

REALTIME TEXT FILE

DISABILITY AND HEALTH PROGRAM
DISABILITY COMMUNITY PLANNING GROUP WEBINAR
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>> BRYAN RUSSELL: Good Friday afternoon, everyone, this is Bryan with the Disability and Health Program. Welcome to the Disability Community Planning Group's regularly scheduled webinar for March 29th.

Thank you so much for joining us. And I hope y'all are having a wonderful day. The weather is gorgeous here in Tallahassee, so I'm hoping it is clear where you are.

I am going to turn this over now to our wonderful colleagues, Claudia and Meagan, with the University of Florida and they are going to take it from here.

>> CLAUDIA FRIEDEL: Wonderful, thank you, Bryan.

Hi, everyone, this is Claudia Friedel and I am going to introduce Meagan, Meagan has been working with us for many, many years as our program assistant here at the University of Florida. Meagan Sullivan is a second year MPH student at the University of Florida. She graduated with bachelor's degrees in both Psychology and Criminology from UF in 2017. She has been involved in Gainesville's Deaf community for five years and has a research interest in Deaf health disparities. She has been involved in both psychological and health related research and hopes to pursue a career in research to address health disparities in people with disabilities

Today she is going to be speaking about her trip to the APHA meeting, the American Public Health Association meeting last fall in San Diego and she will be recapping some of the presentations that she attended on that trip.

So, we'll let you take it away, Meagan. Thanks for joining us.

>> MEAGAN SULLIVAN: All right. Thank you, Claudia. Hi, everyone. Thank you for joining us for our quarter three webinar, I'm really excited to talk to you guys with the 2018 APHA annual meeting. The theme for this year's meeting was Creating the Healthiest Nation: Health Equity Now and was from November 10-14 in San Diego, California.

I'll start off by going over a little bit of a background about APHA and the meeting and I'll go over some presentations from the disability section and finally bring it back here to the Florida Disability and Health Program.

[Pause].

>> MEAGAN SULLIVAN: There we go. So what exactly is the American Public Health Association annual meeting and expo. What you're seeing on the screen is from the website, but the goal of the annual meeting and expo is to bring together public health professionals, researchers, and the like and discuss research in the field and what they're doing and learn from one another.

Within APHA, there are what are called SPIGS and member sections and a Special Primary Interest Group, or SPIGS, is a member sharing a common occupational discipline or program area of interest who don't elect to join one of the member sections.

Now, the member sections are one of the primary professional units of the association and they represent different discipline and programs. There are 31 sections and you can see the different ones on the table in the slide. The section that relates most closely to us here at the Disability and Health Program is the disability program for obvious reasons and that's where I spent most of my time at this year's meeting.

All right. Again, this is pulled from APHA's website and, according to the website, the mission of the disability section is to raise awareness and promote actions related to public health issues that affect the health, functional, social, and environmental aspects of disability. These issues include the causes and prevention of impairments and disabilities, especially secondary conditions; health promotion and rehabilitation; barriers and facilitators, both physical and social, that affect participation of people with disabilities in all aspects of society; and advocacy for public policies for individuals with disabilities.

So, this mission is a mouthful, but it really aligns very well with our mission here at the Florida Disability and Health Program.

Now, before the start of the conference, I had the opportunity to attend a pre-conference workshop for the disability section and it was entitled Examining Health Equity Using the International Classification of Functioning and Disability and Health Throughout the Lifespan and it was a wonderful experience to spend the day in a room with professionals from all over who were all interested in disabilities.

For those of you who might not be familiar with the International Classification of Functioning, or ICF, it's the World Health Organization's framework for measuring health and disability at both individual and population levels. During the workshop, there were four presentations that I'll go over today.

Okay. So the first was presented by Dr. Nieuwenhuijsen and was titled Health Disparity: Bridging Gaps using the ICF throughout the Lifespan. She started her presentation by discussing the issues measure health disparities for people with disabilities, mainly that there are inconsistencies in data collection and the focus on the medical model leaves much to be desired in terms of accounting for the social determinants of health, like where people live, their amount and quality of social support, their socioeconomic status, and their access to healthcare. She empathized the need for standardization in data collection, which is where the ICF comes in.

She explained that the ICF is the only classification system that accounts for environmental factors, providing us with a way to standardize how we collect data on PWD that gives us the most holistic picture of people's circumstances. The framework is there for you guys to see on the slide and you can see that it includes a person's health condition, a functional aspect, their daily activities, their participation in society, and then contextual factors which are the environment and personal factors.

The point of this framework is really to give a picture of the interaction between a person's health condition and those contextual factors. And finally, she really drove home the point that utilizing the ICF in our research helps us to get the fullest picture of the experience of PWD, making it possible to identify the reasons behind health disparities in the population, which is often a result of the interaction between the person's condition and

their environment.

