

"Let's Learn About Community & Social Determinants of Health"

Erica Mones

International Disability Rights Affirmation Conference 2025

Thursday, November 6

[2025/11/06 07:30] Elektra Panthar: Hello everyone.

Today's presentation is being transcribed so those without audio or who require text only can participate in real time.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

You will see the transcription in local chat.

Transcription is provided by Virtual Ability, Inc.

The transcriptionists are Carolyn Carillon, Elektra Panthar

The following initials in the transcription record will identify the speaker:

EM: Erica Mones

[2025/11/06 07:35] Gentle Heron: Welcome everyone to the 2025 International Disability Rights Affirmation Conference.

The theme of this year's conference is "No Health Without Peace."

Certainly health is important to everyone with a disability.

That's why our community maintains the Healthinfo Island to the west of us.

You will find a notecard about the 8 informative poster sets that are over there for the month of November in the blue sign behind me to your left.

Peace is also important to persons with disabilities.

Our worldwide community has fought for decades for justice, inclusion, adequate care, and lots of other things that people without disabilities don't often worry about.

Peace in one sense might mean that we are now treated equitably everywhere.

Or personally, it may mean making peace with our own symptoms and limitations.

The two nouns--health, peace--can be defined in a wide range of ways and contexts, from quite personal and individual to communities, to nations, and to our entire planet.

Today's conference will explore many of these interconnected ways of looking at health and peace.

In my mind, this broadens the scope of our conference a bit.

If you think about it, that topic applies to everyone, not just to those of us with disabilities.

Everyone wants to be healthy and at peace.

Here's how we came up with this conference theme.

Among the papers we read about six months ago to identify potential speakers was one titled "No Health Without Peace".

It was published in the journal *Academia Medicine* in April 2025.

In this paper, the authors identify their profession (medicine) as a political entity, having responsibilities to communities and nations as well as to individuals.

Responsibilities to not just react to crises, but to help prevent them.

They mention several related imperatives, such as developing global strategies based on people's social needs, improving community resilience, and ensuring equitable access to healthcare.

Addressing manmade crises, they say, is a way to address deeper societal structural failures.

You can read this short article here: <https://doi.org/10.20935/AcadMed7637>

Many of our speakers today will take a similar stance, even beyond the field of medicine. No doubt our audience will be interested to compare and contrast different approaches. Now I am going to exercise my prerogative as a community leader to insert additional research-based information related to the overall theme at the beginning of the breaks between individual sessions.

I encourage you to review the research as well as to try out the suggested activities.

I'd like to start my contribution with some information about one of the things I find both energizing and calming: music.

Music definitely affects our minds.

Musical selections are sometimes divided into yang or yin, which are terms from Chinese culture to describe interdependent but opposite natural characteristics.

Yang music is strongly rhythmic, powerful music. It energizes you.

Yin music in contrast seems softer and rather ethereal. It encourages relaxation and peaceful thoughts.

An example of a yang musician is the late great jazz drummer Jack DeJohnette. He said: "We can move to better places of understanding and a place of enlightenment. I'd like that to be my contribution to the music."

Hear him play on this video:

https://www.youtube.com/watch?v=a3CZHR5uiNM&list=RDa3CZHR5uiNM&start_radio=1

Famous violinist Yehudi Menuhin said:

"Music is a therapy. It is a communication far more powerful than words, far more immediate, far more efficient."

Here is an example of Menuhin playing some yin music, the Adagio from the Bruch Concert No. 1 in G minor.

https://www.youtube.com/watch?v=Qeyl_eT9-ml

You can learn about the research on the impact of music on mental health at the Healthinfo Island poster set here:

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/172/155/22>

We all have much to learn from our presenters and panelists today.

Please do not interrupt them while they are speaking. I encourage you to take notes during the sessions, especially writing down questions that the presenters bring to your mind.

There will be a short time for audience Q&A at the end of each session.

There is never enough time!

You are welcome to contact presenters by email after the conference to continue the conversation they will begin here today.

If you leave for a bit now, please be back at 7:45 so the first session can begin on time.

Thank you.

[2025/11/06 07:44] jiwings Resident: Hello. I am jiwings, or Jill.

I have a degenerative disc disease and spinal stenosis. I also have mental health disabilities.

I have found a supportive home here at virtual ability and many friends and lots of educational opportunities.

I am grateful for virtual ability and their work and feel privileged to be here today as an introducer to one of their speakers!

Thank you Andee Cooper for voicing for me as I was a selective mute as a child and still suffer some anxiety, and needed a voice for me.

It is a true privilege to welcome Erica Mones — a bold voice, a fierce advocate, and a storyteller who challenges perceptions and uplifts communities.

Erica is a YouTuber, writer, and disability rights activist whose work centers on visibility, inclusion, and authentic representation.

