

REALTIME TEXT FILE

DISABILITY COMMUNITY PLANNING GROUP WEBINAR

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REMOTE CART CAPTIONING PROVIDED BY:

Lisa B. Johnston, RMR, CRR, CRC

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Edited

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>> CLAUDIA FRIEDEL: All right. Hello, everyone. Welcome to our quarter three partner webinar for the Florida Disability Community Planning Group, our DCPG. A little housekeeping before we begin. We will be recording the session and we have ASL and live CART captioning available.

For those of you who would like to view the captions, please click on the closed caption button at the bottom of your screen to view the captions and you will be able to adjust the font size there as well.

For those of you who would like to spotlight or pin our interpreter, please go to the participant list on the right-hand side of your screen and hover over the interpreter name and see the three dots next to his name and once you do, you will be able to click "pin" on that.

You should be able to see the interpreter as the main box on your screen when you do that.

We are going to hold questions to the end. If you have any that pop up, feel free to type them in the chat or wait until the end and we'll have time to read questions or have folks unmute or ask them at that time.

I am going to resume the recording now.

All right. I am happy to introduce our speaker today, Meagan Sullivan. Meagan is the DHP program assistant for our program, for the Disability and Health Program. She is a dual graduate of the University of Florida. She graduated with a bachelor's degrees in both psychology and criminology from UF in 2017 and a master's in public health in 2019.

She has been involved in Gainesville's Deaf community for seven years and hopes to research deaf health disparities.

Without further ado, Meagan, take it away. Thank you for presenting today.

>> MEAGAN SULLIVAN: Thank you for having me, Claudia. We'll go ahead and get right into it.

Just kidding, we won't... now we will.

So, I'm going to be presenting today on the ARC's National Convention that was held in 2020. It was held virtually. It was originally intended to be held in New Orleans, but that did not happen because it was 2020 and there was the COVID pandemic.

So, for today's presentation, I'm going to start off with a little bit of a background about

the ARC as an organization and then go into some session highlights from the conference.

And then some next steps from how DHP intends on integrating the knowledge that we learned from this conference into our provision of services to people.

And then some links and resources and then open the floor up to questions, as Claudia said.

So, to start off with, the ARC was started in the 1950's by families of people with intellectual and developmental disabilities. And this was at a time when the only services really available for people with ID/DD were institutionalization, and these families wanted to be able to have the ability to raise their children at home and have them lead fulfilling and integrated lives in the community.

But still have that support that they needed.

And so the ARC was born. And you can see here their mission is to promote and protect human rights of people with intellectual and developmental disabilities and actively support their full inclusion and participation throughout their lifetimes, which is a hefty mention to have!

And so they have some core values and guiding principles that really drive home this mission.

The first one is people first. They want people to realize that people with ID/DD are defined by their inherent worth as people. And people with ID/DD should be afforded the exact same dignity, respect, rights, safety, security as someone who is not disabled. Community, so there should be an opportunity for people with ID/DD to live full and integrated lives within the community and be accepted by society.

Self-determination which is a really big one we saw at the conference is one with appropriate support. People with ID/DD are able to make their own decisions and should be allowed to make those decisions and have a seat at the table that is discussing their well-being.

And so the self-advocacy within the ARC is very, very important.

Diversity of thought and also of identities is also something that is very important. So... um... a wide range of identities. So, between race, gender, sexuality, anyone can have an intellectual or developmental disability and so something that's very important is that those characteristics are valued and add -- add good, positive things to the organization.

Um... for some of the guiding principles, again, with that self-determination, participatory democracy and really giving people meaningful opportunity to guide and inform the organization is something that was really driven home.

Visionary leadership, so a positive vision of the future for people with ID/DD and carefully plan and well executed goals and action strategies.

Public interest. So, the support and acting on behalf of the better interest of people with ID/DD to make sure that the community as a whole has an improved really quality of life is what they're getting at.

