

REALTIME TEXT FILE

DISABILITY AND HEALTH PROGRAM
DISABILITY COMMUNITY PLANNING GROUP WEBINAR

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>> CLAUDIA FRIEDEL: Hello, everyone. Welcome to the fourth quarterly Disability Community Planning Group webinar. My name is Claudia, I'm here with Bryan Russell and Tony Delisle. Tony Delisle is the executive director of the Center for Independent Living in North Central Florida and professional behavior in the University of Florida and he has done research working with minority populations including those living in poverty that have disabilities, young adults with intellectual disabilities, and students diagnosed with learning disabilities that attend UF. We're excited to hear from him today. Thank you, Tony, for joining us.

>> DR. TONY DELISLE: Thank you.

>> CLAUDIA FRIEDEL: And, I'm sorry, one last housekeeping thing I forgot to mention.

If anyone has any questions during the call, please put them in the chat box and Bryan will address them throughout the call and ask them to Tony so he can address them. Excuse me. Now take it away.

>> DR. TONY DELISLE: Thank you, Claudia, Bryan, and everybody who has been working to host these webinars. I've been sitting on them for a little while, I'm very impressed and always learn something from them, so to be a presenter in one, I'm very excited and very happy to do it.

For those of you that are listening in, I want to reiterate what Claudia mentioned, if you have questions, comments, anything that you would like to insert, please do so.

You know, these webinar-type presentations can usually be a one-way type of conversation and I'm a person when presenting that would love to have an interactive conversation. I'm happy to be interrupted at any time during this presentation for questions and comments.

But this presentation that I'm bringing you today is focused on the aspect and

importance of community and its role in health promotion efforts. And this is something that's near and dear to me, and I've got a lot of experience in working in. I'm constantly learning from the involvement of the community into health promotion efforts for people with disabilities.

In today's presentation, you know, Claudia, you pretty much did a good background on my experience, so I'll spend minimal time on that.

But I'll try to get to the heart of the matter in terms of community and engaging the community, we can unpack that and have courses on what does community mean, but in terms of this presentation, the target community being people with disabilities, talk about the benefits and barriers towards involving them in health promotion efforts.

But also another aspect of community, which is the community-based organizations, or CBOs as I have abbreviated them in this presentation, which could be any types of agencies or entities that may be involved in your community and in multiple facets.

And I also have some examples of community-based organizations; in other words, where the target community, in this case people with disabilities, are involved and sometimes the primary driver in community-based organizations and I have a couple of examples of those as well in this presentation.

Right now I am the director of Center for Independent Living in North Central Florida, I've been here nearly two years. Centers for Independent Living is a national organization, there are many in our country, we have 15 of these centers in the state of Florida and our center serves a 16-county catch area and we serve a wide variety of programs for people with disabilities.

I have more information about this at the end of the presentation that I'm happy to share, time permitting, but it's safe to say the multitude of services that we provide cover a wide breadth of needs for people with disabilities.

And a lot of these services really go to the heart of social determinants of health. We work a lot with getting people with disabilities employed, trying to get them eligible for paratransit type services and working on independent living skills, financial management, and then multiple types of services that really do go to the heart of health promotion in many aspects.

Before coming to the center and being at the University of Florida, I was involved in many programs and projects.

And each of these programs and projects had something in common: They were community driven, involving the target community in all phases of program planning, implementation, and evaluation.

Being at the University of Florida, these are theoretically grounded and used program planning models to help guide in the creation and delivery and evaluation of these programs.

And these programs that I was involved in, spanning over roughly ten years that you see here, like the quality of sand, people with disabilities, University of Florida, people

with disabilities, low income neighborhoods where prevalence of people with disabilities was pretty high, I worked with the VA for a while, veterans who had disabilities and many organizations and programs that I was a part of.

I'm going to go over this slide to set a little bit of the context in how I see health promotion. And this was a road map that we utilize in all of our programs, just about. In order to identify how we would go about creating a program, we would first, the couple cells that you see up top, the health outcomes, certainly the two, you know, outcomes that people recognize most in health promotion is getting people to live longer and trying to prevent disease or mitigate disease, if it's already there.

These health outcomes can manifest in a lot of different types of areas; you can add quality of life, you can add in clinical indicators, blood pressure, body composition, these kind of things that we were keeping track of.

