DISABILITY COMMUNITY PLANNING GROUP WEBINAR

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>> CLAUDIA FRIEDEL: Hi, everyone, this is Claudia Friedel, I'm here with Karen Restrepo and Bryan Russell from the Department of Health.

We just wanted to go ahead and get started. Thank you all for joining us for our second Disability Community Planning Group meeting and our student here, Karen Restrepo, is going to talk a little bit more about the 2016 American Public Health Association meeting.

So, hopefully you all can see my screen. And, Bryan, if you could keep an eye out for any questions that pop up. And we'll just go ahead and get started. Here's Karen.

>> KAREN RESTREPO: Hi, everyone. Thank you for joining us today.

If there are any questions, I would be happy to answer them as I go through the presentation.

So, I was able to attend the 2016 annual meeting and expo for the American Public Health Association better known as APHA and that was in October of this year.

We're going to start off with a brief introduction of what APHA actually is. It’s an opportunity for public health professionals and advocates to join together and network and also share some of their research experiences working in the public health sector.

And the neat part about this meeting is that not only can you network with others, but there's also organizations ‑‑ excuse me ‑‑ for-profit, not‑for‑profit, and governmental organizations that come to speak a little bit about their programs and what they bring to the public health industries.

There are also universities showcasing some of their talents and what they have to offer in their public health program.

That's the expo portion of the APHA meeting.

So, specifically we were able to attend and present research regarding the disability section. There are 31 total primary sections, and that's a way for APHA participants to choose a member section that they most identify or are interested in learning about or participating in.

And these are all core disciplines in public health, and it's just a way to share any research or policy papers and. Also, each section has networking opportunities and, usually in the evening, members can meet with their sections to network and share, there research or discuss, career development opportunities.

And here are some of the sections. I was able to learn mostly about the disability section and a little bit about the mental health section. My main focus was on the disability section.

Moving on, this is a little bit of information to share what they do.

They want to ‑‑ or this member section in particular, recognizes that disabilities are a National Public Health issue and all of the section meetings are geared towards advocating for persons with disabilities and how we can better improve service for everyone.

And then this is the mission of the disability member section. And, of course, as I mentioned, it's focus is to raise awareness and promote actions that will directly have an impact for improving the environment for persons with disabilities.

And anyone that's ‑‑ excuse me ‑‑ those that were in attendance included persons with disabilities, advocates, and people doing research and learning more about persons with disabilities and how to improve various aspects for them.

So, I would like to share a little bit about what this section ‑‑ what options you have to learn about the disability members section. So, there is a forum and also a poster presentation. The forums are more of a lecture‑style opportunity to learn more about research that's ongoing at the moment.

And in particular, these are the forums that I attended that I thought would be most beneficial to bring back to all of you. And it was health and healthcare access of people with intellectual and developmental disabilities, approaches to physical activity and healthy living for persons with disabilities and program experiences of caregivers, family members, and persons with disabilities.

And I'll share some research done under each of these forums and, again, there were many presentations ongoing but I thought these are the ones that I hope you all would appreciate learning about.

So, to start with, Barbara from Florida A&M, shared her research on designating people with intellectual and developmental disabilities as a medically underserved population, and how to move policy forward. This was new important information to me. There is a designation known as medically underserved population and the way this is determined, it has to deal with how many primary care physicians are in a particular area, the percent of the population that lives below the federal poverty line, infant mortality rate and how many people are over the age of 65.

And so how is this relevant to persons with disabilities? Well, the reason is that there are some persons with disabilities that would technically qualify for this designation, which would allow them to seek resources in 25 different federally‑funded programs.

However, given that they are not located all in one central geographic location, they do not get that designation of medically underserved populations.

And this is really important, because there are research grants, there is opportunities for persons with disabilities, or just anyone that qualifies, really, for this MUP designation. However, persons with disabilities do not qualify for it.

And the core problem is that persons with disabilities will be unable to meet that designation since they don't necessarily all live in the same community. Clearly, persons with disabilities exist in various areas and different regions and it would be unheard of to have such a large group segregated in their own communities.

So, that is a problem with the MUP designation, that though certain persons with disabilities might qualify in terms of they don't have an adequate amount of primary care providers available as a resource or they live below the federal poverty line, they don't however qualify for the designation, again, because they do not live in segregated communities.

So, Barbara gave a solution, a few solutions. The first one was to update the definition, which seems to be the more logical one.

However, Barbara explained in her presentation that after 14 months of deliberation, there was insufficient consensus to change the definition itself on the federal level.

So, we move on to the next solution, which would be the exceptional medically underserved population. And this is a request that the State Governor makes to the Secretary of the Human Health and Services department, excuse me, federal agency, and with the support of local and public health facilities, the Governor would point out to the Secretary that there is inaccessible resources or there is this need at the local level to serve persons with disabilities and to please allow these individuals to have this MUP designation.

