

for 10 days at a government-run

medical special needs shelter,  
which led to severe edema

in their legs.

The Partnership was able  
to assist in the delivery

of an appropriate bed for them

provided by the American Red Cross.

These things should not happen.

So collaborating inclusively.

Identify the problem  
solvers, people who come up

with solutions, people who have  
great ideas for innovation,

ways to partner and  
collaborate to get things done.

Who's already serving  
the disability community

in disasters and emergencies?

Establish a shared purpose.

What's the goal?

For example, access, equity, safety,

replacement of equipment, making  
accommodations for people.

Agree on a plan of action.

Who does what with what and for how long?

And that's about identifying  
capacity and capabilities,

what a group brings to the table.

How long can they bring it?

Because resources, including  
time and humans, run out.

Disasters are hard and they  
get very difficult for people.

You can burn out.

I have, and you have to take a break.

But knowing who can be  
there and who can bring what

and do what and at least having an idea

of how long everybody can sustain that.

Will they need to take  
a break here and there?

Also, implementing and exercising

the plan you come up with.

Practice, practice, practice, practice.

And evaluating the plans  
and exercises regularly.

What works? What needs improvement?

What can we maybe take a  
different perspective on

and come up with something  
totally new by way of a plan.

Other ways to engage

disability-led organizations as partners.

There's something called an  
overnight shelter exercise

where you can set up a  
shelter and encourage people

within the community, not  
just people with disabilities,

but bringing people into that shelter

to find out what it will be like.

You know, how's it gonna work?

What do you maybe need to do differently

when you're actually opening up a shelter?

It also helps you understand the facility

that may be chosen and  
is it really accessible

or is it some place that  
needs to not be used

and do we need to look at something else?

Participating in tabletop exercises

like the one we're doing tomorrow.

Getting lots of different perspectives

on how to make things work  
in response and recovery.

Participation in large-scale exercises.

There was recently a  
national mass-care exercise.

Our directors, German and Shaylin,

were able to attend that,  
and Priya was there as well,

and got to have a lot of  
input and provide feedback

and also do some educating  
of some of the folks

who were there.

CERT training.

Community Emergency Response Teams

are a critical piece of response

and encouraging people with disabilities

to become CERT-trained  
is a really good way

to get their perspective on things

and to have people who can interact

with those folks in the  
community who may need

a different way of  
responding to their needs.

I'll tell you a quick  
story about CERT training.

I had a friend who was a triple amputee.

She was about to do CERT training

and they said, "Okay, so  
we need you to tell us

what we need to change or alter for you."

And she said, "How 'bout this?

Train me the same way  
you would anyone else

and I'll let you know if  
there's anything that I need

or that I can or can't do."

She went through the whole thing

the way it's normally delivered

and got certified immediately.

FAST training like June  
talked about this morning.

Very important way for our  
community to contribute

and an important way to get that guidance

and technical assistance  
and lived experience.

Community preparedness events.

These, I think, are so, so important,

because the better prepared we are,

obviously the better we survive  
when the balloon goes up.

Working with CILs, putting on  
community preparedness events,

other disability-led organizations,

being there to do those events

where you may be  
providing a weather radio,

things that are not always easy to come by

when you're trying to build a kit.

One of the approaches that we take

is low and no-cost ways to build that kit

and kind of building it up over time,

because not everybody can go out

and put together a go bag and  
a kit all in one fell swoop.

Effective approaches for better outcomes.

Hold regular meetings with  
stakeholders from across sectors

and across the disability community

to identify barriers and  
create collaborative solutions.

Stakeholders include  
emergency management agencies,

public health, decision and  
policy makers, disability-led

and disability-related  
organizations, schools.

All of the groups that  
are represented here

are important stakeholders  
in these meetings

and planning sessions and making  
things go better next time.

And now I'm gonna talk quickly  
about promising practices.

In Washington state, there is a coalition

on inclusive emergency  
planning, which is a statewide

cross-disability advisory  
group that works with state

and local emergency  
management stakeholders

to build disability  
accessibility and inclusion

into all aspects of emergency management.

This group is funded by a grant

from the Washington Department of Health

Executive Office of Resiliency  
and Health Security.

So there's another little  
lesson there in, you know,

go look for funding.

Look for people who are looking  
for innovative solutions,

who are supporting  
disabilities-led organizations,

who are supporting, you  
know, response initiatives

and that kinda thing.

There's grant money out there.

So another promising practice, in Florida,

the CIL network has come  
a very, very long way

in becoming a cohesive group of people,

group of agencies that  
respond to disasters.

In October of 2018, Hurricane Michael

struck the Florida Panhandle.

It's a devastating Category 5 storm.

The Florida Statewide  
Independent Living Council

and the CIL network  
encountered many barriers

to meeting the needs  
of disabled survivors.