So it's not isolated, this health outcome comes in a broad category and you can see two dominant ones we look at in the health field there.

But this information here comes to us from the Robert Wood Johnson Foundation that helped county data and did big data mining to figure out well, what is it that determines how long we live, our resiliency to disease, and what it largely focused on was four factors that could predict how long we would live and resiliency to the chronic diseases and those areas included health behaviors, the field that I come from, how can we promote healthy behaviors in people, how can we get people that might be practicing unhealthy behaviors to either reduce or eliminate some of those unhealthy behaviors.

And 30% of that is believed to be attributable based on data and research towards how long we live and prevent illness and disease.

The next factor that they looked at were those that were within the clinic, access to quality healthcare, which seemed to have about a 20% impact on how long we live in resiliency to disease.

And the social determinants of health, that factor being 40% attributable and that, of course, being education, employment, social economic status, transportation, access to vital resources. And 10% being the built-in environment.

Now, we know, for example, the great work that the Disability Health Program does and we look at the prevalence of chronic disease among the population of people with disabilities, it's quite higher than people without disabilities and I'm assuming people on the phone here are probably well aware of the great data that you all, the Disability Health Promotion program has put out there on that, and exponentially more likely having cardiovascular disease, cancer, stroke, very big and prevalent in the general population, exponentially more than people with disabilities.

When I look at the population of people with disabilities and trying to create a program, I usually go to this kind of, you know, a map to really kind of dive down and figure out analytically and think about all of these different factors when planning a program.

And you'll see down there on the bottom left, that last cell being once we can

understand all of these different factors and how they're attributable specific to the population we're looking at, we can figure out well, what kind of intervention or program that we can do that can help to promote the health outcomes or improve the health outcomes and interests.

That's kind of a background on how I approach health promotions in terms of coming up with the analytical descriptive approach to it.

One of the things that I found my expertise, really, is derived from is an area that's been dubbed implementation science. It's only a National Institutes of Health and others have really embraced this and it's an important part and if you're going to develop a program concerning health promotion, that there should be very, you know, scientific way about going about doing it.

And traditionally and in the training and in the practice of health promotion, you know, academia, you certainly will have hopefully had a healthy dose of the importance of having a theoretical framework to build your program off of.

And also along with that, as you're doing a program, programmatically you should have some kind of a systematic road map to evaluate that program that should be grounded in theory.

And there's many different program planning models and there's many different types of theoretical approaches towards health promotion, and so once you understand the population that you're working with, the specific type of health issue that should be able to surface the appropriate type of theory.

And also the appropriate planning model that should go along with your efforts.

So there's been, you know, decades now where there's been a lot of health promotion programs that are out there that have these elements to it, and, hence, in a field of implementation sciences has been really coined within the last decade to embrace some of this.

Now, along the way, and one of, I think, the reasons that the rise of implementation sciences has been getting a lot of attention is that even though the best designed programs out there to promote health in a population or in the community that has been tested, for instance, at an academic level, shown to be advantageous and sometimes effective has trouble translating into the general population.

In other words, you know, where we get, you know, funded to do a research project, we would have money and resources and personnel to develop, implement, and evaluate a program.

And, you know, lo and behold, we come up with a program and activities for people with disabilities and had a great theoretical framework and great model and now we want to disseminate it out to another location where you don't have that grant, you don't necessarily have the same personnel to administer the grant or to evaluate the grant.

And there's been a lot of issues in law that happens when these types of programs in

the academic setting have a tough time translating into the "real world" and/or field, however people might want to dub it.

And what we're finding is, you know, you might have an effective intervention, but due to ineffective implementation of it, it may not lead, and often does not lead, into the outcomes that you're looking for.

And herein lies what seems to be a big gap of translating research, good research and good programs into practice elsewhere and the generalized ability has been questioned at times, even when resources to deliver that aren't available.

And so my approach was certainly we need to keep the theoretical frameworks and things in line and one of the things why programs aren't translated into the general population often has to do with involvement or lack thereof of the target community where you're trying to get your program or project translated to.

And that involvement has been getting more attention since, you know, for over a decade now, but I think it's become really invoked in the last five or six years, as being a critical element and piece of implementation science that we need to take into consideration and put into play as we do our theories, as we do our program planning models.

