- [Germán] This is Germán,
welcome back everyone.

We are getting ready for our
final activity for today,

a panel.

My name is Germán Parodi.

I am a Co-Executive Director along Shaylin

of The Partnership for
Inclusive Disaster Strategies.

You've seen me in the back all day,

and thank you for staying
all day for this great panel

we have next of subject matter experts,

people that know the field

and will share about things
that they're doing locally

and in the area and wrap us
up on a great event today.

To my left, I have Sue Johnson

from the Illinois
Department of Public Health,

Office of Preparedness and Response.

Sue is one of two access and
functional needs planners

with the Illinois
Department of Public Health

Office of Preparedness and Response.

She is a certified
rehabilitation counselor

with over 15 years of experience

as a vocational case manager
and a job placement provider.

Sue also served as a
volunteer outreach coordinator

with the City of Independence in Missouri

Emergency Preparedness
Department prior to joining IDPH.

Next to her is Thane Hunt.

He's a special guest.

We were going to have Kira Meskin

from the Progress Center
for Independent Living,

who also is a chairperson

of the Illinois Emergency
Management Agency's

Access and Functional
Needs Advisory Committee.

And thank you Thane for
stepping in on her behalf,

she's sick and couldn't make it.

Thane is with the Center for
Independent Living in Peoria,

Advocates for Access.

Thane started at Advocates
for Access in 2014.

He's an access and
functional needs committee

of the Illinois Emergency
Management Agency as a member.

He previously worked as a
foster care case manager

upon his retirement
from the city of Peoria.

He was a Peoria police
officer for 10 years,

and he enjoys being able to help people

remain independent in their
home and in the community.

He earned two Bachelor's
of Science degrees

from the Western Illinois University.

Next to him is Jae Jin Pak

from the Institute of
Disability and Human Development

at the University of Illinois in Chicago,

and a co-founder of the Chicagoland

Disabled People of Color Coalition.

Jae Jin is a social justice
advocate, educator, and ally

with over 30 years of experience.

He identifies as an Asian
immigrant with disabilities.

He has worked on issues
of gender-based violence,

anti-trafficking prevention,
mental health, disability,

immigration justice, and anti-oppression.

He has conducted thousands
of hours of training

with diverse communities and
professionals nationwide.

His core values of collaboration

and recognizing
intersectionality has allowed him

to build strong connections

with diverse communities and providers.

As a co-founder

of the Chicagoland Disabled
People of Color Coalition,

they work to promote disability pride

in communities of color.

DPOCC brings awareness to the issues

that face the disabled, autistic, deaf,

and neurodivergent people of color.

Jae Jin is the Coordinator
of Community Education

for the Institute of Disability
and Human Development

and Self-Advocacy Training Mentor

for Illinois Land at the
University of Illinois in Chicago.

Lastly, he serves on
the Quality Care Board,

Access and Functional
Needs Advisory Committee,

Disability and Immigration
Task Force of Illinois,

and the National Human Trafficking

and Disability Work Group.

He's a graduate of North
Illinois University

and an IL Land Fellow.

Next to him is Rodney Garrott,

FEMA's Region five disability
integration specialist.

As a Region Five Disability
Integration Specialist,

Rodney provides technical assistance

and advisory service to
region five emergency managers

and community partners
on disability integration

and coordination.

This is done through the
development of strategies, tools,

and tactics that ensure the
access and functional needs

of people with disabilities are including

in all aspects of disaster
planning, response and recovery.

He has led disability
inclusive emergency operations

on multiple major disasters
across the nation.

Rodney has led exercises,
presentations, classes,

and workshops on inclusive
emergency management

and provided input for various regional

and national level
policies and directives.

Rodney is the secretariat

for FEMA's equity community for practice,

and prior to FEMA, Rodney has experience

as a clinical coordinator
providing case management

and residential support to people

with access and functional needs.

We have a new addition,

Clark Galvin from IEMA.

Care to introduce yourself,

Scott Galvin from IEMA.

- [Scott] Clark. Actually, that's a first.

- [Germán] Almost there.

- [Scott] No, it's okay.

Good afternoon all, my
name is Scott Galvin.

I am the Manager of Strategic
Operations and Preparedness

for the Illinois Emergency
Management Agency

and Office of Homeland Security.

Been in the field of emergency
management for 22 years.

So my role is really the
chief planner for the agency.

I also serve with Jae
Jin on the Governor's

Access and Functional
Needs Advisory Committee.

Been serving in that capacity
for the past three years,

and it's my job to integrate,
per the legislation,

integrate access and functional needs

language and doctrine into our
planning at the state level,

and help to facilitate it
down to the local levels

to enhance primary and
secondary response mechanisms

for all Illinoisans and all visitors.

Thank you.

- [Germán] Thank you Scott.

And lastly, not least,

we have Mary Casey-Lockyer

from SpringLock Disaster Consulting.

Mary is currently a Director

of SpringLock Disaster Consulting.

She retired in 2023

from the Disaster Health
Service Program Lead

at the national headquarters
of the American Red Cross.

For over 20 years she fulfilled this role

for the program development

and continuous quality improvement

for Disaster Health Services program

at national headquarters
and managed a cadre

of more than 2,600 disaster
health service volunteers.

As a Disaster Health
Service manager and chief

with the Red Cross, she has
been on 22 national deployments,

including the 2018 Disaster
Relief Operation in Saipan,

and multiple assignments supporting other

Red Cross Disaster Relief Operations

from national headquarters

Disaster Operations Coordination Center.

Mary was assigned as a
Senior Medical Advisor

to Red Cross's national
disaster operations

during 2020 until her retirement.

Mary acted as the Red Cross' liaison

to the Secretary's Operations Center

at the Department of
Health and Human Services

and served on the Board
of Healthcare Ready.

She has published many
articles, most recently,

"Healthcare and Supportive Services

in General Population
Shelters" in August, 2023,

"Disaster Medicine and Public Health."

Mary received a Master's
in Homeland Security

for Public Health and Preparedness

from Penn State University in 2010,

and is an RN in critical care background.

What a great panel.

Let's just give them a round
of applause to get 'em started.

We'll have a series of questions

and we'll have the panel
answer them as they would.

Why don't we start, Sue,
how can emergency managers

be more inclusive for
people with disabilities

and access and functional
needs from the outset?

- [Sue] Well, of course we're.

Yeah, hello?

So obviously we've all been
talking about inclusion

and so that's my perspective.

Inclusion from all phases,

with all phases of the
emergency management cycle.

Definitely having participation
of drills and exercises,

after action reviews, and just definitely

throughout the whole process.

I think Scott could
answer a little bit more

as far as the emergency
management process,

but knowing your community
and those resource needs,

I think that is gonna
be a critical component.

- [Germán] Thank you, Sue.

Thane?

- [Thane] So from a Center
for Independent Living's

point of view,

when we look at how do we include
persons with disabilities,

it's just that, starting at the beginning,

starting from writing your plans,

starting from your meetings.

And one of the ways that
you can do that is reach out

to your local Center
for Independent Living.

Most of us come out and
do trainings for free,

and we cover multiple topics,

everything from service animals
to person-first language,

but being on board from the start helps

so that plans don't have to be written,

well, lemme rephrase that.

As we all know, the best laid plans

typically end up rewritten anyway,

but if we participate from
the beginning as partners,

it makes it less likely

that those plans are
gonna have to be rewritten

or completely overhauled.

That being said, as Centers
for Independent Living,

while we are subject matter experts,

we can't be experts in everything.

So there may be areas that
emergency planners come to us in,

and we may refer you to
another disability organization

or specialty organization.

But if the planning is put
in place from the start

with inclusion in mind,

it'll work better in the
long run for everyone.

- [Germán] Thank you Thane.

Jae Jin, and again, for everyone,

how can emergency
managers be more inclusive

of people with disabilities
and access and functional needs

from the outset?

- [Jae Jin] I think it is, as
we've been discussing all day,

and as folks has mentioned already,

the idea of starting with
the principle of inclusion,

and

you know, looking at the definition,

and being very proactive
and intentional to include.