Living with multiple disabilities, including cerebral palsy, Erica brings lived experience to her advocacy.

Her blog, *Running With Crutches*, is a powerful platform where she shares personal reflections, cultural critiques, and calls to action — all with wit, honesty, and heart.

Through her videos and writing, Erica dismantles ableism, amplifies marginalized voices, and invites us to reimagine accessibility not as a checkbox, but as a shared responsibility.

Her work has resonated across social media and beyond, inspiring others to speak up, lean in, and build a more inclusive world.

Please join me in welcoming Erica Mones — a changemaker whose courage and creativity continue to move the conversation forward.

[2025/11/06 07:47] Elektra Panthar: EM: My name is Erica Mones and today I'll talk About Community & Social Determinants Of Health

It's important to remember that if you don't have basic needs met or live in an environment with certain conditions it'll be much more difficult to be healthy

WHAT ARE SOCIAL DETERMINANTS?

“Social determinants are the conditions under which people live, and the economic and social forces that shape our lives from birth and childhood through [adulthood,] aging, and death.”

Christy Harrison, M.PH.,R.D The Wellness Trap

FIVE SOCIAL DETERMINANTS

1. Quality jobs
2. Education
3. Housing
4. Safe environments
5. Healthcare

1. Many people get healthcare only through jobs
2. People need to be aware how to be health and live in a way that optimizes health, it also intersects with jobs because without good education it's more difficult to get a job with good healthcare benefits
3. Unhoused people are more exposed to health risks
4. Lack of safety brings a lot of stress which impacts health
5. This one is the most straightforward, as the cost of healthcare impacts the ability to access care

INTERSECTIONS

- Ableism

- Racism
- Classism
- Homophobia & transphobia
- Fatphobia
- Misogyny

Nothing exists in a vacuum; this is not an exhaustive list but these are major ones
 Oppression affects access to healthcare, certain groups face more discrimination and have trouble accessing good level of care

ABLEISM

Prejudice against a person based upon disability

This shows up as:

- symptoms dismissed as “part of one’s disability”
- inaccessible exam rooms
- Forced sterilization
- inaccessible communication

Even if somebody doesn’t have a disability but for example has cerebral palsy like me, doctor may discount their concerns as effects of the CP

A lot of exam rooms are also inaccessible

The exam tables are also not accessible if you have a disability that affects your movements

There's also a history of sterilization against people's will, it's not as widespread as before but it still happens

For deaf and hard of hearing there's often trouble communicating because interpreters aren't widely available in doctors' offices

RACISM

- Lack of awareness of dermatological conditions on deeper skin tones
- Environmental racism (living in proximity to factories, dump sites, and other polluted locations)
- Belief by med students and doctors that Black people “feel less pain”
- History of fear and mistrust (Tuskegee experiments)

Skin conditions present differently on different skin tones and textbooks aren't always presenting all of them

So doctors aren't always properly trained to spot skin conditions and symptoms on black people

Unfortunately many medical students and doctors take black people’s pain not as seriously

There's a lot of fear in the black community because historically experiments have been conducted on people of color

MISOGYNY

- Lack of research on how conditions affect those assigned female at birth (AFAB)
- Belief that AFAB people are “hysterical” or attention-seeking
- Attribution of all symptoms to the menstrual cycle
- Tend to be responsible for childcare and homemaking

Up until very recently research has been done only on male bodies - even things like seatbelts

AFAB have also been accused of faking symptoms or told to 'just calm down'

Many symptoms have also been attributed as normal cycle when in reality it's not normal to be in excruciating pain

Women are also often busy with childcare without much support so they don't have time to take care of themselves

FATPHOBIA

- Attribution of all symptoms to weight
- Lack of awareness of eating disorder presentations in larger bodies
- Belief that all people in larger bodies are lazy and immoderate

Many fat people's ailments have been dismissed as 'this is because you're fat' even if the ailment has no correlation at all

Many fat people are also accused of being lazy even when they have an active lifestyle

OTHER FACTORS AFFECTING HEALTH

- Transportation gaps
- Health care gaps
- Mistrust of medical system

[2025/11/06 08:07] Carolyn Carillon: EM: HEALTH JUSTICE IS SOCIAL JUSTICE

Until we address systemic issues within our healthcare system, health will only be attainable for those with privilege.

Nothing exists in a vacuum

Until we address these systemic issues -- even just thinking about where people live

Like close to a grocery store --

It will impact their health

Until we address these issues, health will only be accessible to those in a higher social class who are white and abled

CONCRETE STEPS

• Advocate for healthcare (if you are in the U.S. you can call your senators or representatives. Personal stories can be powerful).