The second presentation "The ICF and You: Public Health Applications" was presented by Erica Twardzik, a PhD candidate from the University of Michigan. She briefly went over the coding scheme of the ICF, which you can see it that incredibly high-quality picture from her presentation with the colorful Xs. But basically, the coding scheme includes alpha numeric codes that align with the different aspects of the framework I mentioned earlier.

She then went over how the environmental factors influenced the other factors in the framework, particularly the activity and participation component. The physical environment's accessibility has a large influence on how much PWD can participate. She emphasized the need to include disability in all areas of policy in order to create the most inclusive society and create health equity and also the need to move advocacy efforts for PWD from the charity model to a human rights model. to get the best advocacy that we can.

The next presentation was Using the ICF to Understand the Role of the Built Environment for Participation in Adults Aging with Physical Disabilities presented by Dr. Clarke. First she introduced the concept of aging with disability (so having a disability early in life and growing old) instead of aging into disability (which would be more growing old and then experiencing a disability), which are two separate experiences for PWD.

And individuals who are in that first group experience health inequities throughout their lifespan. For adults aging with physical disabilities, a good example that illustrates this is barriers to physical activity. Most of these barriers are socio-environment, like inaccessible or nonexistent sidewalks and paths, equipment barriers at recreational facilities and negative attitudes of people without disabilities.

These can keep adults aging with disabilities from participating in physical activity throughout their lifespan, making them more at risk for chronic conditions and comorbidities like heart disease and diabetes as they age. Again, the ICF is useful because it can account for those environmental factors. And the limitations we see are created by our society and how we structure things, which are changeable things.

The final presentation of the workshop was Health Equity, Children, and the ICF-CY presented by Dr. Lollar. He started by pointing out that despite data that we have about prevalence, that getting funding for children with disabilities can be tricky, particularly because politics can come into play.

And the suggestion to mitigate this was to focus on putting the funding into functional areas so we don't compete with each other for this funding, and he described why there's a need to add a consideration for children with disabilities into the ICF and the original framework had very little emphasis on children and use and was meant more for health professionals, but people like teachers, parents, social service professionals who work with children with disabilities also need a framework to help them, and so he pointed out that adding the CY or the children and youth to the ICF could be a very useful tool and that different -- children are a little bit tricky in terms of using this ICF-CY by itself because of things like the concept of play.

So, we would put that maybe in something like recreation for adults, but play is really an important factor of childhood and that's really where the work is done for a child.

So, because they are conceptually different, there needed to be a CY added.

He also pointed out, like most of the other presenters, that there were environmental influences that became barriers for children with disabilities and he went over some of those things that are affecting our goals in promoting health and mainly this was the need to empower PwD and really have them take ownership and be able to have autonomy with the ability to self-advocate, even for children.

And, self-determine what's gonna happen and not disempower them.

To aid in our effort in achieving health equity, his suggestion was that we focus on function and use the ICF to our advantage because it had a functional component to it.

Now I'm going to go over a couple of presentations that I had the opportunity to attend throughout the conference.

The first was Conducting a Needs Assessment for Deaf and Hard-of-Hearing Populations by Dr. Michael McKee and he's a physician and researcher from the University of Michigan.

Dr. McKee is Deaf himself and he described his experience with conducting research in the Deaf community. He went over that it is difficult to measure Deaf American Sign Language users and even harder for people who are Deaf-blind and this is because of a lack of access to data collection modalities, like telephone surveys, because they use ASL which is a visual language.

And this lack of inclusion in our data collection really creates a surveillance bias and that surveillance bias leads to underreporting of Deaf signers.

And he also made note that the census doesn't include ASL as a language option, so we're missing a piece of data there as well.

Then he went over his experience conducting a needs assessment for Deaf signers and his needs assessment was in Michigan, so one of the challenges for him was actually the Flint water crisis and that was completely outside of the realm of, you know, what someone could prepare for.

But one of the challenges that he could prepare for that he masterfully accomplished was conducting meetings and so when you have different people with different communication modalities, sometimes meeting together can be a very difficult feat and so one of the things that was really important were these team meetings because that included everyone in the community that he was trying to study, because it really helped the community take ownership of the research process and empowers them.

So, they did these team meetings by utilizing all of the communication technologies that they could, so they used certified interpreters, CART, tactile sign, and this ended up being successful and they could successfully meet as a team to create their survey.

So they created their survey questions and aligned them with other health needs assessments and this was particularly the BRFSS and that was a comparison component and they could translate the question into sign language. And this included what he called a 3 week "bootcamp" with real-time feedback, translation to and from ASL, and multiple times filming until you finally got the questions and concepts back in both languages and you got across what the question was trying to ask.

He suggested that for researchers, that priority should be advocacy, legislation, provision of services, and addressing the failure to accommodate, and he also mentioned that social media and town hall meetings were useful for him and that this type of research that he conducted should be done with groups of other disabilities, but the real important thing is that they have ownership of the research.