Since then, they've collaborated  
with emergency management

and public health to remove  
many of these barriers.

Major milestones have been  
that the Florida SILC director,

Statewide Independent  
Living Council director,

has a seat in the  
Emergency Operations Center

and the CILS have access  
to state housing resources

so that they can assist  
in finding accessible,

affordable, transitional  
housing and permanent housing.

So any questions?

We really should've had that  
candy on the table, man.

(Shari laughs)

So now we have another activity for you.

Ideas for your community.

Is this me or you?

- [Melissa] Yeah.

- [Shari] You?  
- [Melissa] Yeah.

- [Shari] Thought so.  
- [Melissa] It doesn't matter.

We can do this together, Shari.

- [Shari] We can.

- [Melissa] (laughs) So the activity...

See, you're not asking questions,  
so you're gonna do work.

The activity is ideas for your community.

Discuss with your table  
how emergency management,

public health, including hospitals

and the disability community,  
and public schools,

can collaborate to improve resilience.

How will you change or  
expand disaster planning

based on what we've discussed today?

And what organizations or individuals

might you add to your planning group?

And assign a spokesperson,  
because there's still

tons of fabulous prizes.

- (inaudible)

- [Shari] No.

(Shari laughs)

- Okay, I'm going ahead,

even though there's background noise.

- [Melissa] Mm-hmm.

- We discussed, in regards  
to what we could do

for our community, I think  
we're rather unique here

'cause we already know each other.

We didn't have to network  
to a certain extent.

We believe we have the mechanism

to be able to get everybody together

and start to bring up how we need

to get people with the  
AFN more involved with us,

including the Independent  
Living organizations

and anybody else that would  
have specific interests,

and we could start a grassroots effort

to review what we  
already have as a county,

or we also, some of us  
serve multi-county areas,

and then decide steps that we need to take

to modify any plans or procedures

to make sure that everything's covered,

including inventory resources,  
where the interpreters are.

Again, we're lucky in Sangamon  
County being the capitol

that we have many of those resources

located within an hour  
or so, but we still need

to identify 'em and do better at that.

- [Melissa] Right. Great.

- And that's basically about it.

- [Shari] Thank you. Who's next?

Don't be shy.  
- [Melissa] The prize.

Prize.

- [Shari] A prize for you.

Let's do that.

Okay, don't be shy, y'all. Come on.

Somebody tell us what you came up with.

Ricky? Go ahead.

Well, we have a mic coming your way.

- So I did mention that for us,

it really hit home  
today when you guys said

we have a plan for you, not with you.

We have a lot of folks that  
are getting up there in age,

they're in assisted living  
facilities and stuff like that.

We do have plans for them obviously;

an an EOP is required. But it  
is for them, not with them,

and I think we need  
representation at the table

from these facilities in  
order to make a better plan

to make sure it's actually  
gonna work as well.

- [Shari] Great. You  
get two fabulous prizes.

- Hi, my name's Lisa, and  
just to build on that,

and then take those  
partners and then put them

in our exercises, 'cause  
they're often very missed

when we're exercising  
our plans to get to that.

So I would say we  
definitely need to include

them in our exercises.

- [Melissa] I wanna clap now, so I'm

giving you hands clapping.

(all laughing)

Thank you.

- [Melissa] We got two minutes, I guess.

- [Shari] Okay, we have about two minutes

left for this session.

- [Melissa] Yeah, so we need to close.

- [Shari] Okay.

Wanna discuss-

- We're interns for the  
Illinois Pharmacist Association,

so we don't really have  
like super high roles

where we're at, but we  
discussed including places

like SILC and Centers  
for Independent Living

because we know there's a  
lot of pharmacies closing

and that's gonna create an extensive need

but be under-resourced.

So if we have these other  
organizations in place,

we can all work together to figure out

how to meet the needs of everybody.

- [Shari] Yes.

- [Melissa] And you get a Rubik's Cube.

- [Shari] Yes, and I'm just gonna say,

I'd like to give you  
all a round of applause.

Thank you so very much.

- [Melissa] And I wanna  
point out to resources.

Again, Equipped for  
Equality, which is your

Protection and Advocacy office.

Illinois Council on on  
Developmental Disabilities.

Disability and Human Development,

which is a University Center on

Excellence in Developmental Disabilities.

Statewide Independent Living Council,

and the Illinois Center  
for Independent Living,

and I wanna give Luthie, our  
fabulous prize runner, a car.

So you get a new car for yourself-

- For me?

- [Melissa] - for giving out  
prizes. Yes, that is for you.

- [Shari] All right!

- [Melissa] Thank you all so much.

And we have the next panel coming.

- Thank you.  
- [Shari] And our last slide

has our contact information.

You got Melissa's from the one before,

but mine is up there too  
and we're both available

to answer any kind of  
questions you may have

or listen to any new ideas anytime.

Thank you again.