

DAWN RUDOLPH:

Hello everyone, good afternoon, good morning, depending on your time zone. Welcome to today's you said -- UCEDD directors meeting. I am Dawn Rudolph, we are so glad that you are here today. To share some time together, to get some helpful updates and to network with colleagues.

This meeting is typically held during the AUCD conference, it was a bit delayed this season, to accommodate schedules. And to reduce time during the annual conference time. We want to thank you for sharing the time together today.

I have just a couple of housekeeping items. The event is being recorded, for anyone who wants to go back and review some of the updates. The breakout rooms will not be recorded. There is a captioner here, so you can click the CC button, at the bottom of your Zoom to access closed captioning.

The captioner will be in a breakout room, so there will be a transcript of the conversation in that room. Notes will be taken in all of the rooms. We ask of course, for you to mute yourself if you are not talking. But if you do not mind leaving your camera on, we would love to see your faces. Because we miss you. That would be great.

For introductions, we would love to know a little bit more about who is here today, but we did not want to do it in the chat box. Because there are a lot of people.

So if you do not mind, either scanning the QR Code that is on the screen here, with your smart phone. Or maybe, there might be a link that is going to be dropped into the chat box. To that spreadsheet. Which is a different document, but for fun, if you could add your name, center and state, and most importantly, a mantra that helps you get through tough times, hopefully sharing the small self-care strategy from each of you, will help build a more collective resilience. I am certainly looking forward to seeing your mantras, and I hope you enjoyed sharing them with each other, and reading through some uplifting, positive, resourceful, grounding messages that we tell ourselves. To help us get through.

I hope that is enjoyable for you. I have a little example here, my anger holds despite the storms. Interestingly, as I say that, I do think of many of you. I think of the collective you, as being part of my anger. So I want to thank you for that.

I'm happy to deal with some recognitions. We like to take this time to make sure everyone is up to speed on who is who, and who is holding what seat in the network. We want to offer some gratitude to retiring directors Dan Crimmins, and Olivia Raynor to the dedication to the field. Their dedication to the network, and the support of AUCD.

Both Dan and Olivia have served as AUCD board president at different times, and their leadership at the local, state, and national levels have led to positive systems change, meaningful collaborations, and certainly paved the way for ongoing growth and impact. So, thank you.

And then of course, welcoming new directors. We are certainly happy to highlight these new directors, all of whom have had deep experience in one or more UCEDDs prior to taking on their new leadership roles. We are excited for you, your teams, and look forward to working closely together.

We also encourage UCEDD directors to reach out, individually, to welcome and get to know the new UCEDD directors. And continue the strong peer support that is so vital for the success of UCEDD network. So, just sharing a hello.

I also wanted to make sure that you all know who is who on our team, here at our team of AUCD, at the UCEDD resource Center. Katie Johnson, the brains behind this particular meeting. Is working on our equity diversity and inclusion action plan initiatives. Working on plain language initiatives. The AUCD Network narratives podcast, and the TA Institute.

Jeanette Cordova, is working with the Spanish language caucus. And also works on some partnerships and collaborations with Spanish speaking community. Maureen Johnson works with emerging leaders, supporting lots of trainee efforts and initiatives, AUCD leadership Academy, applications are open right now – and the equity diversity and inclusion hub. And Jamie Koenig supports Admin Essentials, both the Webinar and the tip sheet series. And if you work groups including business managers, Indigenous communities, and territories, as well as supporting new UCEDD directors orientation, and cohort chickens. -- Check-in's.

Other staff, for me, you are welcome to reach out to me with UCEDD statutory compliance and performance measures,

No question is too big or too small. Letters of support, anything you might want to be reaching out for. And then Anna Costalas, is part of our team. In addressing things related to communication's, dissemination, media, and marketing. You are welcome to reach out to any and all of us, individually. I also included a link here on this slide under Anna's name, the public promotion request form. If you are not familiar with this, you're certainly welcome to email Anna directly, if you want to get something into the AUCD weekly newsletter, or the AUCD 360 monthly newsletter, to brag about your work, or share new resources. Celebrate successes and compliments at the network. Which are also welcome to use this online forum, to just populate quickly, and get it into a newsletter.