The idea of inclusion is
every community and everybody.

As policy makers, as you design plans,

you design how you
operate and work together,

start with that idea of
inclusion as a core principle.

And ask questions, who is missing?

Who is missing at the table?

Who is missing at our outreach?

And start to think, and if
disability is a community,

then be thoughtful of, as
we've been discussing all day

and understanding that
disability is diverse,

just like communities
of color, multicultural,

multilingual communities.

Human beings, by nature of
who we are as human beings,

we're diverse.

We need to be open, and
welcoming, and thoughtful,

and in consideration
of all our differences.

And specifically to
disability, be proactive.

Understand that we have
consumed, all of us,

disabled, non-disabled
and everything in between,

have all consumed messages of disability

as a negative stigma.

Understand those messages are out there

and make a choice to put those stigma

and stereotype messages aside

and make good faith efforts to connect

to disability organizations

and groups like the Centers
of Independent Living.

In addition to that, connect with,

look around in your
counties, in your townships,

in your towns and cities

of the different
disability provider groups

and agencies that are in your local area.

What disability-led groups are out there

that you can connect with?

And as was mentioned earlier,

invite them to a planning meeting

or ask,

can

someone from your office
attend a public event?

Or just attend a public
event and start networking.

I will say one of the
things, one of the realities,

and I identify as an Asian
American, middle aged,

multi-disabled person,

and growing up disabled

and having conversations with
many disabled colleagues,

friends and peers, one thing
that's important to understand,

like with any other marginalized community

growing up with discrimination
and negative stereotypes,

is that we carry that with us.

If you cold call us or invite us,

there is a sense of,
we're not going to be,

"Oh, yay, that's wonderful!"

We're gonna say, "Why? Why?

What do you want from me?

Am I gonna be your token?

Am I going to be used for something?"

There is some reluctance
and you have to earn trust

with the disability community,

because we are marginalized,
we have experience,

and we have been pathologized.

So just understand that reality.

Everybody with disability is
gonna respond differently.

We're all different individuals

and we're all different
disability communities,

whether we're Deaf, hard
of hearing, epileptic,

intellectually disabled,
neurodivergent, use wheelchairs

or other - communication devices.

All of them are unique and different.

And it's important to
be respectful of that

and acknowledge that.

And also as we mentioned today,

we're the experts in our disability,

and if you approach us with
kindness, with respect,

and recognizing our lived
experience as expert information

and give us the opportunity to
give you technical assistance

and guidance and feedback, and you listen,

and you hear, and you
consider in meaningful ways,

it will help grow that rapport

and have a sustainable
working relationship

in creating a good partnership.

And I've talked a long
time, so I'm gonna stop now.

- [Germán] No, thank you so much.

So really going into that deep dive

and as you said, building that trust

and outreach as it's been
mentioned throughout.

Thank you Jae Jin and everyone.

Rodney, please.

- [Rodney] Yeah, really quickly,

I'll piggyback off the inclusion comment.

I think Jae Jin really
took it a level deeper

where it's kind of inclusion
with intentionality.

So you have local, state, federal levels,

different types of committees,
trainings, education,

different events.

And so just inviting
someone as a placeholder,

like you said, as that token
to say we check the boxes

related to access and functional needs

doesn't quite hit the mark

and can also be a little tongue in cheek.

So it's really not only
evaluating that community partner

and taking the consideration to say,

"And where are they best suited?"

I see Libby out here who worked on

an access and functional needs task force

down in southern Illinois

because she was a local community partner

and can provide that level
of intimate engagement

and awareness of what's
going on at that level.

But then you also have
state level entities

that may be better suited

for different types of engagement

with Scott and IEMA.

And so it's being intentional about that,

but also with that it,
it's, to use a phrase,

it's kind of offering a seat at the table

without the path to get to the table.

And so the education and
training behind that,

just not to say,

"Hey, we need you on
the stakeholders call,"

but, "We need you on the stakeholders call

to provide X, Y, Z situational awareness.

Here are the outcomes and
here's kind of the next steps

to paint that picture."

So that you don't have that response of,

"What do you want, why, and
where's the strings attached?"

And so as I heard inclusion,

that was something that came to mind.

And then I would just say making
accessibility the standard

and not the modification.

So if we show up at a disaster

and we know that we have a
budget that we need to stick to,

we stick to that budget.

Almost to the dime.

So similarly with accessibility,

setting that as the standard,
not only by the laws,

but even going above and beyond that

based off what we know the
needs of the community are

is really how you push that forward

and make inclusion not a best practice,

just the way we do our work.

So those couple nuggets on that.

- [Jae Jin] And if I may,
when you said budget,

that struck a chord with me.

I think it's also important
that there be intentionality

of pushing for and including
accessibility accommodations,

like ASL, like CART, like large print,

other forms of accommodations
that may come up

into your budget of planning, trainings,

meetings and whatnot.

So that, because I will say,

one of the most frustrating things

for me as a disabled person,

and I have the privilege of having

a fair amount of usable vision,
but I do use large print

and there are situations
where I will request

for audio description.

And sometimes I've done
that for conferences

or large events

and have been told, "Well,
it wasn't in our budget."

Or, "We can't, we don't have
the money to pay for that."

That's insulting to me
personally as a disabled person.

And that is a failure on that system.

And I say that very directly

and with some passion as you can tell,

because I want you to
understand the reality.

We've talked about accessibility

and accommodations throughout the day,

and I appreciate the
intellectuality of it,

and I know everyone has
the best of intentions,

and this is not a personal
attack on anybody,

but it's more of a critique of the system

that there has to be better thought

from whoever the people
are that have the authority

to authorize and prioritize
budgets and supports

for accommodations like
ASL, large print, CART,

ramps and physical
access, lighting changes,

whatever the accommodations
that may come up,

to make that very intentional.

Just saying, just having
a space, or summit,

a conference, a meeting that
the front door is wide enough

for people with wheelchairs to roll in.

That's not access, and
that's not access for me

and for many of us with
different access needs.

Thanks.

- [Germán] Thank you Rodney,

and thank you for the addition, Jae Jin.

Scott.

- [Scott] Yep, I was pausing for thought.

Illinois is a very diverse state.

I think we can all agree.

My coin phrase right now for
planning is cater to Chicago.

We are a very diverse, very different,

very

in some locales extremely capable

and other locales not as
capable to do certain things.

I'm coming from the
perspective on this topic

that I really believe to
get to where we collectively

want to be, it's gonna take a village.

And so what I'm saying
here is that it may not be

the knock on the door from
the local emergency manager

to your organization,

that my charge back is,
don't wait to go ahead

and knock on their door.

And that may be not appropriate,

may not be what should happen,

but I think if we want to get
to where we want to get to,

it may be the right thing to do.

And I'll give you the example.

Our legislation that
created the governor's

Access and Functional Needs
Committee did not come,

it was not born from
the emergency management

community practice.

It was born out of a group of advocates

who saw deficiencies in a system

for people who have access and
functional needs during COVID

and said, "This isn't right."

And because of that, we
now have legislation.

We are now doing things, it's
my charge and my expectation

to build as good of a program,
if not better, than Sadie's.

I'm following in her footsteps.

I'm a disciple.

So I don't think it's a bad thing.

I think that there is a good
place and opportunity to meet.

I think it's a great way for organizations

to become educated.

And I do believe in most cases
there is a realm of education

that needs to take place.

We need both keys to
turn at the same time.

We need community
leaders in the community.

We need advocates, we need nonprofits,

we need that whole community

to marry up with emergency management,

but we also need emergency management

to marry up with that community.

At the end of the day, if
we get to the promised land,

does it matter who knocked on whose door?

I don't think so.

The intent and the mission
here is to make sure

that when the bad day happens,

the people who need help, need
those resources, get them.

If you need help and you live in Cairo

and you get help after a major flood,

are you gonna wonder who
knocked on whose door?

Are you gonna care?

I don't think you will.