Collaboration, making sure that there's effective partnerships between individuals and organizations and coalitions.

And then transparency, integrity, and excellence.

So accountability, open, honest communication, and striving to do things well.

So, that's a little bit about the ARC.

And so for the conference itself, there was actually a wide, very diverse set of topics.

So anything that you could think of to be interested in was probably a session. And so I just went ahead and picked what I thought historically some of our partners might be interested in having highlighted.

But if you want a deeper dive into any of these topics or what you're seeing here isn't exactly, like, your cup of tea and you think they probably presented something about whatever you do, these sessions were all recorded with full accessibility and put on demand for you to still -- they're still up for you to go and watch some of these more in-depth.

So, feel free. And there's links at the end for that.

So, just to start off with... um... caregiver support in the time of COVID was a very interesting topic to go to.

It started off with, um, general information about the caregiving experience. So if -- for those of you who are not aware, there's really two types of caregivers. There's paid and unpaid.

And when we say paid, we don't always mean professionals or designated service people, we can also mean family members who are in a waiver program to get paid to be the caregiver for their child or family member or whatever that is.

And then unpaid.

So, you could kind of guess that the supports needed for paid versus unpaid and the economic burden tend to be very different and, um, that's something that within the webinar, different people talked about.

Um... there's -- across the range of paid and unpaid, the support type seemed to really ring true for what people need and that is informational and referral services, instrumental goods and services, and then emotional support.

If you could really hit on these three things, you could have a more holistic support system for your caregivers.

And the COVID virus really meant different things for these two groups. So, for designated service people or support people, excuse me, they had a greater risk of contracting the virus and taking it home to their families and their other people that they served.

Well, people that, you know, could isolate and were maybe unpaid and just family members, they really lost their social support, which was a big problem, and that isolation caused bad things for mental health, and I think we can all jive with that idea.

So going to the family caregivers, there was, I believe this was Anthem, so that's a Blue Cross/Blue Shield's little organization and they came up with, um, this three-tiered, I want to say, like, comprehensive supports that they have within their website, which is really cool.

So, the website itself has a repository of information, which can be really helpful, because when you go and are looking for information, not only is there a lot of misinformation, but it's just a big beast to tackle.

So there's a lot of stuff out there. And all of it seems really relevant, and most of it is, and so having that all at your fingertips kind of organized is really helpful when you're stressed during a caregiving experience.

Um, the toolkit itself is actually -- it's physical and they also put it online. But it's -- you get some stress-relieving things, like balls, like squishy balls [laughs] for stress relief. But the main big-ticket item in there is this organizational binder for family caregivers to write down, and maybe ask them prompts that they haven't really thought of, of how their caregivee receives the caregiving that they give, so if they were sick with COVID or couldn't do it or whatever happens to them, somebody could read that and take over at least for the time being.

And so it was a good kit for just to get organized, like medication, what food do they like, what time of day do they go for a walk, that kind of thing.

And then the assessments was also a big thing that they did. So they do screeners for

their members to see if anyone needs any extra supports and services. And it's not just the members that get that service, it's also the caregivers of the members, which is really important to really focus on caregiving.

Um... the next part of that session really focused on designated service support person. And so this is a professional who takes care of someone. And this job has a high dropout rate. There was a few reasons discussed, but a lot of it, there's the economic burden for both [chuckles] family caregivers not getting paid. And for being underpaid and underemployed as a DSP.

And then there's also expectations about what the job is and what you'll need to be doing, not being very clear and not having certain supports in place when you get on the job.

So I think the stat was, like, like, over 50% within the first six months, ended up quitting that profession.

And it's a real shame, because it can be very rewarding work and they're definitely -- there's definitely a need for it.

So this group talked about the five Cs of trying to combat that and so you want to earn commitment from the workers and cultivate -- that's the second C -- that include the workers and their perspective.

You want to establish workplace connectivity, that was a really big one, and I'll talk about a little later.