For any TA related to NRIS you can contact nirs at aucd.org, or you can contact me directly. What I would like to do next is share some TA updates.

The URC goals for our current contract here, really focus on increasing accessibility in our TA activities. Increasing awareness of new and existing resources, what we are highlighting some here. Also increasing engagement at our TA events, as we continue hopefully for not too much longer, in a

virtual space.

I am going to move the slides out of a way for a moment, and share some websites with you, so you can see some of the resources that we wanted to highlight.

The UCEDD resource website, please share it with all of your faculty and staff who may be interested in finding anything related to TA resources, and with UCEDD's it hosts just about everything that we have available for you.

We have recently added to this website, we have uploaded our most recent evaluation report, we now do – over the past few years we have done an annual evaluation of the TA that we provide, and how it has impacted you, individually and you as a network.

If you're interested in reviewing that, you are welcome to do so here. We are currently recruiting for two positions on our team. One is the senior program manager position, to replace Sarah DeMaio, who recently departed for another excellent opportunity for her career. We certainly are grateful to Sarah for her dedication and support to AUCD, and the UCEDD network. She was here for six years and contributed a tremendous amount.

We are also recruiting right now for a data support manager, to support the data coordinators across the network and NIRS, so you if you know anyone who may be interested, you are welcome to pass this along.

A few of the newer resources that might be unknown to you, yet, we wanted to make sure to highlight here. AUCD leadership map, this was created as an approach to help some of the professional development and leadership trajectory pathways within the network.

As I scroll down a little bit... Just to the introduction section. It really talks about recruitment strategies, retention strategies, the work – the resource here was created through a lot of data review. Some interviews across the networks, and some surveys. And are really intended to provide the resources for you to strengthen your teams, grow your teams, support promotion and professional growth among your teams.

I know a lot of folks have been experiencing some staff shuffling in the great resignation – or the great staff reshuffling, so we wanted to make sure this resource was at your fingertips if you found it to be helpful.

We also have an updated set of organizational charts. This set of charts provides an outline of the different UCEDD's who have similar administrative homes. We often get questions around you know, who is in and another administrative home like us? How can I organize and who can I talk to about that? You can find some of that information here. These resources are all linked into the slide deck. And then it actually goes into the actual organization charts. If you want to see how other UCEDD's organized you can do that.

We have a new video called What Is a UCEDD? We have had a lot of questions about how do we describe our UCEDD to our trainees, or community partners. We have had some messaging strategies in the past, they were not as strong as hoped, so we were hoping this video would be a good resource for you, for that.

We are happy to highlight the AUCD Network narratives. This new pet test series was launched this year -- this new podcast series was launched this year, the first one addresses equity diversity and inclusion, and provides real stories for successes, and even some missteps. What has worked, and what has not along the way, across several of the network members. We look forward to continuing future seasons.

We had the UCEDD tip sheets. This is a series of tip sheets that are intended to support your operational, management practices. They are in categories of administrative essentials, and categories of core functions, and the category of grant management.

If there are some topics that you would like to see that you do not see in this list, as you scroll through, feel free to just send us a note. Call us up, we would be happy to add something into the queue.

And then the last two things I wanted to highlight are some plain language resources, Katie has done a lot of work to get a lot of basic information available, made available in plain language. We hope this is helpful to folks that you support, your CAC members, if you are looking for explaining things in a better way, this should be a resource for you. And finally, thanks to Jeanette, we have a page where we have got a lot of similar materials, translated into Spanish. For your Spanish-speaking partners, and faculty and staff, and community. So, thanks for waiting and listening as we were highlighting those resources. They are linked into this slide deck. Looking at the time I realize I am already a couple of minutes over. I want to just make sure you have on your calendars, a save the date for the TA Institute, which did need to switch to virtual again this year. It will be spread over for dates. A couple of hours each day. Not to take too much of your time each day. And I think that was all of the highlights that I wanted to start with. To not take too much time to being talked at naval ship now into some roundtable discussions.