All right. And then I went to a presentation that was Perspective of Adults with Disabilities on Access to Health Insurance and Health Care presented by Dr. Hall and she conducted a qualitative study and she did telephone interviews and had a convenient sample of 22 people with disabilities and five key themes emerged and they were insurance, information, and understanding coverage, out of pocket cost, prescription medications, provider network, and transportation as barriers to healthcare.

So, she also introduced the concept that I found really interesting is a narrow margin for health for people with disabilities, meaning that for PwD, a loss of coverage to care is detrimental to their health more quickly than people without disabilities because they need

to be connected with healthcare because of their disability as well.

So, like, if I were to lose my health coverage, maybe someone who needed a certain medication to manage their disabilities would have a narrower margin of health than if I lost my coverage. It's detrimental to both groups, by the margin of health is more narrow for PwD.

And then I want to bring this all back to what we do at the Disability and Health Program and our mission here is to maximize the health, well-being, participation, and quality of life throughout the lifespan of all Floridians and their families living with PwD.

So this really matched up very well with both the mission of the disability section and the theme of the conference, which was promoting health equity, because this is really a group of people that has health disparities but should -- but has -- has a great potential for those to be eliminated since a lot of them are due to those environmental factors that are keeping us from being able to get rid of them.

So, in order to achieve this maximization of health and to achieve health equity, we need to keep in mind that those contextual factors that affect PwD, we need to help eliminate them.

And also important is finding a way to accurately measure PwD and making sure they're included in our data, that's the first step of any process, we don't know what we're up against at this point, so being able to accurately measure PwD is the first step of getting this addressed and get access.

We need to empower PwD to self-advocate and have autonomy and nothing should be without the input of those we're trying to serve--and nothing about us without us, that concept, and then finally the picture on the slide is from the meeting itself, and it says I want to change the way we... blank and people ended up writing what they want to see change in public health.

For me, I want to change the way we view disability, health, and access and shift focus to the interaction between people's health and their environment.

All right. So, thank you all for joining us. And then these are some pictures from La Jolla Cove in San Diego I took while I was there. Thank you all for joining us today, are there any questions

[Pause].

>> MEAGAN SULLIVAN: Hello?

>> CLAUDIA FRIEDEL: Well, if anybody thinks of any questions for Meagan, you can e-mail when we send out the notes for the call.

>> MEAGAN SULLIVAN: Yeah.

>> CLAUDIA FRIEDEL: I'm trying to think... if anybody wants to post any questions, we can put them in the chat box, or -- I believe everyone is muted at the moment.

So we'll just give it a couple seconds, and then...

>> BRYAN RUSSELL: Yeah, everybody's muted, but if they want to unmute, you know, they can unmute themselves if they have a question. Or just put it in the chat box.

>> CLAUDIA FRIEDEL: Okay. Thanks, Bryan.

[Pause].

>> CLAUDIA FRIEDEL: All right. Well, I have a quick question, actually. That last presentation with Dr. Hall, did that happen to be --

>> MEAGAN SULLIVAN: Yeah.

>> CLAUDIA FRIEDEL: -- Allison Hall? Is that who the presenter was?

>> MEAGAN SULLIVAN: I did not write down her first name.

>> CLAUDIA FRIEDEL: Okay. Yeah, she used to work with us on this project, so I'm pretty sure that's who it is.

>> MEAGAN SULLIVAN: Oh.

>> CLAUDIA FRIEDEL: She was the PI here at UF for... um... so, yeah, that was just interesting. I'm almost 100% sure it was her, but I was just curious.

>> MEAGAN SULLIVAN: Yeah.

>> CLAUDIA FRIEDEL: All right. Well, seeing as we have no questions at the moment, we're gonna let everybody go a little bit early.

And thank you so much, Meagan, for your time doing this presentation and then also representing us so nicely at APHA last year.

>> MEAGAN SULLIVAN: Of course. Thank you.

>> CLAUDIA FRIEDEL: Thank you, everyone. And we really appreciate it. Have a wonderful Friday.

And I have also sent out information about the annual meeting, registration information went out yesterday, so hopefully we'll be seeing more people in person on May 7th.

So thank you again for your time, everyone. Have a wonderful weekend.

>> BRYAN RUSSELL: Thanks, Claudia.

>> CLAUDIA FRIEDEL: Thank you. Bye-bye.

>> BRYAN RUSSELL: Bye.

>> MEAGAN SULLIVAN: Bye.

**Edited **

Recommendations and findings:

- Environmental factors (such as lack of access to care, socioeconomic status, physical barriers, etc.) create health disparities for PWD and need to be addressed in order to achieve health equity.
- Best practices for conducting research for PWD includes giving PWD ownership of the research process.
- Recommendations include focusing on eliminating the environmental factors leading to health disparities for PWD and conducting more research on PWD health disparities.