You want to train to increase the capacity of the workers within themselves.

And then you also want to hire enough people so there's capacity in the workforce so that not everyone is overwhelmed,

And so with the COVID issues, that are connectivity was actually really highlighted as a problem, because a good way to make sure that someone doesn't drop out of being a DSP is being a mentor and those mentorship experiences during COVID was a problem, because you couldn't be in person and there was a contact risk, really.

And so that was something that they noticed with their DSPs. But I think they talked about, um, really using digital means and being clear and cultivating that kind of interaction between mentors to really drive home the clear expectations of what the job is, what's expected of you, and that kind of a thing really helped with the dropout rate, so....

That was all I got from that session.

One of the really interesting session was an advocacy power hour, which is kind of an odd name, but really, it was giving you examples of how people's stories can be used in advocacy.

And I found this very interesting.

So, what the quote that I took away from it was: How do policies impact someone's day-to-day life?

And so someone's story can be probably one of the most powerful tools in advocacy, 'cause it personalizes it, it makes it so that it's right in your face, you can't deny that somebody is going through their lived experience.

And it really highlights the specific issues that policy has on a real, actual person.

And the ARC itself historically was built off of the stories of family, like I said at the beginning, they wanted to raise people at home and make sure that they were in the community and not institutionalize someone.

So, historically it has been a really big part of this, um, organization.

And so you can see, to your right or left -- I don't really know -- but to the side, um, there's a graphic representation of what some of these stories might look like in a short form that you could be used for advocacy. They have other things, like these graphics

available, and that's also linked at the end.

If you have some advocacy that you want to do and use some of their stories. Or just use it as kind of a template for your story, um, that will be available.

Just from hearing the stories of this advocacy power hour, I took away several needs during COVID times.

One was the need for, um, people with ID/DD to keep busy because of the stress of not having their regularly-scheduled supports and the disruptions being really distressing.

The other one was siblings, so the siblings stories highlighted really the need to talk regularly and check in on your sibling with ID/DD.

And also to make sure that you're listening and prompting to what they fear about the pandemic, 'cause that's how you get real solutions, you know, so....

Your story is a very powerful tool is the main takeaway of this. And so when you're trying to advocate, adding that personal narrative and that personal touch can really drive the point home.

So, this was a very interesting session. It was from the self-advocates of the ARC, which I kind of alluded to earlier, was a really important part of that self-determination and that, um, inclusion of people with ID/DD in the organization.

And this particular, very timely [laughs] session, was about interacting with the police and this is something that they needed to really adjust because of the pandemic. So it seemed like on their -- during their session, they alluded to having a speaker set up to talk about the law enforcement side of things.

But when it fell through with the pandemic, it became kind of, we're gonna get some more information about these good questions for maybe next year for this person.

And so they really focused in on this is a bad situation, it's definitely a system-level issue but what can people with ID/DD do today to make themselves safer in interactions with law enforcement?

And one of them was being ready to say the phrase "I'm disabled, I need XYZ. I have autism, I'm having a meltdown and I need this sensory need met," right? Just being trained to say over and over again.

Because when you're in a crisis situation and maybe the person that's talking to you is gonna have some pre-conceived notions of what they should be doing and how people should act, being able to be very clear about why you're doing what you're doing can be life-saving.

Another one that they brought home was just be aware that some officers might wear plain-clothes but should have their badges and you should be aware of that.

All of this was done with polling questions and it was neat to see people's misconceptions.

One was that got people, stop don't move, does that mean literally stop? And that could really mean show me your hands. So it could be really cautious of taking things too literal and that way you're just freezing is not what they're actually asking for, which is really tricky.

I think next year that should be the focus on training law enforcement to be a little bit more clear. But just being aware of that fact can make you safer.

Medical IDs need to be visible. So if you have it, like, on your wrist, that's very visible, but maybe, like, on your shoe, it's not. So if you have one of those, making sure at all times that it can be seen so that it can be useful.