The next probably 45 minutes of the meeting, is really dedicated for you to engage with each other. The breakout room, they are self select and we have eight options. Room 1 is authentic community engagement and partnerships. The second one is an subminimum wage and system transformation. 3 is promoting care and well-being in the workplace 4 is having people with IDDM meaningful roles of research projects 5 is technical -- technological capacity building 6 is navigating relationships with University 7 is how you said or using public health workforce funding and number eight is post COVID-19 transition for staff.

The breakout rooms are self-selected, if they are not open can we open that Anna? Thank you so much I will stop screen sharing.

DAWN RUDOLPH:

I think a couple of folks are coming back in from their breakout rooms. Do you mind giving a heads up it looks like most folks are back? Or thumbs up? I think we are good to go thank you.

SPEAKER:

Hello everyone it is so nice to reconnect and I'm here with the team and really appreciate the opportunity to engage with you. I want to thank AUCD for their great work and Katie and John a special shout out to thank you very much. I want to first kickoff by sharing that we have a new commissioner and her name is Joan Jacobs. She has more than two decades in the disability services while and is actually joining us from the IL community where she served as executive director for a CIL in California. We were very impressed with her grassroots organizer and more so as she campaigned

for FDR to be seated in the wheelchair in the monument at DC. It's a beautiful monument and I hope you get a chance to visit.

I did have a chance to meet her yesterday at her leadership is very visionary and thoughtful and I know you will like her very much. Initial export to engaging with all of you very soon. I think that might be at the TA Institute conference in April or May. Let's go to the next slide. And the Next slide.

I know with a lot of folks that enjoy research data, if we look at the past one of the things we have included in our updated UCEDD page, is the 2020 outcome data table. We have the link here, and we will make sure you get these slides afterwards. I am excited, because I feel it is so important, when I was monitoring the New York program, when you can benchmark states against each other.

When you look at specific reports that are available, you will have the opportunity to compare yourself to another state. If you see someone doing really great, with great numbers, that could motivate you to reach out to them.

So we want to let you know about that resource. So let's drill down a little bit on the PPR data, this should not be a surprise. PPR data, is from the fiscal year 2020, capacity building. That is very consistent on the fiscal year 2019 data.

What I like about this slide, is that it not only tells us the activities, but it also tells us the area of emphasis. There are a lot of layers going on. If we look at the far right column, the top three areas are going to be in the following ranking order, education is number one at 34%, employment at 12%, and held that 22%. Those numbers are consistent from last year. But I like about the chart is we can look at areas of emphasis by activity categories. If you look at the column where you see advocacy, the focus of health, leads at 859. That is a sizable lead number.

Under the capacity building, education is dominant. It really leads the pack at 9632. And for direct services, health leads at 622, followed by education, and for systemic change interestingly, employment leads at 936. Followed by education.

I really enjoy looking at this slide to look at the different correlations. I think you will enjoy that as well. When you have this to view further.

For this one, but I try to do, I am trying to look at trends. I look specifically at the 2019 data against 20/20 data. I am going to point out a few rows here that I like to highlight. On the row of participant in Continuing Education, that has experienced a significant increase for this year, 2020. An increase of 7718, to get at 514, 944 participants. So a big increase.

For the two rows following, participants in PA program, that actually experienced a decrease. 189,864, to get the number 437,179. Further down, participants in research and evaluation activity, experienced a very significant increase of 103,975, with 443 322. Finally at the bottom, we have the figure there 609,702,061.

This is a very important slide, because at the end of the day it is about serving the customer. 68% of respondents said they were highly satisfied.

I highlighted all the different quantitative data, but also, it is important to know the qualitative factors as well. So the team that consulted with them, I said what do you want to see improve for the next PPR reporting? These were some of the feedback items where they feel like qualitative reporting can be improved with the narrative.

The following are in these categories, the impact of interdisciplinary training, research, community service and dissemination in one or more areas of emphasis.