And when you look at implementation sciences as defined by the National Institutes of Health, they, I think, are going towards exactly what that means. And this definition, you know, or position statement that they have about the next generation of researchers, being able to build those linkages between the researchers or the academics, the target community that they're trying to promote the health in, the people that might be implementing the program.

There again, if you're trying to disseminate a program that you are not the primary person to implement the program and you're relying on other people to do it, making sure that you have those linkages to those people are quite critical.

And obviously policymakers play a very important key role into getting something disseminated or translated into a broad context.

So I'm really happy and pleased and I think that the National Institutes of Health are identifying this is a critical aspect of those components that are included in implementation science.

And as it pertains to those of us that are interested in promoting health in the population of people who have disabilities, this has important implications. And it really can benefit our efforts into trying to get any of the programs, projects, or efforts that we're trying to do out into the general population.

One of the things that I found that has been very important and is in the planning process, and identifying what the needs are of the population that you're targeting.

For example, in my work here at the center, I've convened several different advisory groups comprised of people who have disabilities, to help identify well, what are their

biggest needs in terms of living an independent life?

And when asked those questions, many of them, the top three responses I typically get are housing, employment, and inclusion in the community, and to be able to live in an engaged life.

And that may vary among different types of people, but, you know, it's very helpful in identifying those kind of things.

Once, you know, that information gets shared and there's a consensus on a particular area of need, then involving them in coming up with different types of goals to meet those needs and how can we address those needs can really be a very interactive and iterative time where people can participate and coming up with different kinds of ways that we might be able to address issues; ways in which you, the program planner, might not have come up with.

Many times people are planning health promotion programs without involving people with disabilities in that planning process. And may be missing a key piece of insight that would be very beneficial in that planning process.

And I'm a very big advocate of this up-front planning of any kind of health promotion program or project.

You know, we may have heard those clichés where failing the plan is planning to fail. And in terms of health promotion, if we were going to look at it in terms of planning implementation and evaluation, I have personally found that this phase is more often than not the most neglected and overlooked phase.

And, you know, there's -- you know, up until PCORI came along, there wasn't a lot of accessible funding opportunities that would go towards the planning process. And that was, you know, something that I'm pleased to see that there's more attention being focused on the importance of planning something.

And sometimes when you're, you know, if you're, for example, writing a grant, they already want you to kind of have that idea of what you're going to do up front; the idea of saying well, we're kind of unsure what we're going to do, we're going to wait and involve, you know, the target population and kind of surface it from there.

And it's not something that the funders typically want to hear. Yet, if we really want to develop programs that are in line with the interest needs with the target population, we have to put some work into doing that.

And then often that work is not funded and that goes into the barriers on the next slide that I'll talk about.

But coming up with strategies, too, in the planning process, involving people with disabilities is very critical as well, because, again, they will likely come up with some ideas that you may not have about how to actually achieve a goal and to get into that.

The importance of implementation and involving them in the evaluation process as well, one of the programs that -- many of the programs that I do has a component where

there's a peer component towards it; in other words, we often will utilize the strategy of peer supports and the implementation of a health promotion project.

So, someone with a disability, for example, one of the programs that I've worked with that's continuing to go on now at the University of Florida is the inclusive sickness (sp) and unified sports program and it's a program that brings in kids from a local school here, a self-contained school, Sidney Lanier and students have intellectual and cognitive disabilities.

One of the key components in the implementation of it is that students that have intellectual and cognitive disabilities who have graduated from the program and who are able to come back to the program, we utilize them as peer mentors. They help in actually implementing the program, leading the physical activities, helping to coach some of the participants in the program.

They are instrumental often in helping to engage the students that we're trying to get them to increase their physical activity in and they have been very powerful in doing so. And so they're very important in that implementation of it.

And certainly in the evaluation of a program, and we're, you know, people who are program evaluators and assessing the outcomes of our program, there are many different ways that we're already things that we're going to be looking at, you know, if that's health outcomes, if that's any kind of clinical indicators, those things are already set in place and we'll be looking at those and those are very important to us.

But also, you know, taking it from the perspective and sometimes, you know, there so often will be qualitative information, getting the perspective of the people that participated in the program is very important. And that can capture some very important information that are clinical indicators or other health outcomes may not be capturing.