Another one is if you have medical ID cards, to not put your hands in your pockets because that could be misinterpreted as something else, and so....

That was a very interesting -- just kind of peek into what the self-advocates, um, really do, which is educate each other and mostly others about their needs. So that's good.

Um... this was a set of two, um, sessions that I found really interesting. The first part, reconstructing program and financial plans, and then the second part, reflect, refresh, and rethink.

They really went together and had a lot of overlap on purpose to really drive points home.

But it was really all about managing through a crisis and being prepared before a crisis hits.

So, like, the pandemic was a crisis they could use to talk about it, so a lot of it was examples. But, um, when you're disaster planning for your organization, right, it should be an ongoing -- and they suggested annual process -- it should be integrated into your strategic planning to have risk assessments and including drills of potential risk and emergency situations, right?

And so that could look like what you do expect, but you don't expect.

Terrorist attack, political unrest, natural disaster, the pandemic, just really anything and being prepared for that.

They really drove home the point that it was important to have this disaster plan to get some confidence in people, that they were going to have -- you were going to have their best interest at heart when things did hit the fan.

So, at the end of the day, it can save lives. It saves resources. And it definitely saves time to have a plan of what you're going to do in an emergency.

Um... a lot of what you need is to have internal and external stakeholders really get that buy-in, and that includes being, one, ready for the crisis; and two, having points of contact with them before the crisis and really cultivating that relationship.

And so they suggested having seven points of contact about every year that did not include an ask with your stakeholders.

So, we're just opening the floor, we're upsetting holiday things, we're really opening up to cultivating relationships and that way you know that we're here, we know that you're there, and we're going to be able to, in an emergency situation, rely on each other, right?

Memorandums of understanding was another big thing, maybe like with a shelter or with other organizations similar to you. If our place is, you know, we have an emergency, do we have -- can we shelter in place in your place, right? And having that already set and planned in motion.

The best advice I think I got from this was the financial planning portion of it. And so the best practice is that any organization that's not-for-profit should have three months' operating cash available at any given time. So really being able to liquify the assets in an emergency situation.

And for all of these plans, it was driven home, don't reinvent the wheel, these things are written down and a master plan for a disaster preparedness.

So look online. And there's links on the ARC to do it as well.

Think of worst-case scenario and that would be -- worst case increase in your expenses and decrease in your revenue, and that should be really your financial disaster portion of it.

Um, in terms of the second webinar, I found it really interesting to talk about not just surviving the wave, but really, the aftermath. So it's talking about how can we use what happened and us getting through it, which is very important as well.

But moving forward after is also a really big portion. So the moving-on period.

And one of them that was really driven home was that flexibility can really mean doing more with less and streamlining and that might be something that can save you money and also that you can take down the road, like maybe we should be having Zoom

meetings instead of meeting in person.

It saves on travel. It gets more turnout, that kind of thing.

A lot of things intentionally in this webinar were call backs to the first one. So diversifying your funding is really emphasized. Making sure you have different revenue sources.

And then being open and honest about communication with your stakeholders and doing it timely was really heavily emphasized to build that trust factor.

And it was really important to talk about the business continuity plan versus the disaster recovery plan. So really, business as usual or keeping at going at a minimum level of services is the business continuity plan and that should be, like, when it's going on, what you're doing, right?

But for the recovery plan, you want to be a little bit more reactive and think about how we're moving forward. And as an organization, you should really have both. So you should be thinking about how we're going to survive and then how are we going to integrate all of what we've learned and then move forward with it?

Um, keep in mind the available assets that you have and keep an inventory of them for -- you don't want to be in the middle of a crisis situation and say oh, I don't even know how many masks I have or, you know, who should I call?

Keep regular tabs about what your resources and inventory are.

And doing, um, risk assessments annually again was driven home through, like, in this one.