How people with IDD are meaningfully engaged in the research process as co-collaborators, co-leads, or in another capacity. And the barriers impeding inclusive research and proposed solution strategies.

So there are ways in which you could include more examples, in those narratives, it would help -- a great deal. But overall we are pleased with the quality of the PPR's.

Funding information. So, we are now transitioning to the present. So let's go to the next slide. UCEDD CORE awards, as you know we are in a continuing resolution that does expire on February 18. The house has passed ACR that will go through till March 11.

So I predict that we will be under another CR. We are working under a lot of different scenarios. For the new CORE grant funding, DCR level will be 42.1 million. We estimated that each UCEDD will get 577,000 roughly. As the house Mark total is 47 million, roughly in the estimate each UCEDD to get 608,000 for each center.

The fiscal year 22 applications are due for 42 new UCEDD's and I want to show you that we are working very hard. We have been on the phone with OTM this morning, to get the out and out as soon as possible. So we do anticipate a release – make a release of the NOFO by the 20th of this month. You will have 60 days from the posting of the announcement, and we think this could be helpful to you. Perhaps that is something that you would like to review.

Again, we are working fast and furious on this, under the interesting dynamics with continuing resolution. But you know, we are on track right now. Next slide.

UCEDD public health workforce funding, this came out in January. Again, we mentioned that UCEDD program will be allotted approximately \$7.6 million. If all 67 UCEDD apply, we will have to make sure each UCEDD would get 113 \$670. The application is next week, February 23. And I reached perceived an update from Pam, that nine UCEDD's have submitted. And a shout out to those. We know that more will be coming.

We perceive that the project start date will be April 1, and it definitely will end on September 30, 2024. That is a definite. We have resources for you. We updated the FAQ. And if you are not able to participate in the webinar from January, we have a link here with a passcode.

The question we often get, is there a reporting requirement? The answer is yes. So I will not read the first part, but in short, the key things that we want to know is the number of full-time equivalents. The type of public health professionals hired, and the activities they are engaged into advanced public health. That is kind of the gist of the information we are getting, we are seeking to make this seamless by using your existing reporting system, and your program Officer will be working with you on that.

I want to make sure I am good on time, so I do not get in trouble from dawn. The next slide is the CDC funding. Again as you may recall, it is something that we launched last year. Each of the programs were allotted the UCEDD program was allotted \$4 million. All 67 have accepted the funding. And I believe each UCEDD received approximately \$59,700. That performance period will end this year on September 30, 2022. Program officers will work with you as you develop your PPR.

With what materials should be incorporated. Include both quantitative and qualitative data. And examples of qualitative include collaboration with other community based organizations, overall lessons learned, and recommendations for future activities.

Engagement calls... You know, as we look to the future we want to say that we have really enjoyed engaging with you last year. We got to know you, and hopefully you got to know us. And you know, I want to give a shout out to a lot of the presenters who presented to the regions. But you also educated us.

Looking back, here are some of the key dates that we actually engaged. If we look ahead for 2022, I note the senior leadership looks forward to engaging with you during the upcoming TA Institute. And within our team, we look forward to engaging with you in June, or late summer, and we are thinking about the possibility of exploring how UCEDD can learn more about different programs, and the ways that we can collaborate in those areas.

I want to wrap up by sharing with you the key contacts. We had the UCEDD contacts here. Then we have the fiscal team contacts here.

And finally, thank you. I know many of us are feeling very fatigued by COVID-19. But I have to say, your work really does inspire us to work harder. So we are very appreciative of that. We actually did an exercise recently, where we had to share a favorite song.

So I want to close by something... Enlightening. In light of the said situation in Ukraine, with how dire that situation is, but also how and lightning next month will be, being (Indiscernible) awareness month. The theme for DD awareness month is "World Reimagined", so we came up with this exercise of choosing a favorite song. So I chose John Lennon's Imagine. So in closing, I want to say, you may say I am a dreamer, but I am not the only one. I hope someday you will join us, and the world will live as one.

Again, thank you so much for all you do, we look forward to connecting with you again, and I hope this summary is helpful. And I hope the slides will be helpful, when you view them in detail. So thank you

again.