If you live in Chicago
and there's a heat dome,

and you need help getting to a shelter,

and you finally get there to cool off,

are you gonna care whether or
not a nonprofit organization

knocked on the door of the Office

of Emergency Management of
Communications of Chicago

and said, "Hey, things aren't right here."

Or does it matter if OEMC reached out

and knocked on the nonprofit's door?

At the end of the day, what
matters is that that person

who needed to get cool got cool.

And I think the more we collectively do

on either side of the street,
the better we're gonna get

at building that inclusive relationship.

Because it's, as Jae Jin
said, it becomes the norm.

It becomes the norm.

It's not special, it's not extra,

it's not something we're
doing above and beyond.

It's just the way it's supposed to be.

And so it may take, in some jurisdictions,

you're all from various
locations around the state,

it may be working really good.

I ask you, how did that happen?

We do this all the time
in emergency management.

We do things right and we
screw a lot of things up

and then we learn from it.

If you're having success
in venues like this

with your local emergency management,

not just emergency management,

but fire, keep in mind,
fire, law enforcement, EMS.

Emergency management is
just one piece of that pie

in a local public safety entity.

If you're having success, how are you,

how did you get there?

Share that.

Share that with with
your nonprofit friends.

If you're not having success, talk it up.

And I think we've gotta talk it up

on both sides of the street.

We are gonna get there.

The more opportunities
we have events like this

and the more we share
cross-jurisdictional,

the closer we're gonna
get to making this normal.

- [Germán] Thank you Scott.

We need to make it the
norm, not the exception.

Not the special, thank you.

Mary.

- [Mary] Well, good afternoon everyone.

I just wanna have a little disclaimer.

I am retired from Red
Cross, so any opinions

that I might give here are not
those of American Red Cross,

they're my own, from my own experience.

That being said, I wanna talk
a little bit about mindsets.

And I think I see a lot of
IDPH people or tags out there,

table tents.

And one thing I think we need to work on

is the difference
between the medical model

and the social or functional model.

I think that's a really important mindset

that needs to be changed from everyone.

I'm a critical care nurse, okay?

I took care of very sick
patients one or two at a time.

I completely crossed over to taking care

of 330 million people
across the United States.

And so I think what we need
to do is change that mindset.

And it really is, it's hard.

It's hard to do that.

People with disabilities are not sick,

they're not patients, they're clients.

And I think emergency management

needs to change that mindset.

I think sometimes public health
needs to change that mindset

because public health has a
lot of healthcare professionals

embedded in public health.

And so they kind of think more medically,

and we need to think more functionally.

And I tell the story all the time,

most emergency managers
get really wide-eyed

when I tell the story.

So there is a teenage girl

that goes to her local high
school, and she loves football,

and she goes to every Friday night game,

and she sits on the 50 yard line,

she has a motorized wheelchair,

she has a personal care assistant,

and she has a ventilator
and a feeding tube,

and she lives at home, and
she goes to high school,

and she's very good at her studies.

If we plan for that
person in that community,

we will plan for all of the community.

So we need to take that
medical mindset out

and think about the social
and functional mindset

because I guarantee you,
when I'm in the wheelchair

with the oxygen, Sadie and
Scott, I am not disabled.

And so we're going to need to
look at the whole community.

Thank you.

- [Germán] Thank you all.

What a great way to get us
started on this conversation.

Thane, we'll start you and move onward.

How can local communities,
emergency management agencies,

and public health
departments work together

to improve accessibility and support

for people with disabilities
during disasters

and public health emergencies?

- [Thane] So like we've
all said before, inclusion.

But how do we use inclusion to
make it better for everyone?

And we do that by not
having gotcha moments.

It's all about learning, and
learning from each other.

So when we work with our local EMAs,

and we do trainings,

and something isn't right,

maybe we bring a lot

of our consumers who have AFN

because we're requested to,

and the buses take us out to
the land site for the drill,

but none of the buses
are handicap accessible,

meaning none of them have lifts.

We don't go back for the
debrief and complain.

We go back and we learn
it as a learning lesson.

The buses that we bring in,

we have available buses with lifts,

but that was not thought
about in that drill.

Is it easily overlookable?

For someone who doesn't
need that lift, absolutely.

Is it the end of the world?

No.

That's why we do the drill, to learn.

The way that we make it better
is to work with each other,

to have learning experiences.

How many people here know how to find

a Illinois licensed ASL interpreter?

Can I have a show of hands?

Okay, how many people in this room

know that there are licensing
levels for ASL interpreters

and what they can or cannot
interpret legally in Illinois?

So if you asked for interpreters

and you had an intermediate,

but we're in the COVID era,
so we are going to talk about

government proclamations that are law, or

could change or adapt laws,
you would need a master level.

Also, we are talking about what

when we talked about COVID?

Medical issues, right.

So the fact that you bring
an interpreter in is great,

but when we train together,
that's how we learn

that there is a statewide
interpreter database

and that there are different levels.

And again, not to play gotcha,

I will tell you there are a lot of us.

I was a police officer for 10
years in a high crime city.

I wouldn't dare tell Rodney or
Scott how to handle a flood.

I lived in a river town, we had floods,

but that was not my purview
as an emergency manager

when I was working in
emergency response services.

We all learn from each other,
we learn what's needed,

we learn what can and can't be done.

So we look at all of these exercises

working together as learning
experiences, not gotcha

or trying to make somebody
feel silly or stupid.

We all learn and we only
know what we've been taught,

which is why we attend
conferences like this today.

- [Germán] Thank you so much, Thane.

To keep the conversation going, Jae Jin.

- [Jae Jin] Could you ask,
could you repeat the question?

- [Germán] Of course.

How can local communities,
emergency management agencies,

and public health
departments work together

to improve accessibility and support

for people with disabilities
during disasters

and public health emergencies?

- [Jae Jin] I think,

I guess to be a little redundant,

I think as I mentioned earlier
with the first question,

and as all of us have
mentioned, the idea of inclusion

and just inviting people
with disabilities,

disability organizations to the table,

and letting us know that

there's or it's a sincere invitation

and that our input,

our lived experience,

and for those of us who like go to school

and get training to be experts in ADA

and accessibility accommodation
or specific disabilities,

that that is going to be valued

and that that seat at the table

is a real seat

and it'll be an ongoing conversation,

even when there are disagreements.

One of the things I
appreciate about working

with Scott on the AFN is that

there is a diverse group of folks

with different perspectives.

And like with any diverse group of folks,

there might be disagreements
or misunderstandings,

but there is a respect of
listening to each other

and everyone has the intention of

hearing each other

and working together to
build that understanding.

And I think if that, again, is
that core principle of that,

it will sustain the relationship

and sustain the connection.

The communication keeps going.

And the willingness to
adapt to the accommodation.

If the person's communication
style is through text

or through adaptive equipment,

that that's worked with and adjusted,

it will help build that connection

and that positive working relationship.

And from my personal experience

of sitting on various
boards and communities

where that has been the kind
of like that board's culture

of welcoming, inclusion, respect,

communication, and adaptability,

I look back at those
committees as feeling like

it's one of the times when I
feel like I've been valued,

the work that I contribute
to I'm very proud of

as a group and as a committee.

And I think that's something that, again,

having that intentionality,

it will build that kind of connection,

and the product that comes out of that

will be that much richer.

- [Rodney] To jump in on this,

I got a couple acronyms
I'm gonna try not to use.

So federal government, we're
really bad for using acronyms.

I know on the intro we mentioned

the FEMA equity community of practice,

and so we're asking, at a local level,

what are some good resources

related to inclusive emergency management?

And I think establishing
that community of practice

in those local, whether
it's a village, city,

county, whatever the size is,

to say who are the players in the game?

Is it Department of Health?

Is it HHS?

Is it Veterans Affairs?

Cast as broad of a net as you can to say,

who has a stake in supporting people

with access and functional needs?

And then start to have regular
engagements with those groups

to say, what are the issues,

what are the opportunities?

And then that's how you bring
synergy around these things,

which leads into resources.

Sharing of resources,
co-locating of resources,

which helps with obviously extending

and making better use of what's available,

but then also avoids duplication.