You could be improving social competency and social skills, an aspect of quality of life through participating in a program that you might not be capturing if you're doing clinical indicators of health outcomes.

And to getting a perspective of participation in the program could be very important in doing that, getting their perspective on what worked and what didn't work outside of the program would be very important as well. And that can really help to modify any kind of programmatic efforts you're doing if you're able to capture from their perspective to get out of the program.

More likely to sustain health promotion efforts. I know, Claudia, you all and Bryan have been doing some work related toward --

[Telephone ringing].

>> -- having peers, community health workers, help to promote health and populations for persons with disabilities.

I know in some of the experience that I've had in working with community health

workers, to get them on board up front did require some incentivizing and -- but that incentivizing, you know, in money or food or whatever might be to get them on board would ultimately be finite and would go away.

But if we were able to get them to come on board with these incentives, usually they would get the buy-in along the way. And when the incentivizing went away, they still wanted to stick with the program for altruistic reasons and in the CLDSD (sp) project we did with the University of Florida, we paid graduates, people with disabilities to work with the program, to work with students who were undergraduates who had learning disabilities.

[Telephone ringing].

>> Many on their exit surveys were saying, you know, even though the project and their involvement in the project was ending, they still wanted to work on the project, they still wanted to be involved, despite the incentives and everything running out, they wanted to be involved in on that.

And so this is very important in a lot of the senses of when resources, whether they're financial or material may have some finite endings to them.

If you can get people who participated in the program, your target community, excited about the program, they feel like they're stakeholders in the program, they've been able to have their fingerprint put into the program, when some of those resources tend to dry up, at least the human resource element of it, their involvement --

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>> -- is still somewhat sustainable and can really carry the program forward, despite having some limitations of any of the materials, finances, or resources to continue the program.

So, getting that buy-in up front for incentive is important, but to continue and sustain those efforts, if you're involving the community that gets to have more buy in and do that.

Certainly facilitating dissemination of information. And by just the inherent nature of, you know, of your target community, it's a culture; people do communicate.

I often think of the people who are deaf or hard of hearing that I work with and for any of you that have been working with people that are deaf or hard of hearing, this may resonate particularly with you.

It is a very strong cultural unity within this subset of people who have disabilities, and, you know, I found that they communicate quite regularly with people. And information within that community can spread quite rapidly, and if you have a health promotion program or project that you're doing and want to get that information out to them, to this community --

[Telephone ringing].

>> -- there's no one better to disseminate this information to the people you're targeting and involving the people and disseminating a lot of the information throughout your program is one of the ways to do that.

Certainly there are a lot of barriers towards involving people with disabilities in any type of your health promotion efforts.

One is accessing the community of people with disabilities.

You know, when I worked at the VA, one of the hardest challenges that we found was I'm trying to reach those veterans that were not disclosing that they had a disability. As many of you know, the hallmark disability from a recent combat era is PTSD, TBI, depression, and/or any combination of those.

And what was very troubling was, and research would back this up, is veterans that had any one or more of those were not likely seeking services from the VA or elsewhere for their disability.

And it was only a very small percentage of veterans who have mental health issues were accessing services.

Many of them did not want to disclose that they had a disability. And that, in my perspective, is the high-hanging fruit. Who out there with disabilities is not disclosing they have a disability but could really utilize their services?

And it may be people who are aware of having their disability. Like I mentioned, veterans of PTSD might be aware that they have that, but may not be disclosing for a variety of reasons, such as stigma.

Or it may be people who do not -- are not aware of their disability. For instance, going back to the project I worked with the University of Florida, students with learning disabilities, many were not realizing the extent to which their disability, that they even had a disability.

Many of them were coming to understanding that they had a learning disability while coming to the University of Florida, and many didn't have a 504 IEP in their primary or secondary education and a lot of them was making them -- if they're at the post-secondary level, why they might be struggling academically and trying to put those pieces together.

There are many people out there that aren't aware to the extent they have a disability. So how do you reach those people in that sense?

And that can be a tricky one to disseminate.

Obviously there's no directory or list, thank goodness, for people that have disabilities. But at the same time it makes it harder to reach them as well. There's no geographic demarcation that's out there, you know, that people with disabilities tend to cluster in certain areas.