• Join a mutual aid hub (<https://www.mutualaidhub.org/>)

• Fight for relevant social justice issues

Sorry for those who don't live in the US

I don't know how every system works

Personal stories help

For example, one of my close friends recently passed away due to neglect from the health system

I believe if he had gotten the care he needed, he might still be here

You can also join a mutual aid hub

Where people will go and help others

If they're able to provide food, they do that

Or transportation

Fighting for social justice issues -- nothing exists in a vacuum

It all intersects

All these issues feed off one another
Until we address these issues, they will crop up
Here's a list of resources I used for this presentation:

Adamson, B. C., Adamson, M. D., Littlefield, M. M., & Motl, R. W. (2017). 'Move it or Lose it': Perceptions of the impact of physical activity on multiple sclerosis symptoms, relapse and disability identity. *Qualitative Research in Sport, Exercise and Health*, 10(4), 457–475.
<https://doi.org/10.1080/2159676x.2017.1415221>

Centers for Disease Control and Prevention. (n.d.). Social Determinants of Health. Centers for Disease Control and Prevention. <https://www.cdc.gov/public-health-gateway/php/about/social-determinants-of-health.html>

Harrison, C. (2023). *The Wellness Trap*. Little, Brown and Company.

Pomeroy, C. (2012). Social Determinants of Health. YouTube.
<https://www.youtube.com/watch?v=qyKD-2AXKIU&t=503s>

Scott-Fulton, V. (2021). How Social Determinants Impact Healthcare. YouTube.
https://www.youtube.com/watch?v=xAlxtog_4ns

Spence, S. M. (2024). *Live Nourished*. S&S/Simon Element.

What I like about these resources is that they go into the deeper issues -- especially Spence
She's a registered dietician
She heard doctors talk about noncompliant patients
But when she talked to the patients, they would say they just ate the food that the homeless shelter provides
No doctor had asked her that before
If you look at my feet, there's a box
With these resources
Thank so much
Any questions or comments?

[2025/11/06 08:13] Gentle Heron: Your information was a great introduction to the conference theme, Erica. QUESTION- Erica, you have lived in different parts of the same country. Do the Determinants of Health differ across the US?

[2025/11/06 08:14] Carolyn Carillon: EM: I've lived in different parts of the US, and social determinants differ from place to place
I've definitely seen different barriers to health
Right now where I live in Wyoming, there are places where people have to travel miles and miles
Hours!
To see a doctor
That's a big problem
Here, a lot of people mistrust doctors
Because they mistrust the system
Or they have an idea about people pulling themselves up by the bootstraps

In NYC, a lot of it is poverty and not having insurance
Even though people in these cities live close to medical care
They just don't have the money and resources
Or they may not live close to a grocery store so they can get food
Any other questions?

[2025/11/06 08:16] Namaara MacMoragh: I spoke with a friend in NYC who pays \$2000 per month on ACA plan, For 2026 it'll be \$2,400. Average people, let alone those with disabilities, can't sustain that for insurance.

[2025/11/06 08:17] Mook Wheeler: COMMENT: Agree that nothing exists in a vacuum. Your dietician example is powerful. The current fashion/tendency for medicine to become ever more and more specialised is also adding to this problem.

[2025/11/06 08:18] Carolyn Carillon: EM: exactly, because if you have to see 10 different doctors for the same condition & you don't have decent insurance, that will cost so much money

[2025/11/06 08:18] Gentle Heron: QUESTION- Is it important for people with disabilities to blog about their lives? What do disability blogs add to advocacy?

[2025/11/06 08:19] Carolyn Carillon: EM: yes it's important in every way

Disabled people should be out there and show themselves
And show that disability is a natural part of the human condition

I read Keah Brown, [a blogger with cerebral palsy]

Alice Wong, [of the Disability Visibility Project]

She uplifts other voices

It's just really important to be out there and exist loudly

In a world that doesn't want disabled people to exist and thrive

"I'm here and I'm not going away"

Any other questions?

[2025/11/06 08:21] Namaara MacMoragh: Comment ... Thank you so much for a relevant and engaging presentation Erica.

[2025/11/06 08:21] iSkye Silvercloud (iSkye Silverweb): Gentle has been known to say that most people are TABs Temporarily Abled People because everyone experiences disability at some point in life.

[2025/11/06 08:21] Carolyn Carillon: EM: yeah, it is important to remember that disability is a natural part of the human condition

Unless you die young, you're probably going to age and experience natural aging process which includes reduced mobility and abilities

You can sustain an injury that causes a disability

[2025/11/06 08:22] Itico (Itico Spectre): One quarter of Americans will get some sort of disability before age 65.