And the last solution would be to have Congress amend the Public Health Services Act to make the I/DD population a special medically underserved population. This is important since there already is a group that has the designation, special medically underserved population, such as persons living in federal housing, homeless, and seasonal and migratory farmworkers. And, there would be a relatively easy transition to have the I/DD population under this designation, so they can also enjoy and take advantage of some of the services that the MUP designation offers, which, again, is just access to certain public health resources.

So, I thought that was just really neat to be aware of. And it's exciting that there are public health professionals that are on the front line of trying to make these changes possible.

And moving on to the next presentation that I just thought was very insightful, it was a presentation by Vijay and the title is an examination of how people with disabilities rate barriers at fitness centers. There are some disparities in activities of persons with disabilities and persons without disabilities. The persons with disabilities seems to have a 47% rate in physical activity, whereas persons without disabilities the rate is about 26%. And his research focused on finding out how fitness centers play a role in this physical activity topic.

And particularly some of the barriers that persons with disabilities may experience at fitness centers.

So, the five main themes that were identified were the built environment, the equipment itself, the program, policy, and the staff.

And as you can see from this table, it seems as though the program itself, having ‑‑

[Telephone beep].

>> KAREN RESTREPO: Excuse me.

>> CLAUDIA FRIEDEL: Go ahead.

>> KAREN RESTREPO: Pardon me.

It seems as though membership fees is one of the barriers that persons with disabilities rate as being one of the highest reasons that they are not utilizing a fitness center resources.

Another one would be also that the equipment itself is inaccessible. It's important to identify and see where, as public health professionals, we can try to bring down some of these barriers so that fitness centers become more accessible to persons with disabilities.

And some of the key takeaways, moving on to the next slide, is that only two barriers had a frequency barrier of greater than 50% but on a scale of 1‑5, it was either four or five. And, that means that when there is a barrier, persons with disabilities perceive, they see it as a very large barrier.

So, it's important to identify whether certain barriers are perceived or are actual barriers.

So, before ‑‑ excuse me. So, before persons with disabilities even enter the fitness center, if they think it's too large of a barrier, they might not even want to become physically active because they perceive it as being just far too large, even if there are protocols in place to try to bring down these barriers.

So, for example, membership costs have been ‑‑ were reported in this research as being the highest rated and most frequently reported barrier.

And certain persons with disabilities, at least in this study, might not be aware of the other barriers because they do not even get into the facility to experience these positive features the fitness center has to offer.

So, it's important to note that the ratings might increase once persons with disabilities actually enter this fitness center or utilize the resources that are available; it just seems as though the cost barriers may be a little too high.

So if there's a way to maybe work with health plans to allow persons with disabilities to engage in these fitness centers, it would help drive down perceived barriers ‑‑ that was one of the big takeaways from Vijay's presentation.

And now moving on to the third presentation I thought was very insightful, it seems to be a very burgeoning topics. It is titled impacts of self‑compassion on health‑related quality of life for individuals with multiple sclerosis and Mara presented on this. I thought it was interesting how compassion can help improve some of the outcomes in particular for the MS community.

And it's very important to note that persons with MS, they not only experience primary MS health outcomes, but also secondary ones, and that all aggregates together to bring about unpredictable symptoms.

And many MS patients ‑‑ or patients with MS, excuse me, have greater psychological challenges, and so the onus is on health professionals to improve the outcomes for this population and others that might experience great psychological challenges.

Mara's study focused on utilizing self‑compassion in order for patients with MS to reframe how they perceive their current state in regards to their condition and their abilities, and ultimately also increase their health‑related quality of life.

And I'd like to explain a little bit more about what self‑compassion is. As you can see, it has three main components, mindfulness, being aware of you ‑‑ yourself, recognizing when you are stressed or just struggling with certain emotions, and being able to do something about it to shift your mindset.

Self‑kindness focuses on being supportive about your situation and, you know, being kind to yourself when experiencing difficult times, instead of being so critical.

And the last portion is connectedness and that's being aware that it's okay to make mistakes and, surely, your experiences are difficult but no one is going through this necessarily alone. There's always someone to connect with or a way to connect with others.

And this study, particularly, was able to establish what self‑compassion does and how it increases a person's ability to make a mindful attitude and engage in daily activities and, in essence, not just for persons with MS but this can be for other persons with disabilities, how they can be compassionate towards themselves, find a positive coping strategy, and promote resilience. And, I thought this study was very comforting and encouraging to hear that though there are many people that have certain conditions that might be particularly difficult to cope with, there are strategies or lifestyles that can be adopted in order to improve quality of life, develop coping strategies and promote resilience.

And then there was also ‑‑ those were the forums, and those were just the few highlights of what was presented.

And now I would like to move on to the posters themselves. And I will mention two in particular before I delve into the one that we've presented on.

And the first one is called California Autism Professional Training and Information Network and the focus on that was very similar to a program we do here at the Disability Health Program, Train the Trainer. We help health professionals be mindful of interactions with persons with disabilities.