Now, certainly people of lower social economic status may be people with disabilities and with my work, low income neighborhoods and neighborhoods of people living in

poverty is certainly more evident, as the research backs up, in my experience working with this, there's certainly more evidence, but nevertheless, it's a lot harder to access this population in many aspects, compared to other populations that might be at risk for health disparities.

Engaging people with disabilities. Now, like with any community that you're going to, you know, engaging and earning the trust is something that is very critical, especially up front.

But this was something that needs to be maintained and facilitated and fostered throughout working with people with disabilities.
Now, my experiences in this is that --

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>> -- for some efforts, it's really easy to earn the trust and gain access to the community of people with disabilities, if you or someone that is trusted by the community that can link you in, that can definitely help to facilitate the buy-in from the community.

This often takes time. You know, I'm going to the general barriers down here, but that engagement and that earning of trust, you know, where there was a community member, someone with a disability that was really, you know, "show me, don't sell me," and that takes time, to show that, you know, you're engaged, you're willing to show up, you're willing to interface with people, you're willing to take the time to get to know them, their community, others, to listen to them. That takes a lot of time. And we're busy people. And that can sometimes be brushed aside, but if you really want to earn the trust, it is about showing them.

And we can sell them all we want, but at the end of the day, action does typically speak louder than words and having that finite commodity and a priceless commodity of time is one of the barriers towards that.

Often our jobs and how we get evaluated on our jobs don't take that into consideration, necessarily. We're more graded on, you know, getting funding or getting these other kind of things that are related to evaluating how we're doing and not necessarily well, how closely tied in are you to your community?

Now that's played out in other aspects, but that could be a very big barrier.

Transportation I put on there thinking of people with disabilities that is a major barrier. Getting them access to transportation.

We have a high school program, we're in five counties, with roughly 12 schools, we have a lot of people we work with. We have great workshops and career exploration opportunities in the community.

And one of the biggest barriers that we have is transportation of these students to these opportunities, to these workshops, to these career exploration field trips that they're doing.

And often many of them are coming from homes that they just don't have the

transportation to be able to get there.

It might not be on fixed bus routes or even accessible with paratransit-type services. Transportation is a major barrier that cuts across many of the different services that we try and provide for people.

And even if you're someone in the network of, say, the University of Florida, my goodness, if you wanted them to come to you, parking, et cetera, on campus, you getting to them, if you're interested in promoting health in the community of people that have disabilities in the rural areas, you getting to them, we're in a 16 county catch area and it's not just transportation to you but you getting to them can be problematic at times as well.

And certainly, just the amount of money and resources sometimes and staffing that it takes to collaborate with people can preclude involvement because it does take each of those important resources to engage people with disabilities in your target community.

I'm only bringing this slide back to bring up the point that when -- when at least according to this research, the Robert Wood Johnson Foundation, the majority of influential factors that are attributable to how long we live, resiliency to chronic disease occur outside of the clinical setting.

We put a lot of time, effort, and energy into the clinical care of people, as we should, not to diminish any of that by any means, but you look at the amount of influence that those factors that are outside of the clinical setting have on health outcomes, at least according to this research, it's around 80% that occurs outside of the clinic, and this is starting to become more and more recognized, that we need to make sure that we're looking at the community that's outside of the clinic, not just the community of people with disabilities that we need to have at the center of our plan and implementation and evaluation of our health program, but all of the different sectors that involve and make up a community.

And when you unpack that, there's a lot of different aspects of community and involvement and within each of these different sectors, you're going to have agencies and organizations and these can be, you know, governmental-based agencies, you know, whether they're at the city, county, state, federal level, these could be private sector businesses, there could be non-profits that are involved in each of these sectors that comprise a community or a part of its infrastructure, whether that's recs and parks and whether that's emergency management, whether that's the government operations, transportation, electric, utilities, just the infrastructure of the community geographically and itself in the physical environment, there's a lot of different sectors that comprise a community and within those sectors are what I'll dub as community-based organizations that are critical and act as a facilitator to accessing your community.

And this is a graph that I took from a funding announcement that came out a couple years ago from the Department of Health and Human Services and it was a joint announcement between them and the Social Security Administration and this was -- some of you might have taken advantage of this grant opportunity, but this graphic really shows the heart of the aim of this funding opportunity. And it goes back to what I was saying, trying to address those factors that impact health outcomes that

are outside of the clinical setting.