DAWN RUDOLPH:

David, thank you so much, for being here and sharing that information. And for quoting John Lennon. That was lovely, thank you.

And I am so glad that this gives us a couple of extra minutes for the panel, because I am very excited about this Panel Discussion. And to move into the next slide, and then I will turn off the screen sharing so that you can see the panelists.

But I want to start with introducing Danielle Augustin she works for the you said in Kentucky, working for the Southwest COVID-19 hub. Thank you so much Danielle, for moderating this panel, and thank you so much to the panelists for being here.

DANIELLE AUGUSTIN:

Thank you so much Don for the introduction. Hello everyone I am Danielle. I am a young white woman, with shoulder length red hair, with glasses, wearing a white sweater, standing next to a colorful bookshelf. I'm excited to be here with all of you today to moderate this important panel regarding our networks ongoing COVID-19 efforts.

As we enter, if you can believe it, year three of the COVID-19 pandemic, it is important to reflect on the vast changes that we as a society have undergone. Words like pandemic, vaccine, variance, boosters, and quarantine have become part of our everyday vocabulary. I think I speak for everyone, echoing what David just said, as we all have some exhaustion, and fatigue. But, we as a network has been able to respond to COVID-19 Network members have carelessly supported disability community with dissemination of plain language health information, collection of meaningful data and much more. As we all know the work is not done.

Today this panel will discuss effective outreach strategies that you said and other areas are needing to support the disability community as we persist in our response to the ever-changing environment. On the panel today we have four individuals we have Max from the GMS a and is so joined by his son and advocacy leader. We are also joined by Emily was an assistant professor of medicine at UCLA David Geffen school of medicine where she serves on the leadership team of the Autism enters pension research network or the ARP project. Lastly we are joined by Mary Willard, she is the director of training and technical assistance for the Association of programs for rural independent living. We will put the link to the full bios in the chat if you are interested in that but we will go ahead and get started.

First I will post a question to the group as a whole and we will go to Danielle and Max and Emily and Mary. Many of us are feeling fatigue in our outreach efforts going into this third year of the pandemic. How have you and your team for navigating this symptom called COVID-19 fatigue?

HASAN KO:

We're having trouble we like to be together for the first time I get to self advocacy and get to meet self- efficacy is from the different state and when it comes to the pandemic I get to come to the pandemic

(inaudible) network just like now. Now what I know and Max?

MAX BARROWS:

But I can say to this is our team is not really experiencing a lot of fatigue. Finally, more people have gotten access to devices and accesses to technology. The skills of people with all kinds of disabilities has drastically improved.

Self advocacy, teams across the country quickly adapted to working remotely. People should not assume that people with disabilities cannot learn new ways to do things. Our focus is working live on line and we now have more self advocates join us at least once a week than ever before.

In January of this year our number of regular attendees went up and people love connecting with each other, so sharing ideas with self-efficacy around the country it is not getting old, or losing steam. It is getting better. We never had this regular contact before. Our meetings typically had around 95% only self advocates. The peer to peer connection is proving how powerful we can be.

Now we have created a true peer space and the topics come from the participants and presenters must be self advocates and allies are welcome but we are in charge. And we estimate upwards of 150 people connect with us via that meeting that we have at least once a month.

DANIELLE AUGUSTIN:

Thank you and I appreciate you highlighting some positives that come out of this. I think we can all agree that the virtual world has allowed us to make some of those more meaningful connection so I appreciate you sharing.

Next we will go to Emily.

EMILY HOTEZ:

Hello everyone great to be with you today. Like the most of you, I have experienced zoom fatigue but I will say that Max I am so glad that you said what you said. I was on a panel earlier this week, the same question was posed to a Special Olympic athlete. The question was how do you keep going and what keeps you motivated during this incredibly trying time? She said I just get up have really good coffee and get to work.

That is not to minimize incredible challenges we all face but I am continuously inspired by the narrow divergent people that I work with, the self advocates that I work with, and I think we all can draw from those collaborations in our work to keep us going. So happy to be with you all today.