Oftentimes in the heat of a disaster,

you got the fire department,
the cops, emergency managers,

community members, everyone
wanting to jump to help.

But if you have those
regularly ongoing meetings,

you're discussing these things,

it's just a little bit more functional.

To that, I would also
say at the local level,

amongst those entities, those groups,

having discussions about
formalizing what's going on.

So we're talking about
communities of practice,

but also MOUs and MOAs,

so those memorandums of understanding,

memorandums of agreements.

So if there's another
disaster in St. Clair County

and we're going to work with Libby

in the Center for Independent Living,

if there's an MOU or MOA already in place

or something established,

there may be potential avenues for funding

or different lanes that we can look into

when there are more formalized processes

around these things.

So that community of practice
is a little bit more informal.

MOUs, MOAs is kind of
taking it more formally,

and then also getting creative.

And this is on like a federal level,

we have the phrase EMAC,

which is emergency management
assistance compact, possibly?

- [Scott] Emergency
management assistance compact.

- [Rodney] All right, there we go.

So that's basically the
state of Illinois could say,

"We've ran out of resources,

ran out of manpower,
Ohio, do you have anyone

who can come help with this?"

And then they can EMAC someone over,

we're not gonna get
technical and all of that.

But similarly at that local level saying,

"Hey we know maybe our
Center for Independent Living

isn't as robust, or we know
our Area Agency on Aging

may not be resourced like this county.

So what are those relationships

on that local level looking like?"

I think would just have
those local communities,

which we know tend to struggle
with funding, resourcing,

being able to collaborate
at a moment's notice

just be better positioned for
when those disasters come.

- [Germán] This is Germán, thank you.

Hearing, building
bridges and collaboration

across the sector's whole community.

Scott, again, the question
is, how can local communities,

emergency management agencies,

and public health
departments work together

to improve accessibility and support

for people with disabilities

during disaster study
public health emergency?

- [Scott] So one of my favorite
quotes by a friend of mine

that he uses a lot, he's an
advocate in the city of Chicago

is, "We all do better
when we all do better."

And we have to live by that
at the local community level.

And I constantly say

in our advisory body groups,

our intent here with
the legislation is that

we're really the secondary
tertiary responder.

FEMA is behind us.

Politics is local, so
is disaster management.

One of the lessons learned,

and I'm not digging on any
public health people in the room,

I'm not digging on any emergency managers

or local emergencies in the room,

but we probably weren't
the tightest during COVID.

And I think that's a
lesson we have to learn

and we have to fix.

And before we go further and
expand our capability capacity,

we gotta really get tight.

Those of you who've been
around for a long time

know that a lot of stuff's happening.

I've been doing this 22 years,

months used to go by between events.

I can tell you today on my phone,

15 things have happened today.

You saw the news last night.

I pray for the people up
in Iowa, and South Dakota,

and Minnesota and think
about what's going on

in the realm of access and
functional needs up there.

We're really fortunate to not
be dealing with that today.

And we're watching whether
or not we're gonna be

the recipients of a lot
of water coming our way.

We're thinking about it.

We gotta start there.

My recommendation, if I was king for a day

and I could make things happen,

it would be that at the local level

we have what we have at the state level.

That there are people
from, like I said before,

that there is an advisory
group that advises

and provides input, and
suggestions, and courses of action

to a unit of government,

which is the public health department

and the local emergency manager jointly.

That there is a jurisdictional
advisory body to say,

almost like a listening group.

I know here in Springfield there's a body

regarding community
policing to try and inform

and say, "Hey, this is
how you guys are doing."

You kind of grade, not
necessarily grade them,

but offer advice and suggestion

on how to go about doing the job.

But I think first we've gotta make sure

that the local emergency management

and local public health
are joined at the hip.

To be able to receive,
you gotta be open enough

to receive that information.

I think if you do that,
we're off and running.

And then I always look at,

we've got regions, IDPH has regions,

you find the champions.

You find the champion down
in Carterville, Illinois,

you find the champion in Carlinville,

I like my C's lately,
Chicago, Cairo, Channahon,

throughout the state.

And we point at them and
we raise them up and say,

"That's how we should be doing business."

Small, medium, large jurisdictions,

and now all of a sudden, and I like this,

I like this avenue, because
then it's not a matter

of somebody saying, "Ah,
that can't be done."

Nope.

They did it, and they
did it better than them,

and they don't have a lot of resources,

and they're making it work.

And then when we have
the bad thing happen,

like our friends in
Minnesota, or South Dakota,

or Iowa, I go back to the previous point

that the people who needed
to get inside to get cool

or get warm got there.

Someone who needed the medication got it.

And I go back to, it's
gotta take both sides,

but I think at a governmental level,

we gotta make sure that
we're joining together first

and we're able to receive that
information when it comes.

- [Germán] Thank you Scott.

Mary.

- [Mary] Well I love to tell stories,

but my life for the last
12 plus years has been,

and you heard about this earlier today,

emergency support function
number six is mass care,

of which the American
Red Cross is the co-lead

at the national level.

And emergency support
function number eight

is public health and medical.

So I would always joke to my colleagues

that I am ESF8 in the ESF6 world.

And I think there has
to be a recognition of,

how do these two entities

think their responsibilities
are in a disaster?

And I participated in an exercise

at the National Response
Coordinating Center.

It was about the Cascadia
Rising, they called it.

And one of the disappointments I saw there

was Red Cross was tasked
with the housing task force.

And lots of times in big disasters,

task forces are put together
to manage certain problems.

So I happened to be playing that day

and I said, well, we have
to have public health

and medical be part of
the housing task force.

And I walked over to their desk

and said, we need a representative.

This is at the national
level, national level.

And I asked the representative
of Health and Human Services

for a representative to
the housing task force.

And they said, "That's
not our responsibility."

So I think in the world
of emergency management,

there is a lot of, "That
is not our responsibility."

And sometimes it takes
really the grassroots to say,

"Well, who is responsible for that?"

Who is responsible for getting

the durable medical equipment?

Is it emergency support
function number eight?

Is it emergency support
function number six,

which is mass care, or
public health and medical,

who has that responsibility?

And I think it's incumbent on people

who are looking at
planning and doing plans

to really ask that question in your head,

who is responsible?

And then task whatever emergency
support function you choose

to answer that, who is responsible?

Because that's really the question here

about who is going to get the resources.

And I think, and we
know that public health

is not necessarily a
logistic kind of agency.

And so public health
needs to depend on IEMA

and on FEMA to move things,

to get large quantities of things.

So there has to be a partnership.

I know that at Health
and Human Services, ASPR,

the Assistant, I'm gonna say it wrong now,

Secretary of Preparedness and Response,

they're building a logistics department.

But I think you have to look at that

from what is happening in Illinois.

And I think that legislation is wonderful,

but I think you have to ask the question,

who is responsible?

- [Germán] Such wonderful insight.

Sue.

- [Sue] Backing up what they've said,

I think definitely from public health,

really working with the community,

working with the support
service providers,

I think that's a critical
way of not only trying

to get to the community,

but just increasing the
level of engagement.

I think that's important.

- [Germán] Absolutely.

Thank you all.

Moving us on, Jae Jin
we'll start with you next.

Can you share examples of
successful collaboration

between planners, emergency managers,

and communities with
access and functional needs

that improved emergency responses?

- [Jae Jin] Well one example,

I reached out to our AFN Committee Chair,

Kira Meskin-Schiff, and she shared

some examples.

I unfortunately can think of examples

of successful partnerships,

but not specifically around like emergency

or disaster issues.

And Kira shared

kind of like an experience through COVID.

When COVID hit, as was mentioned,

many of the people with disabilities

had challenges accessing
PPE and getting information,

and through meetings

with public health officials

and within the Chicagoland area

there was convenings of public health,

disability organizations,
people with disabilities.

And where the disability
community provided input

and feedback as COVID started

and information around the
importance of social distancing,

the importance of masking,
how to obtain masks,

and how to obtain PPE.