How can we link clinical care to the different social service agencies that are out there in the community that have -- and the importance being, you know, these are very important factors to be considering in our health outcomes? So how can we link those two together? And it's funny, looking at sources and different types and ways that we can help bridge clinical settings with social service agencies and/or community-based organizations.

So, there's a really big shift in the attention and time of going towards how can we make this all happen? How can we really come up with a very comprehensive, coordinated care system that will allow us to address some of these social determinants of health that occur outside of the clinical setting?

And, of course, there are a lot of different community-based organizations that are high profile and that we can probably recognize that are out there related to disabilities as well.

There are many different organizations that are involved and that we can look towards in terms of our efforts and involvement in our health promotion projects that we may want to be considering in collaborations with.

Now, as I spoke to before, there are a lot of different ways that we could categorize community-based organizations. Again, putting, you know, people with disabilities at the center of all this, what does surround them are these organizations.

And one of the things that I found very exciting about my efforts at the University of Florida was creating what we call community academic partnerships. These community academic partnerships would obviously involve, you know, certainly the University of Florida, but I think this model could be, and is, extrapolated out and generalized and you think about how many colleges that are out there that could be involved in this, but you have your non-profit sector, you have your private sector, you have government-based agencies and you have those that have kind of quasi. Centers for Independent Living are quasi where we receive state and federal money but we're also receiving other types of funding that is important to delivering a lot of our other programs out there and we're classified as a 501(c)(3) not for profit as well, so some of these can be a hybrid as well.

Now, community-based organizations being a part of engaging your community is very important, and there's been a lot of attention in this area as of recent, like I mentioned, the PCORI grants, I sit on an advisory committee on a PCORI grant that is really involved in trying to get community-based organizations on board with serving people who have autism in rural areas. So we're one of many community-based organizations at the table on that.

Again, my work at the VA continues. They have put forth an initiative the blueprint of excellence and a very centered approach in promoting health for veterans.

One of the things we're working on right now is to try to look at the efficacy of institutional collaboration between Centers for Independent Living and the VA. They're

seeing that, you know, they want to reach more veterans and the extent to which veterans are accessing our center and what services they're utilizing is of interest to them.

And also understanding what services they might want to see through Centers for Independent Living that they're not accessing is of interest to them, and so we're, you know, doing -- we've got a grant to do a needs assessment and finding out to what extent veterans are using our centers and in collaboration with them because they do see the importance, not just Centers for Independent Living as being a setting that they can reach more veterans, but there's other community-based organizations that they're interested in as well.

And the idea being that down the road, perhaps there could be some contractual agreements through VA choices that a lot of services that the VA would offer could be offered through different community-based organizations.

Benefits of working with community-based organizations. Since we, community-based organizations and others, work with directly with the population of people with disabilities, we can help facilitate some of the buy in.

We see people quite regularly and interfaced with them quite a bit, and know the ones that perhaps could be very interested and in a place that they are ready to be engaged with, any types of programs or projects that come our way and could direct people and help facilitate those linkages between the clinician or researcher or health program planner to get access to the community.

So, we can definitely, you know, be a useful resource in that.

And we could also talk and have experience in being able to talk about the feasibility of doing things.

Often we will get asked by people at the state level about ideas that they have. For example, there's a lot going on right now with trying to get people with disabilities between the ages of 14-24 employed. This is an underemployed group and there's a lot of effort and resources being allocated in this direction, and we will often get calls from --

[Telephone ringing].

>> -- you know, from voc rehab and Department of Education and those type agencies that are charged with implementing some of these efforts with ideas about, okay, here's an idea that we have about how we can try to get people with disabilities in this age range employed and involved in, you know, careers, and they run some of their ideas by us, because at the state level, at the thousand mile vision, things might sound like a really good idea, but to put something into practice on the ground in the field, so to speak, certain things can be problematic that they might not be thinking of.

And we can help out in addressing some of those things from the big picture's perspective might not be taken into consideration.

And certainly helping to recruit, you know, in participation into any kind of program or project, and I've worked with AHEC (sp) quite a bit, we know who we work with that can

benefit from a tobacco cessation program and where the Centers for Independent Living can directly try to recruit from the population, they might have some challenges and barriers.