And the reason I bring this one up this poster session in particular is because they were struggling with ways to evaluate the success of the program and keeping track of persons that went through the training itself, so it was just encouraging to hear that there are other people doing similar types of projects. And, it is important to constantly find ways to improve, make connections and be aware that there is still a lot to learn from each other. It was great connecting and learning from Patrice.

And the second one, which is regarding national health and disability training for public health professionals and graduate students [coughing] ‑‑ excuse me. This individual, Kendall, is a professor of medical students and she is incorporating the importance of interacting with persons with disabilities and how to be socially competent and aware. It's encouraging to see that more institutions are integrating this type of education in their curriculum for their public health professionals and graduate students. It's so important that when these students graduate, they will be interacting with various types of people, so it's important to be mindful of everyone's abilities.

And now moving on to our presentation, which is titled increasing cultural competency of healthcare providers and public health professionals working with persons with disabilities.

So, as I briefly mentioned, it is a type of program that trains other healthcare professionals about self‑practices or just common knowledge of working with persons with disabilities that they may have not been aware of or it may have slipped their mind. And the importance of this project is to really increase competency and awareness of the health disparities that many or some persons with disabilities may face.

The program itself encompasses a presentation and resources that are provided so that they can ‑‑ these professionals can then use to aid in their connections with persons with disabilities.

And the importance, really, is to ensure that they are more aware of how to interact with others.

And now this is the presentation itself that was presented at APHA and it was well received and people definitely had questions regarding how they can incorporate some of this information into their programs. There was some brochures that were passed out, including some videos that were used in the program itself. And APHA is a great way to broadcast what we have been doing, as well as a great way to learn from others.

So a little bit more about the training program itself. Though, I did not present this at APHA, this slide breaks down the topics covered when these trainings are provided.

And it includes an overview of the different types of disabilities, which is some ‑‑ excuse me ‑‑ which some people may not be aware of and then discussing more about health and chronic disease and then the care experience and how to communicate with persons with disabilities and then, of course, advocating for accessible services, and then healthy diet and exercise.

And a lot of information that's shared, people may not be aware of if they're not a person with disabilities or interact with persons with disabilities.

For example, there are some barriers to healthcare that may not be so well known, such as the difficulty of getting on to an examination table or even just getting into the building.

So, it's basically just dispelling some of these uncertainties that some people have or making them more aware so that health professionals can accommodate persons with disabilities and ensure the best healthcare is being provided.

And moving on to some of the program material. Most of the material really focuses on ensuring that health professionals are aware of the importance of person‑first language and ensuring that certain outdated or just offensive language is not being used in conversation with persons with disabilities or even with persons without disabilities, because there is respectful language out there that should be encouraged and is necessary in order to provide quality care.

And this is one of the tables that I provided so that everyone is aware of what should be said and how it should be said to persons with disabilities in order to be mindful of everyone's conditions.

And during the presentation itself, there is some videos embedded within the presentation. These are videos from the Florida Department of Health and this is, again, bringing awareness to different types of conditions that people may be unaware of, such as hidden, invisible conditions or more well-known conditions.

And these two resources were provided also at APHA so that other people can use it or incorporate it into their programs if they so chose. This includes providing an emergency communication for all worksheet which in case of an emergency can be passed out to better communicate with persons with hearing difficulties, so responders can communicate with them and better understand how they're feeling at the moment.

And there's another pamphlet given out, healthy eating and weight tips and this is good for persons with disabilities, as well as persons without disabilities. This guide can help providers better understand persons with disabilities and help them incorporate some healthy habits in their own life.

And overall it was a well perceived presentation at APHA and it was a pleasure and an honor to attend the meeting.

And if there are any questions, I would be happy to take some now, or feel free to e‑mail Claudia or myself, and here is the contact information if you want to speak privately.

Thank you!

>> CLAUDIA FRIEDEL: All right. So I'll check the chat box to see if there are any questions, anything that you guys want to ask Karen while we have the line open.

So, I'll just wait and let us know if you have any questions about any of the presentations or anything that you want her to explain further.

[Pause].

>> CLAUDIA FRIEDEL: Bryan, do you see anything? I'm wondering if maybe I'm not seeing it.

>> BRYAN RUSSELL: No, I don't see any questions in the chat box.

>> CLAUDIA FRIEDEL: Okay. All right. Well, thanks again so much for joining us.

If anybody thinks of something later and wants to ask, my e‑mail is here, Karen's as well. I'd be happy to connect you with her, so please feel free to get with us if you have any questions you want answered.

All right. So seeing that there are no questions, we're going to go ahead and break and say goodbye to y'all.

Thanks again so much for joining us. And we'll be letting you know when our third call is after the new year.

So, until then, have a wonderful Merry Christmas, Happy Holidays, Happy Hanukkah, and happy holiday season.

Thanks, everyone! Thanks for your time.

[Concludes at 3:31 p.m.]