Some of that information was not reaching

our disability community,
or was not making its way

through the communication channels

that some of our disability,

or many of our disability community uses.

So that was information that
our disability community

provided public health
officials and departments,

and also, and as testing sites opened up

again, our disability
community giving feedback

on the importance of making
sure that those testing sites,

and then when vaccine
vaccines were available,

that those vaccination
sites are accessible,

physically accessible,

and also thoughtful of other accessibility

or accommodation criteria.

And one of the things that actually,

one of the examples that
I just remembered was

within Chicago

was the prioritization and the release

of mobile or at home vaccination services.

As vaccines were rolling out,
initially it was setting up

neighborhood vaccination sites.

People would go and get vaccinated

or get vaccinated in their cars,

that kind of drive through model.

For many of us with disabilities,

especially with chronic health conditions

or who are immune compromised,

just exiting during that
time, exiting our homes

and going out into public
is extremely dangerous.

So again, through
conversations and feedback

from our disability community, there was,

again, from my personal perspective,

it seemed like that helped
speed up or prioritize

creating a mobile system where

providers can provide

at-home vaccination services,
and set up appointments,

and set up an online
system, set up appointments

so that people did not have to,
who were immune compromised,

did not have to leave their homes,

or leave their safe environments,

or have increased risk
by venturing outside.

Even if it is just down the street

or a block or two over.

Again, that input and that collaboration,

that partnership, and that
listening to each other,

and the feedback from
our disability community,

and our lived experience,
disability lived experience

helped create systems.

And that at home vaccination
service could also be general,

could be useful to other folks,

not just to disability community.

And I think that's the other thing

that's important to mention is that

some of the strategies
and the recommendations

that are very applicable to
the disability community,

some of those strategies,
and recommendations,

and tactics

could also be helpful

to the other communities at large.

So it's not just, it
doesn't have to be narrow.

And that's something that I think, again,

is something that's a good
example of that partnership.

- [Rodney] Absolutely Jae Jin.

Just to piggyback off that last comment,

wheelchair access to a building.

I wish I could give someone
the credit for this,

but I forget who said it.

And on that note, this
is my second day back

from paternity leave, so I'm
a little dusty, bear with me.

But if you see wheelchair
access to a building,

yes, someone who uses a
wheelchair may be using it,

but you also see someone who
may be was pushing a stroller,

someone who has a shopping cart with 'em,

whatever the case may be.

So I think that's just an
opportunity to highlight

how crucial and impactful
universal design is.

And I think when it first got rolled out,

it may have sounded very academia,

but there's real lo-fi,
common sense best practices

that come from universal design.

So I appreciate that.

Just to kind of get back on
track with the question though,

some examples,

and this is also something
I'd like to highlight,

because it's not if, but
when the next disaster

comes through Illinois,

it's taking advantage of the
disaster to build back better.

And so how do you, and some
examples of this would be

the Virgin Islands.

Was down there for a disaster.

They received funding for
different things to build back,

and they were able to provide
accessible beach entry

through some emergency management funding.

Now is that tip directly
related to emergency response?

No, but through creative
thoughtful processes,

they were able to apply those
funds to build back better.

Another example of that would be

the Lumbee Tribe in North Carolina.

So I was working out there
post-Hurricane Matthew,

and one of the highlights for them

was they had to evacuate for a flood

but didn't have paratransit.

So all of the older adults

in the community

on the reservation had extreme
issues with evacuating.

So they were able to, with some funding,

with some of the resources,

with some of the focused attention

on access and functional
needs, and education as well,

implement a paratransit system,

and then we were able to provide
some technical assistance.

Access and functional needs task force

I think is something to
highlight in any response,

whether it's a local,

it could be a small man-made disaster,

maybe it's a active shooter,

it could be as large as
the Cook County floods.

And so being able to, we talked about

that community of
practice in steady state.

That's bringing together practitioners,

academia, legislation, all
of these parties involved.

But then at a disaster, being
able to set up a meeting,

Sue was a part of that, Thane
was a part of those calls

for Cook County.

And luckily we didn't see a
high number of cases come in,

but I've been on other
disasters where we do.

We were able to triage different cases

that need some specific assistance

that may be outside of
traditional response.

And so we're able to
get them those resources

in a timely manner.

So I think that's
definitely a best practice

that can be utilized and stood up,

whether it's three people involved or 30.

So yeah, just a couple examples

- [Scott] I'm gonna take a
jump and not look backwards

on previous things but look forward,

'cause I'm really excited
about what we're about to do

here in Illinois.

I'm gonna go back to Sadie's presentation

about how do we get over
just the word whole community

and how we actually get to it.

I believe everything that
we're talking about here

has to start, all the
good, positive things

that we're doing, they
gotta start with a plan.

Because if not, you're surprised
by the thing that happened.

Whether it's a flood, or a
hurricane, or active shooter,

we're all surprised by it.

And then when these issues pop
up, we're surprised by 'em.

That's not the norm.

That's the surprise.

We're about to, in Illinois,

we're about to finalize our current

state emergency operations plan.

It's gonna be finalized
by the end of July.

We've converted from where we were

as agency-centric
annexes to the ESF model.

That's what we've been doing
for the past couple of years.

As soon as we get
through the RNC, the DNC,

and our own conference here,

come back for our conference in September.

After that, we are going to actually build

what I believe it will be a truly

whole community centric plan.

Scott, what do you mean?

When we say whole community,

you probably think we
brought certain people in,

we sat down, we built a plan.

We're gonna do that.

And I can tell you that
some people do that

and then you still don't get the plan

that you actually think you're gonna get.

Here's what we're gonna do.

I'm probably gonna have a lot
of unhappy agency liaisons

and elements in my own agency,

because we're gonna go through
a very painstaking process.

But it's what right looks like.

Over the next three years,
we're gonna sit down

out of my planning cell at IEMA.

We're gonna sit down with single agency,

the American Red Cross,
the Salvation Army,

the Illinois National Guard,
the Illinois State Police,

Illinois Department of Public Health,

and we're gonna go line by line.

Tyler's looking at me going,
"Gee Scott, you're killing me."

Line by line.

And we're gonna ask agencies,

Department of Transportation,
Central Management Services,

who does contracting,
and we're gonna ask them,

does that role and responsibility
include all Illinoisans?

So lemme give you an example.

And Jae Jin's heard this,
so I apologize Jae Jin.

It may say in the Illinois
emergency operations plan

that during an evacuation
of a local jurisdiction,

the Illinois Department of Transportation

or Central Management Services
will provide contract buses

to assist with evacuation.

Does that include all Illinoisans?

No.

What are you gonna get?

Thane mentioned it.

You're gonna get a bus.

What's gonna happen?

There are gonna be people
sitting there going,

"I can't get on that bus."

Okay, it doesn't include all Illinoisans.

When it comes to communication,

when it comes to the ESF
15, external affairs,

it says, "We will provide
communication resources

to assist people in knowing
about their hazards."

Period.

Does that include all Illinoisans?

Nope.

We're gonna go line by line by line.

It's gonna take us a long time.

It's gonna make the plan a lot bigger.

But if you know emergency management,

if you know community
planning, that's your Bible.

Everything you do down from that plan

connects to that plan,
it's connective tissue.

And so if you build an operations
plan for the earthquake,

if you build an operations
plan for an active shooter,

if you build procedures on how to respond

to a certain thing, it
comes from that bigger plan.

So when we look at an
organization, we realize,

man, none of your plans
talk about what we need.

You gotta go back to the big plan.

But the big plan doesn't
address everybody.

We all do better when we all do better.

All those operational
plans, all those procedures,

all those plans for certain hazards

aren't gonna speak to it.

You gotta start there.

I believe we may be the
first in the country

to get this done,

but that's what right looks like.

And I go back to, I've
learned so much from Sadie,

I've learned so much from California.

I want to be one of
those advocates to say,

"Hey, I want to go out and
share what we're doing,

'cause I think this is
what right looks like."

I want to get it back
out to our communities

around the state and say, "This
is how you have to do it."

It's not gonna be fun.