But those -- if they contact us and let us know hey, we're interested in tobacco cessation programming, do you know people? Certainly do.

And we know that some are not in that readiness for change, necessarily, and some are, and we can help with the recruitment of them in their participation and involvement in their tobacco cessation efforts.

Going back to our work with the VA, they're interested in reaching some rural veterans. And we have connections with some of those rural veterans that they're interested in getting recruited into some of their efforts.

So, we've been able to help out in that direction as well, because we already have some of those relationships.

And, again, as with involving your target community, involving community-based organizations can be very helpful in sustaining efforts.

[Telephone ringing].

>> So, in other words, in working with the Alachua County Health Department in recognizing a diabetes prevention program for tailored for people with disabilities and working with our population that we're trying to serve could be something that could actually be sustained because we actually have a setting, we have a, you know, a classroom, we have staff, we have people that if taught and trained appropriately on it, could be a way that we could help in delivering of a program that once money or material resources run out, if it's something that we found to be very effective and useful and we can be trained on it, we can make sure this program continues on once funding and/or human or material resources are ended on the end of the first part of trying to deliver the project.

Again, dissemination, you know, again utilizing Centers for Independent Living as an example, I'm in contact with all of the 14 centers here in the state, we meet quite regularly, we talk about what's working and not working within our own centers.

And not only that, we also have regional affiliations and national affiliations where we share this kind of information with one another.

And in terms of getting the word out about certain things, we can be off in a really good conduit and doing some of those things.

And we have, you know, as the Disability and Health Program has news going out and social media and any community-based organization is going to have some outlet of information that they can put out there to the target community or colleagues in the field and get the word out about some of your efforts.

[Telephone ringing].

>> Again, benefits going towards that, you know, many of the community-based organizations are dealing with issues that the clinical setting isn't addressing, such as transportation, such as improving financial literacy or management, employment, education.

A lot of the community-based organizations that are out there address some of these things, these social determinants of health, this area by many in the health field identify as being some of the most influential factors and many of these community-based organizations are addressing these kind of things.

Often advocacy and policy are very important aspects of what we're doing in terms of achieving the health outcomes that we're looking at, and certainly if you're, you know, paying attention right now to what's going on at the national level, there's a lot of discussion being had about how healthcare may change and the implications for people with disabilities is quite profound. I mean, some of the proposals and issues that are related to some of these changes include cuts to medicare, preexisting conditions. This is going to impact people with disabilities.

Our national organization, national Centers for Independent Living, NCILs, what they call a sit -- instead of a sit in, but a die in, some Congressmen and women out in the halls and you might have seen some of the national footage of people in wheelchairs being arrested because they were advocating and in some aspects lobbying for change regarding some of these issues that are out there, and every legislation session here in Florida, there's days where community-based organizations, whether it's ARC or it's the Centers for Independent Living, other agencies are taking busloads of people who have disabilities up to the Capitol to march the halls and advocate for policy and whatnot.

So, if you're, you know, you've got a really great health promotion program that's not addressing issues that are related to advocacy or policies, that could likely impact what your program is or is not doing, community-based organizations could be a really good conduit for those kind of initiatives.

And community-based organizations could also be useful in really articulating and often some of the social, cultural, normative attitudes that are within the population of people with disabilities, and what I mean by that is disability is part of diversity and being a part of diversity, there is a culture among people with disabilities.

And as disabilities as a whole, as disabilities as being, you know, whether it's specific to a disability, as I mentioned earlier, you know, deaf and hard of hearing has a very big presence culturally.

And community-based organizations can be in tune and be a barometer for what are some of the general cultural dispositions and attitudes of certain niches within the community of people who have disabilities?

And because they interface and interact with these communities, they can be helpful in shaping some of these things.

And these are important things to be addressing as well, because social cultural

normative attitudes and beliefs often do have an impact on, you know, health outcomes and health promotions.

And certainly our barriers in collaborating. You know, many of the barriers towards collaborating with community-based organizations, you know, come down to, you know -- let me use an example that just happened yesterday.

We were meeting with a local partner here in the community for the first time, an agency that's interested in working with male youth, minority male youth, 18-25, who had previous experience within the juvenile justice system, had a record, was wanting to really help some of the issues and needs facing this community. And they were addressing some of those areas.