[2025/11/06 08:22] Carolyn Carillon: EM: Yes, I don't know the exact statistics but after 65, it increases a lot

Because you're aging

[2025/11/06 08:23] McMillan TM (McMillan Resident): Itico, that depends on what you call (dis)ability

[2025/11/06 08:24] Carolyn Carillon: EM: it all depends on your definition

You might be diabetic and you don't see that as a disability

Someone else may call themselves disabled

[2025/11/06 08:24] McMillan™ (McMillan Resident): indeed

[2025/11/06 08:23] iSkye Silvercloud (iSkye Silverweb): I'm actually puzzled by people who have this attitude that people who develop or acquire disability are suddenly of less value to society...

[2025/11/06 08:24] Carolyn Carillon: EM: yeah, I know it's hard for a lot of people who acquire a disability

They're just treated differently

[2025/11/06 08:24] Dr. Henry Germain-McCarthy (VAIPresenter1 Resident): Even while still a TAB, many folks get a sudden intro to dealing w/ disability when a close loved one acquires one, and that typically opens their minds to the injustices and inequities in systems of care and public attitudes

[2025/11/06 08:25] Carolyn Carillon: EM: I've been disabled my whole life

But even when I go to NYC with my family and they see how inaccessible some curbs, etc, are, they notice

I tell them it's incredible that they've known me my whole life and they're just finding out now

But it's good if it just takes something like that so they can see

Any other questions?

[2025/11/06 08:25] Gentle Heron: This is Erica's blog: <https://ericamones.wordpress.com/>

Do check it out!

QUESTION how much time do you spend blogging?

[2025/11/06 08:27] Carolyn Carillon: EM: Gentle, it may take a few days if I'm writing for another site

My process is that I have ideas and I make sense after to make it readable

Something makes sense to me, but not necessarily to others

[2025/11/06 08:28] Christy Rain: What impact has SL made on your ability to interact with people?

[2025/11/06 08:28] Carolyn Carillon: EM: Christy, sadly I haven't used SL much

But the internet in general is a great way to meet people

And be exposed to new ideas

Or even people I know in RL

That I may not see every day

I may text or call or facetime them

[2025/11/06 08:29] Mook Wheeler: QUESTION: The "official" definition of disability is what is followed by institutions and agencies of support. How do you think we can get them to see that disability is more individual, less generic, and that it has a gradient? How do we get the two perspectives to come together?

[2025/11/06 08:30] Carolyn Carillon: EM: Mook, a lot of times it comes down to speaking to people on an individual level

That's what I liked about college

I could talk to people who were different that I was

I would tell them my story and how the medical system has impacted me

How it sees disability

People in medical professions really need to listen to disabled people

Even if you just change one person's perspective, think of all the people that person interacts with

[2025/11/06 08:31] Mook Wheeler: nods. What you said about "personal stories" being incredibly powerful to induce change/legislation.

[2025/11/06 08:31] Itico (Itico Spectre): Several years ago, I spoke with a medical school class and I used the line, "I don't make myself disabled, other people make me disabled."

[2025/11/06 08:31] Carolyn Carillon: EM: Itico, that's the social model of disability Disabled people aren't necessarily disabled by their conditions but by the environment around them and how others perceive them
Speaking with a medical school class is a great way to have impact

[2025/11/06 08:33] Gentle Heron: Erica, thank you for joining us today. This was really helpful to hear, if a little scary.

[2025/11/06 08:33] Carolyn Carillon: EM: thank you so much, Gentle
It's great to work with you again

[2025/11/06 08:33] Gentle Heron: Audience, please thank Erica for presenting.

[2025/11/06 08:33] Mook Wheeler: thank you Erica!

[2025/11/06 08:33] Carolyn Carillon: this is a great community you've built

[2025/11/06 08:33] Christy Rain: 🍷

[2025/11/06 08:33] Lloud Laffer: 🎵🎵 ☀️ Thank you ☀️ 🎵🎵

[2025/11/06 08:33] Elektra Panthar: 🎵🎵🎵🎵 Applauds 🎵🎵🎵🎵

[2025/11/06 08:34] Brian Aviator: Thank you Erica. What a fantastic opening presentation. Really sets the context for the day! Great job!

[2025/11/06 08:34] Eme Capalini: Thank you Erica! Great job

[2025/11/06 08:34] iSkye Silvercloud (iSkye Silverweb): Thank you so much for coming, Erica!

[2025/11/06 08:34] Carolyn Carillon: EM: thank you

[2025/11/06 08:34] Jill (jiwings Resident): /claps

[2025/11/06 08:34] Kreatya Shannon (Kreatya Resident): thank you

[2025/11/06 08:34] Elektra Panthar: Great to have you!

[2025/11/06 08:35] Dr. Henry Germain-McCarthy (VAIPresenter1 Resident): Erica, wishing you continued success & joy in your important work for disability justice & pride

[2025/11/06 08:34] Carolyn Carillon: <<transcription ends>>