But you know what's not fun
is when something bad happens

and you're sitting there
going, "Geez, we knew it,

and we didn't do anything about it."

So that's where we're going.

Into the future, is that gonna save lives?

Yeah.

Is it gonna ensure that
people don't suffer?

Yeah.

It's a process.

Takes a village.

We're gonna work really hard

to make sure that we put
a good program together

in Illinois.

- [Mary] That sounds like
a wonderful plan, Scott.

- [Scott] Thank you.

- [Mary] I just, I'm gonna put a plug in

for how you plan and how you contract,

because one of the stories
that I wanted to share

with all of you was,

and I probably shouldn't name the state,

but I am gonna name the state.

The state of Louisiana we
had big floods in Baton Rouge

a number of years ago, and
luckily the state had decided

to have a contract with
a agency that provided

personal care assistance.

And we haven't really
talked about that today,

but that's a very important
piece in all of your planning,

Scott.

And so having a contract either in place

or a pre-scripted mission
assignment to get that contract

is exceptionally important.

I have had to contract
both temporary nurses

and personal care assistance for shelters.

It takes too long.

You need background checks,

because certainly they
are giving intimate care,

and you do not want someone
giving that intimate care

to not have a very deep background check.

But I will tell you, it took
a very long time in Louisiana

because the courts were closed.

Because the flooding closed the courts.

And so as a cautionary tale,

I think one thing is about
personal care assistance,

you can't, you need to have
a plan specific to that.

Now, I know FEMA has their contract too,

but again, how long is that gonna take?

It's gonna take 15 days if you're lucky.

And so how are you gonna
provide that kind of care

in that gap?

And so I just encourage all of you

to think about personal care assistance.

And they're gonna be impacted.

But the other piece is, if the
client has home health aid,

they certainly can come to
the shelter and provide that.

But there are some states
who will not pay for that

because that is not their home of record.

So you have to be careful
about these contracts,

and what they mean, and
who gets paid for what.

But I would encourage,
that was a great story.

We had, I think maybe eight, 10,

Shari was there at the time,
personal care assistants

who came into a very large
shelter, an event center,

and provided the care for their clients.

And it was very successful.

And so I encourage all of you

to think about personal care assistance.

- [Germán] Great points, thank you.

Sue and then Thane?

Can you share examples

of successful collaboration
between planners,

emergency managers, and communities

with access and functional needs

that improved emergency responses?

- [Sue] Well, with me
being so new to my position

at IDPH,

I'm still trying to make inroads.

And essentially right now

we're working, trying to

work closer with the Illinois VOAD group.

And I'm just learning a lot

from the Illinois Access
and Functional Needs

Advocacy Committee.

So I've got a lot more to experience.

- [Germán] We all do.

It's part of the journey.

- [Sue] That's right.

- [Germán] Thane.

- [Thane] So locally in our
area, this touches on things

that everybody's talked about.

One of the things that
I think of as a success

was planning prior to an incident.

With Peoria County Health Department,

we had signed an agreement to be a POD,

or point of distribution.

Now, none of us thought
that it would be a pandemic

and COVID vaccines that we
would be distributing with that.

Right?

Nobody, even if we had plans for that,

I would tell you those of us

even in the disability community

that were actively involved
did not think it would be

that style of pandemic.

We all thought something
like maybe nuclear fallout

from Clinton or some other solid virus,

but nothing like what
COVID-19 brought to us.

What that allowed us to do,
like Sadie said in her opening,

disability during COVID was
designed very specifically.

So just because you were
a person with a disability

did not mean that you
were going to receive

early access to that vaccine.

Even if you were someone

who really probably should have been.

What being a point of
distribution did for us

was within, I believe it was
five days of it being open

to the public, we had the
health department there

giving vaccines to
persons from our community

and those from the
general population as well

that needed or wanted a vaccine.

And guess what?

When it came time for your second shot,

you came back to us.

If you were not able
to get out of the car,

we had one of the medical
staff come out to your car

and give you your vaccine in your vehicle.

And then one of our staff members stood by

for the 15 minutes to make sure

so that those nurses and
medical staff could continue

vaccinating those in the community.

Now that was through
training, planning, MOUs,

and not something we ever
thought was going to be used

the way we needed to use it.

But I can tell you we were
happy we had those in place.

So that's one where I saw a great success

that allowed many to get vaccinated

that might not have been able to

had we not had that very simple agreement

in place

with the health department
and our emergency managers.

And that would not have come

if my Center for Independent Living

had not been part of the
emergency planning process

longer than the 10 years I had been.

When we talk about, you guys refer to 'em

as personal care assistants,

in the Centers for
Independent Living world,

we call them personal assistants or PAs.

Does anybody know where
you can find a list of PAs

in the state of Illinois?

Okay, I see one person?

One, going twice?

All right, sold, and
I'll give you the answer.

The Illinois Network of
Centers for Independent Living

has a state contract
to maintain a database

of personal assistants
throughout the state of Illinois.

Why is this important to you?

Every Center in the state of Illinois

has that contract as well.

It's important because,
while we would love to think

that our PAs are going to follow

their consumers to the shelters,

the realization is, in an emergency,

that PA very likely will be
taking care of their family

or will be affected by that
disaster or emergency situation.

However, we all know
what affected Cook County

or what affects Peoria County or Sangamon

may not affect the county
touching right next to it,

which could be a 10 minute drive

to have PAs come into
the shelters to assist.

So again, the collaborations are important

because it's not always
about what resource we need

or how we plan, it's about
where do we find that resource,

how do we get to it?

And yeah, there may be
some back paperwork,

we have to fight with the state
to get stuff taken care of,

but in an emergency, do
we care more about someone

having the opportunity to toilet

as independent as they possibly can?

Or do we care about how
happy the state's gonna be

about our paperwork?

So keep in mind that these
agreements, these plans

can make a huge difference in
whether you're set up or not.

Other centers didn't have MOUs
to be points of distribution

or PODS.

We had that.

- [Rodney] Yeah, Thane,
and just to kind of,

I know I mentioned MOUs,

so I'm glad you brought it back home.

And then, not to get too
into the weeds or technical,

but there's life sustaining
and life saving activities

that oftentimes those
untraditional first responders,

our Area Agencies on
Aging, Veterans Affairs,

Centers for Independent
Living, they're just,

going back to the plans, they're naturally

one of our first people to contact.

And so the better position they can be to,

whether it's actively or after the fact,

be able to get reimbursed potentially

for some of those man hours.

I know someone mentioned it

and it's just something to highlight.

Oftentimes people in the community

are asked to help solve
the problem for free

or donate their time while the
person asking is being paid.

And so you just wanna make sure
we're being fair about that.

I know Mary also mentioned
procurement and contracting,

and I think that's a huge piece
in ensuring accessibility,

not only one with accessible contracts

and ensuring that we have those set up,

but then also ensuring that
people with disabilities

are in the race for those contracts.

They do know what's available,

and oftentimes they're
doing that work anyways.

And so that's a whole
nother side of the house.

But getting educated on
procurement and contracts

is also a big piece of this as well.

And then one last thing, I
know I kind of jumped in here,

but I do want to give a couple shout outs,

and they are examples of
what we're asking about.

One would be Sadie in Colorado,

Emergency Management Access
and Functional Needs Office.

Mind you, they have an office.

So if you go across the nation,

and I've worked in every region,

some states have an Access and
Functional Needs Coordinator,

some don't.

Some have it as an auxiliary.

Obviously when we go down
to the local level, most,

it's one of five hats that
emergency manager wears.

And so Sadie and the state of Colorado

have built out an office
to really take charge

and handle that in a real meaningful way.

And I use them at any time
I'm talking to a state,

I refer 'em back to Colorado,
California, Florida,

also Illinois with Access and
Functional Needs Committee.

These are best practices
that we're seeing.

And then also, I want to
shout out Thane and Shelly

for Cook County, Shelly over there,

they both provided just in time training

to the emergency managers, IEMA
and FEMA, for the disaster,

which I would typically do that training

where it's just kind of a high
level etiquette, awareness,

just some of those general best practices.