And one of the things that, you know, was said with this person as we were, you know, first getting to meet one another is the comment that I hear quite regularly, is that, you know, we're all out there working towards the same thing, but we're in our silos, and it's hard to collaborate with someone another, because we're so busy. But it's also because we all might be, you know, competing for the same small pot of money or resources or volunteers. And that could preclude types of collaborations with people.

And what this person had said, you know, and what resonated with me, being a collaborator and not as much as a competitor and getting into turf wars which could be a barrier in collaboration, we tried to break down some of these barriers, because the needs of the community that we're trying to serve are far greater than sometimes these barriers that often preclude us from collaborating with one another.

And it was refreshing to hear this person identify some of these barriers. And towards really trying to get integrated with one another in terms of achieving the same goals that many of us have.

We probably have more in common than we do different, it's just sometimes this competing interest can be barriers towards it. I just recognized I was on the wrong slide; sorry about that.

It takes time and skill to collaborate. Certainly, again, it goes back to the time thing. I'm very eager to collaborate with people. People might be very eager to collaborate with me.

That being said, you know, we're very busy. There's not enough time in the day. Time is a very finite resource.

So, even though we may want to collaborate, the responsibilities and roles that we play, you know, inhibit us from being able to do that.

And it does take skill to collaborate. It sounds simple, but it's not always easy. You know, there are social fluency --

[Telephone ringing].

>> -- interpersonal skills can play a role in this as well, and that can be a very big thing. Cost sharing, power sharing, decision making.

At the university, I found this to be sometimes problematic where, you know, between department I was in, you know, science and research is such an interdisciplinary now and great and needs to be.

[Telephone ringing].

>> At the same time, when you get a grant, who gets to hold the grant, who is going to be the co-I, fee-I, who gets the different things, when you have two different departments and disciplines sharing the same grants, who gets the rights to publish the data, those kind of things often, you know, can be things that really stymie collaboration between different entities.

Certainly competing interests is the bottom line and, for instance, sticking with academia, it's very important to publish and getting set up with that. The community and the community-based organization you might be working with might not be as minded as publications and presentations in the national conferences and their bottom line might be a little different and look a little different.

[Telephone ringing].

>> Getting on the same page and having a shared interest is really important to get over that kind of barrier. And certainly any kind of historical past or current issues related to collaboration, there may be people in agencies out there that may not want to collaborate with our center because maybe they had past experience with a staff or a previous director that didn't go over well and so now they associate our center with being a poor collaborator with someone that's not even here anymore.

[Telephone ringing].

>> So there could be historical context to a lot of this as well and could inhibit any kind of operations.

>> CLAUDIA FRIEDEL: Hey, Tony, before you move on, I wanted to let you know that it's 3:00 o'clock and I wanted to give a few minutes, a minute or two, to see if anybody had any questions, and then to see if you wouldn't mind sending me the slides, we did have a request for the slides.

So we want to --

>> DR. TONY DELISLE: Sure, absolutely. And I can end it there if we're out of time. I didn't even have a watch on.

>> CLAUDIA FRIEDEL: No, no worries, no, you're good. I was trying to wait for a good stopping point.

So, I think -- that was wonderful, Tony, thank you so, so much.

Does anybody have any questions they'd like to put into the chat box? Or we can unmute the line?

We can also -- we'll provide Tony's contact information in case anybody -- or is it in this presentation at some point, Tony?

>> DR. TONY DELISLE: It is, but when I send you the slides, I'm more than happy to include my contact information.

>> CLAUDIA FRIEDEL: Wonderful. All right. We'll go ahead and do that and forward that to everybody. And if anybody has any questions for Tony, e-mail is a great way to reach out to him.

And we just want to thank you again so much for going over this with us. It's very timely, including some of the work we're doing with the PWDs and it's collaborative on what we're doing forward.

Thank you again, so much, for your time and expertise and we thank you!

>> DR. TONY DELISLE: Well, thank you, Claudia. Thank you all for all the efforts that you're doing as well, and I look forward to our collaborations with one another. And I'll certainly send that information to you.

>> CLAUDIA FRIEDEL: Wonderful, thank you. Please do. Everyone have a wonderful day.

[End of presentation].

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