So, they also ended each one with an example. Like a real-life example of a plan. So if you were wondering in practice what it would look like, that session is on demand and you can go ahead and look at it to see, like, how an organization has their disaster planning written out and down.

All right. And this is the last one for the sessions that I'm covering, but it was using data for quality. And this was really to the point. Um... if you want to have person-centered and the most up-to-date best care, you need to keep the most recent data about your...

I think the example they were using was, like, a care center.

So about the participants in your care center, right?

So if you're incredibly overwhelmed as a workforce and there's a lot of shifting in and out, it's really important to have what happened the day before recorded and easily accessible.

So something that was driven home in this webinar particularly was the niceness of having the data at your fingertips and online and not being old school with it and keeping it in a database so that way anyone could access it at any time when they needed to, so that when, you know, an employee needed to know some information about what happened the day before and that would really impact care, they could, and it would be the most up-to-date.

So, saying they had if it was not documented, it didn't happen. So using -- having the best and most thorough data and having it online is something that is useful.

And so what does all this mean for FDHP? It's a virtual meeting and the protocols and access.

So I was really impressed with the interpreting and the captioning and the availability of the on-demand sessions. And even though they didn't get to go to New Orleans, which is a shame, I think that the good thing that we can take and the lessons learned is that at least having an online presence, if you are going to do an in-person event, is really, really important if you want people to show up who can't travel.

And I think being an organization like FDHP where we serve with and for people with disabilities, that's something that travel can be a huge expense and it can be very tiring.

So keeping that in mind, especially for, like, our annual meeting, is making sure when we do go back to it being in person, if or when, we keep an online presence for people to join too.

The caregiver support webinar really, um, inspired one of our educators -- we do educational materials a year, and one of the educational materials this year is gonna be caregiver material, to try and really solidify what to do with, you know, the caregivers in your life and how do you handle being a caregiver, that kind of thing, so it's just a one off the cuff thing and includes a lot of the resources that we learn about the ARC.

The advocacy workshop really showed the need to use personal stories to highlight need, and that's something that we do in our training for health professionals, is we have some personal stories to highlight some of the things that professionals need to learn.

But I think really integrating that more into what we do day-to-day and showing the real-life application of how policies are affecting people with disabilities is how we're going to inspire people that aren't really bought in yet, to make changes.

And then really, just as an organization and for all of our, you know, we have a wide range of people who join us in our FDHP we encourage people to be organized and prepared during a disaster, have quality data, and then be flexible with the times.

So, these are some of the links and resources that I kind of referred to throughout. But, um... there is the on-demand sessions which will tell you a lot of some things that I didn't cover.

And the advocacy is something that they really wanted to, like, if you click that advocacy button for them and you help them take action, they would greatly appreciate it, that's my impression, so....

That is all that I have. But I am open for questions, if anyone has any, about the ARC Conference? Did we get any in the chat?

>> CLAUDIA FRIEDEL: We did. I just wanted to thank you so much for attending on our behalf.

We did have a question from Tyler asking: During the advocacy power hour, did it seem more focused on legislative advocacy or self-advocacy in healthcare in everyday environments?

>> MEAGAN SULLIVAN: So, it was a really a wide range of stories, I would say. And that's -- I think that's the -- when you're using a personal story, the listener is really the person who is gonna say, "What can I do about this?"

So with the siblings stories, it was, oh, my sibling was afraid of XYZ and I did this and they'll say oh, I have a sibling and they would say man, we need more support for siblings, I'm going to write a Congressperson. So it lends itself to whoever is in power and who is listening to the story to do what's in their means and within their realm of work.

Does that answer your question? [Chuckles]

>> CLAUDIA FRIEDEL: I'm sure -- that definitely clarifies it.

I just think this is great and so timely, given that our new notice of funding announcement has just come out, and we have a few weeks to turn it back around.

So, I just -- I wanted to see if anybody else had any questions for Meagan? Or for us at the Disability and Health Program?