But to bring in a community
partner, as we talked about,

with lived experience,
with that background

to really articulate the importance

of access and functional
needs in emergency management

went a long way.

It was one of the best received
trainings of the disaster.

So I wanted to shout them out.

And then also Libby who,

Libby and her Center
for Independent Living,

so St. Clair County had
a disaster declaration

a couple years back.

And sometimes it's one of these programs

that gets turned on.

It's not guaranteed to be turned on,

but they have Disaster Case Management,

which is basically a
long-term recovery resource

that helps people get back to
whatever their new normal is.

And so we provide a contract

and then they work with the VALs,

they work with IA, the state,

I'm not gonna get too into the weeds,

but oftentimes

the cases they're dealing with

are survivors with access
and functional needs.

And so sometimes those contracts

are given to providers that
have a robust understanding of,

and sometimes not so much.

But to mitigate against that,
we were able to tap Libby

and her Center for Independent Living

to be an advisor to that contract,

to those case management
cases that were coming in.

And so that's just a great
example of a best practice

that we should just use in
our business going forward.

- [Thane] And I hate to do this,

but I wanna piggyback on what you said,

'cause Jae Jin and I
were talking about this

prior to the panel.

When we talk about budgets,

not every Center for Independent Living

has a large budget or a large staff.

Those of you who are in Chicagoland

and know Access Living and Progress,

they have very large staffs.

Their budgets are very robust

because of the way that
the contracts are set up.

And that's good.

They're serving millions
of people in a small area.

Other Centers like mine, we
have two direct staff workers.

But we make EMA a priority.

It's something that we know
is important for our people

and so we prioritize them.

There are other centers that
don't have the frontline staff

to send to meetings every time.

And quite frankly, some
don't have the budget

to pay the mileage for them to get there.

If they're covering, you
look at Southern Illinois,

there's one center that
I think he's covering

12 or 16 counties.

So if you don't have a large budget

and you're covering 16, 12 counties,

how do you possibly attend

16 different meetings with EMOs?

Now, I'll tell you, we're lucky.

Three of our counties combine
some of those meetings

where I'm at.

And some of that disaster
planning is three counties in one.

So it makes it very nice to know

that we have a tri-county
area that works well together.

But again, as we all know,
not all counties do that.

And that's not things that
are within our control.

So please remember, if
you're thinking about funding

or planning funding, even
line iteming a little bit

for mileage for partner organizations,

if there's a way to do it.

And no, I'm not a
government budget person,

I don't deal with our budgets.

So I don't know what rules

you guys can and can't use things for.

But a hundred dollars
mileage budget or stipend

for some Centers, or other groups,

it doesn't have to be a
Center for Independent Living

can be the difference whether you are able

to have them attend your planning or not.

Thank you.

- [Germán] Thank you all for giving such

insightful perspectives.

We wanna give space for
you all to have time

and ask your questions.

As you're thinking them,

Sue, Thane, Jae Jin, Rodney,

Scott, and Mary,

thank you so much for your incident time

and all you do for
people with disabilities

throughout disasters.

Give a hand of applause.

(audience applauds)

Then later, we've talked about
how we will have some sugar,

some candies in the tables tomorrow,

even though it's only half a day.

But any questions, feedback
from you all for our panelists?

- I have a comment.

- [Germán] Please.

- If that's all right?

I'm gonna go ahead and use my voice.

I'm able to voice myself,

but I have to rely on
interpreters for hearing things.

Like Rodney has mentioned my name,

my name's been coming up lately.

One thing I wanna share my experience.

During COVID, I'm a Deaf
and hard of hearing advocate

for Centers for Independent Living.

So I had to work with
the IDPH in my county.

And

if I know something that's gonna benefit

the Deaf community or
something, I'm gonna go to IDPH.

Oh, I'm sorry.

I'm gonna go to the Illinois
Department of Public Health

in my county.

If I know something that's
gonna benefit my Deaf community

or something like that,

I will go to the
Department of Public Health

and I will go and see 'em.

We have that collaboration,
I have that open door,

I can go in and see them.

Because, I mean, when COVID
happened, this was new to us.

We didn't know what was gonna happen,

what we were gonna do,
how we were gonna plan.

I mean this was new for me as well,

but I was really concerned
for my Deaf community,

because when we did those
car drive through things

in the Belle-Clair Fairground,

we had this huge fairground

that people drive all the
way around this building,

I mean it was huge.

But I thought, oh my
gosh, the Army guards,

the people that are
gonna be standing there

and checking their driver's license

and their paperwork and everything,

how are they gonna
communicate with Deaf people?

How are those officers, the Army guards

who volunteered to work there to help,

and I was thinking, how
are they gonna communicate

with the Deaf people there? (laughs)

And I thought maybe I
could create a video.

So I signed in the video
like an instruction

for the Deaf people, what to expect,

what's gonna happen at that fairground.

I created a video and I signed everything,

so that way that when the Deaf
person arrives at that event

so they can get their vaccine shots,

and they look at the video
and they see me signing

about the instruction,
what's gonna happen.

And they read it, now the Deaf people know

what's gonna happen at the event.

And then that way I knew
what's gonna happen.

A, B, C, whatever's
gonna happen by the end.

So if you're gonna have someone

in your public health places,

if you know someone that's
Deaf, who's an advocate,

let them come to your place.

We're here to help you
implement some of those plans

that will make your
situation a lot easier.

Whatever, like I said,
COVID was just so new.

That was something and
the idea that it came up.

So it could be,

it's just something that
came up all of a sudden.

So that was one example
that came up during COVID.

Also I wanted to, I
think it's so important

that you need to, with your overhead cost,

it's like when I go to
events, like for example,

I'm trying to think, when
you go to any events,

I always have to tell
them include interpreters,

all these costs, the
Braille paper, everything,

it needs to be included
in the overhead cost.

Because right now we're
seeing more and more things

that are happening, different
events and things like that

are not including the DEIA.

If you're familiar with the DEIA,

diversity, equity,
inclusion, accessibility.

Everything that we do, even
disaster, everyday life,

going to the movie, going
to all these things.

We need to have that DEIA,

have that set at the back
of our mind on those things.

So anyway, I just wanted to kind of share

just a little bit of things I have.

There's so many things I wanna share,

but at the same time, their feedback

and their experiences are
really important to share.

But thank you.

- [Germán] Thank you for your comments.

Very important for us all to be aware of.

Anyone else who would like
to share personal experience,

questions for our panelists?

- [Rodney] While folks
are thinking of questions,

this is just kind of
some food for thought,

and just something I've seen done

in one of our other
region five states in Ohio

where a Center for Independent
Living received some funding

due to a disaster.

And they put on, it wasn't a summit,

but it was a training,
and it was basically,

and I've heard people
mention kind of the concept,

but of that two-way training.

So not only is it people from
the disability community,

people with access and functional needs,

training, teaching on not
necessarily the specifics

of what they do related
to emergency management,

but just the general awareness of,

hey, this is better understanding

of intellectual or
developmental disability.

This is my experience

when I had to be evacuated
from the 10th floor

of a building and I use a wheelchair

and they had to throw
me over their shoulder,

whatever the case may be.

I mean, there were so
many different examples,

but they were able to
give that lived experience

in a more curated, controlled environment,

provide some real education
on the different disabilities,

the different nuances,
communication strategies,

different things like that
to emergency managers,

to public health officials, to,

I forget how broad the audience was.

And then the second day of that event

was the emergency managers,
the public health folks

communicating to the community

and educating the
community on best practices

that they need to have
and kind of put through

the filter of, "And what does this mean

for me having X, Y, Z access
and functional needs?"

So as we look to make this
something we do every year,

I think an auxiliary to that could be

some type of workshops, whether
it's added to a day here

or something outside of this,

I think could feed into
this and really bake it in.

Right?

- [Scott] I just wanna wanna
add to that, and Thane,

you mentioned, how do
we get that poor fellow

in southern Illinois who has 94 counties,

how do we get him to get in front of,

fortunately at IEMA we have
regions like IDPH has regions

and we have quarterly regional meetings.