>> MEAGAN SULLIVAN: Yeah, did anyone see anything that I didn't highlight but did mention that we could integrate into FDHP? I'm really curious about that.

[Pause].

>> MEAGAN SULLIVAN: Feel free to e-mail, too. My e-mail is here if you don't -- if you're shy. Or you're watching this recorded on the website, please feel free to e-mail

me questions and feedback.

>> CLAUDIA FRIEDEL: Yeah, I'm trying to -- I'm trying to -- you provided a lot of really great information that I think we will be able to use a little bit about this new funding opportunity announcement.

The CDC is putting out a new call to state that... um... focuses on adults with intellectual and developmental disabilities and adults with mobility limitations, and some of the things that they are wanting us to do are... um... to, you know, strengthen our partnerships and we're very lucky to have great partnerships in the DCPG and they want us to do a needs assessment for this particular population.

So, adults with intellectual and developmental disabilities that are underinsured and also, um, for adults with mobility limitations that are underinsured.

With the thought, to use that information to develop a demonstration project. So we would be, if funded, we would be working with organizations to -- to locate individuals with intellectual and developmental disabilities specifically. The demonstration project would be for that target population specifically.

And help connect them with local resources to improve their access to preventive healthcare and health promotions, evidence-based health promotion programs.

So, um, it's a little bit different than the work that we have been doing up until now, but... um... I think we're confident that we have great partners that we would be able to employ to help us with this.

Um... another thing that's along the same lines about -- of what we're doing now is continuing our training of healthcare providers that we have been doing for the past few years. So we would continue that.

And then also, we would... um... uh... work with evidence-based health -- evidence-based programs to work with people with intellectual and developmental disabilities and mobility limitations, to get them in those evidence-based health promotion programs.

So, that is along the same lines about -- of what we're doing now with the Diabetes Prevention Programs and the comprehensive school physical activity program, except we would be working with adults specifically.

So, right now we're just feverishly writing and then we're going to really hope [chuckles] that we get it. And we should find out, you know, late summer, July-ish.

And, of course, we'll let everybody know what happens.

I anticipate -- our annual meeting is going to be on May 25th. And we'll be talking more about this at that meeting, along with hosting a few great speakers from our partnership and beyond.

So I just wanted to put a bug in your ear about May 25th and let you guys know about what we're working on right now.

And if anybody has any questions about any of that or any questions for Meagan, you can let us know now or you can e-mail -- Meagan can connect to me easily.

And, yeah, I'm just -- that's what I've got on the mind right now.

So this is actually -- feeds really well into that, being that the target population is adults with intellectual and developmental disabilities, so....

So, I will be touching base with you, Meagan, to hash out how [chuckles] we can integrate some of the knowledge you've obtained from these presentations.

>> MEAGAN SULLIVAN: For sure.

>> CLAUDIA FRIEDEL: All right. So, I will give -- we'll give it a couple more seconds to see if anybody has anything.

Oh, we have something, from Devon saying thank you all. Great presentation, Meagan, thanks for sharing these useful insights.

>> MEAGAN SULLIVAN: Thank you.
>> CLAUDIA FRIEDEL: All right. Well, that sounds like a great way to sort of wrap up.
Thank you again, Meagan, and to all of you who were able to join us.
And everybody stay safe!
>> MEAGAN SULLIVAN: Yes!
>> CLAUDIA FRIEDEL: All right. Thank you, everyone.
>> MEAGAN SULLIVAN: Thank you.
[Concludes at 3:38 p.m.]

**** Edited ****

Recommendations and Findings:

- Caregivers require supports in three domains: informational and referral services, instrumental goods and services, and emotional support
- Personal stories are an invaluable advocacy tool.
- Keeping a disaster plan for an organization up-to-date is vital to continuing business as normal during a disaster, and recovering as an organization after.
- Recommendations include providing caregivers with all 3 types of support, adding personal narratives to advocacy materials, and updating disaster plans on an annual basis.