So we have an opportunity
where each regional coordinator

meets with all his or her EMA directors,

whether those are at the
county or municipal level,

depending on how that's cut up.

More municipal up in the Northeast.

There's an opportunity there
where that one gentleman

from that organization can
sit down with everybody

in region 11 and say,
"Hey, let's talk about this

so we can solve problems."

The other thing I would like to say

is that I think that
there's a lot of interest

on our side at IEMA to
help with this event again

next year and to get more emphasis.

What I would love to see is
then a regionalization of this

maybe on the next day just to sit down,

so if we can get people to come here,

you never exchange business
cards on the field of battle.

This is the place to
start making connections

and making that marriage

between the organizations
geographically, right.

So I think that's one
of the biggest struggles

when we on our side talk to
local emergency managers.

There's so much going on in our space

that this seems to them,
and I don't agree with it,

it's like, this is just one more thing.

Just like we have the one
gentleman in southern Illinois

who has 16 counties, we have that one guy

in southern Illinois who does
this job for $300 a month,

who's also the assistant fire chief,

who's also the dog
catcher, who's also the guy

that drives around and sprays for bugs.

I mean, he's got other jobs,

and so we've gotta kind of merge,

we gotta make it easier.

At our levels we gotta make it easier.

An event like this, getting them here,

and getting the right people
from that region in the room

to say, "Hey, I am right here."

And then find out,

oh, I actually live one
county over from you.

And to have that conversation,
this gets easier.

The more opportunities we get
to put both sides in the room

to understand that there
are easy solutions to this,

to tell the guy in southern
Illinois who has 16 counties,

"Hey, you can go to one meeting
and talk to 12 counties."

Wow!

We just made his life a lot easier.

And now we get the right information

in front of the right people.

We get back to what I said before,

we actually start getting
those people who are hot, cool,

the people who need medicine,
getting them the medicine,

the devices that they need

because we're putting
the people in the room.

We can do that.

- [Thane] And when we look at
access and functional needs

in the state of Illinois
or Independent Living,

there are three sets of organizations,

the Statewide Independent Living Council,

Centers for Independent Living

and INCIL, we all three partner together.

INCIL is sort of the collaboration

of all 22 Centers for
Independent Living in the state.

SILC helps write the plans

as to what the Center's
focus for that year

on Independent Living is going to be,

it's called the SPIL.

The focus of this year's
SPIL is emergency management,

whether it be through helping
people with disabilities

prepare for emergencies,

collaboration with our
local health departments

or emergency managers.

So as a state, on our side,

it's not just a few advocates
or one or two Centers.

It is a part of the statewide SPIL plan.

And I say Centers for Independent Living,

'cause that's where I work.

But various disability
groups, whether it's DD,

so developmental disabilities,
physical disabilities

are covered by the SPIL and participate.

So this is a great year if
you have not reached out

to reach out.

And likewise, we are telling our centers

and our other groups that advocate

for persons with disabilities,

this is here, start reaching out.

Remember, ask for trainings.

Most of us will show up and do
a training for you for free.

It's part of our I&R,

our outreaches through Centers
for Independent Living.

And that's your foot in the door.

That is your easy way,

hey, can you come do a disability
advocate training for me?

And then once they're there,
you start talking to 'em

and you bait 'em in.

It's a sales pitch.

This is why we feel
you're important to us.

I know why I think my emergency
managers are important to me

and hopefully my agency
expresses that well

throughout our county, our state,

and working with our region
five federal representation.

- [Jae Jin] And the other aspect of that,

which I think I need to say
because I work at a university,

is the importance of data and research.

And at UIC, my Department of
Disability and Human Studies,

Human Development, we
have a lot of faculty

and we have a lot of
collaborations partners

and grad students who do
research on disability issues.

If IDPH or other
organizations wanna partner

with our faculty, our grad students,

or undergrad students to do research

on emergency preparedness
and related topics,

I am very confident that we are very open

and wanting to talk with you.

Because there is, on the
grand scheme of things,

there needs to be more research

on our diverse disability communities.

There needs to be more research

on how COVID has affected
the disability community,

different disability communities,

how long COVID is affecting our disability

and diverse ability communities.

And if IDPH, and DHS,

and FEMA, and IEMA,

and other agencies, and
departments, or organizations

are wanting to partner with that,

I think whether it be our
university or other universities,

that's an avenue that I
think I would very much

like to encourage and support.

- [Rodney] Yeah, Jae Jin,
that's music to my ears.

I know most folks in
here are practitioners,

and that academia piece is greatly missed.

Data analytics and research,
just for that example,

not my strong suit, but I'm
asked more and more in my job

year by year to do more data analytics

to base what I'm doing off of research

and kind of what those outcomes are.

Yet we don't have MOUs with
UIC, with Northwestern,

with the University of Illinois.

And so those are low hanging fruit

as far as that relationship between,

and I also think it's
because emergency management

is kind of a newer science,
or a newer field so to speak.

And so we're kind of catching
up on that relationship

and how we connect and
coordinate with academia.

But it's a huge opportunity.

I mean obviously as simple as you said,

but then more broadly
the entire university.

A quick example of that,

Wayne State University in Michigan,

and this is a no-brainer

that you would think we do all the time,

but because of some relationships,
some works being done,

we were able to establish an MOU

to where the social work students

were able to assist with case management.

And so that's a no-brainer.

You would think that's
just how we do business.

But that was an abstract, that
was kind of an aha moment.

And so I think the more
academia can engage

with emergency managers,

and then specifically
looking at accessibility,

can really move the needle.

And I know we didn't get into it,

but with that specifically, technology.

If you go into our DRCs,

I think our accessibility kits
are a little bit outdated.

But that's because we're
not getting the forefront

of what's available through technology,

through these different resources,

just 'cause you know what you know

or you don't know what you don't know.

And so the more that we can engage with a,

say pass it on center
from Georgia Tech or UIC,

I just think the sky's the limit

and there's so little of
that currently going on

that I'd be surprised where we could go.

So we'll definitely connect
offline on that one.

I'm glad you brought that up.

- [Jae Jin] And I'll just
say, anyone who's interested,

feel free to contact me.

I'll be more than happy to connect you

with our department and our faculty.

Thank you.

- [Germán] So much appetite for discussion

and knowledge share is needed.

Sadie, I see you holding the
mic, you have a question?

- Yeah, this is Sadie, I have a question.

Especially for the State
Plan for Independent Living

as an opportunity to be able to help

work with Office of Emergency Management

and also emergency
management advocacy systems

and individual advocacy.

In your state, when you do
the survey out to community,

do you include emergency
management community

in that survey to ensure
that emergency management

is a topic that can be
adopted by that State Plan

for Independent Living?

- [Thane] I would love to tell you I

have the answer for that.

I would actually have to
ask Shelly on that one

because she's the
Executive Director of SILC.

So she is the one who
sends those surveys out.

I know they go to our Centers
for Independent Living

and other disability related groups, DD,

but I don't know if they
went out to EMAs or not.

I'm not sure

- This is Sadie.

I will let you know that
we were able to get success

in Colorado because collaboratively,

the program I'm in,

working with the State
Independent Living Council, SILC,

we were able to include

all of our emergency management cadres

to be part of that conversation.

And now it is being adopted in our 2025

and the three year plan.

So just opportunity for US champions

working with emergency management

to be able to take that
back and be able to have

some of that funding tied to
being part of the conversation.

- [Jae Jin] Thank you, Sadie.

- [Thane] Thank you very much.

- [Germán] What a
wonderful day one has been.

Up to the minute.

Tomorrow we want to have an exercise

and start promptly at 8:30.

So if you could start arriving
around 8:10 to settle in,

we will have areas
designated for each of you.

And we will quickly
and seamlessly show you

where to sit for tomorrow's exercise.

For today, if you can please
fill out the online survey

so it can help us make this
event even better for next year.

And let's again give a round applause

to our wonderful panelists.

(audience applauds)