DANIELLE AUGUSTIN:

Thank you so much for sharing that. Mary, the same question to you.

MARY WILLARD:

This is Mary, I hope I'm not the Debbie downer but I do want to say that I work primarily with folks at centers and at independent living and statewide Independent living councils of which most are persons

with disabilities.

People are fatigued, they are watching their colleagues and coworkers get sick, many of them getting sick themselves, isolated and super understaffed. They are working with folks in some pretty dire situations like nursing homes with COVID-19. And so a lot of times what I do is I hold a lot of peer support calls with them and they really allow myself to also be vulnerable and I just sit with them in the ick. And let them know I also feel that. I am honest with people, I started counseling during the pandemic and we talk about what it looks like to set boundaries with your work and do self-care.

And really I think is holding a space for people to feel okay talking about it. Because these are people who have to hold space for everybody else and sometimes do not do that for themselves. I hope that is not too negative!

DANIELLE AUGUSTIN:

No thank you for sharing that and that is wonderful. I think it was a good spectrum of recognizing the positives and being quite frank that we also have challenges and barriers so thank you.

Next I have two questions for Max and his son. The first question I want to post you all is what lessons has Green Mountain self advocates learned in doing COVID-19 information sharing with self advocates?

HASAN KO:

Thank you for inviting us to be in the group. Also, thank you working side-by-side with us for self advocacy. During the pandemic we learned to be remote and independent in our own way and our own efficacy world and we are always helping each other.

Also it gives us the energy for us (inaudible) so in our advocacy, they want to have a friend. But for us we need somebody to support us by someone who can understand us. That is helpful for us. Max?

MAX BARROWS:

You know, peer support is stronger than ever. You know, a positive outcome of the workforce crisis is that we are turning to our peers for supports and staff are really available. When we are working together, we get a lot done and we can do anything.

We learn to take the time to clarify what support people need. Even now, the COVID-19 rules are changing constantly and we need to be vigilant. There is a lot of information available in plain language but it constantly needs to be updated.

Let's see, also prioritize effective communication. Make sure people have devices, access to the Internet and how to use it. People need to presume confidence when supporting us. People feel like we have lost a lot of freedom and we have lost ground in our like to live independent lives. We are often treated like children with parents and providers constantly checking in on us. We appreciate the support that we do not want to be protected from living our lives.

Giving us the same COVID-19 messages over and over again gives us the impression that you think we are not very smart. Just because we have questions about recent variants or boosters, that does not mean that we are unaware of the basic safety protocols for living our lives during the pandemic. It comes to a point where people feel like they are being watched as if a bunch of security cameras have been put on them.

DANIELLE AUGUSTIN:

Thank you both for sharing that and that sort of goes into my second question that I have for you all. What you think is important for UCEDD directors on this call and other AUCD network centers to know as they continue to share information with the disability community about COVID-19?

MAX BARROWS:

That is a really good question. I would say, what we believe is that you need to be in touch with people on the grassroots level all the time to see what people need help with. Our concerns are constantly changing. Forget any misconceptions that you have, you know, pre-COVID-19. You have lots of experience including self advocates as equal partners on your CAC's. Start with the new pallet, make sure that all of the values of the self advocacy movement are your primary colors used in all of you do.

This is a new day, self advocates are pros at working remotely. You can include self advocates on all of your projects, all of your projects! When you were working on diversity, include hiring people with intellectual and developmental disability as project staff. Our suggestion for strategy for sharing this information with the disability community of the COVID-19 is COVID-19 just keep working with us in higher self advocates on a local level to develop and disseminate information.

Do you have anything you want to add to that?

HASAN KO:

There are so many different cultures, and language and barriers. Those kind of things and those people need to understand what we are trying to say when it comes to plain language. People always try to be. Careful with what the words mean and what the other words mean. It's always a hard time for people who do not understand about the different language or different culture things. So that needs to be looked out for those people who need that. You know?

DANIELLE AUGUSTIN:

Thank you both for sharing, I just want to say that you all have been invaluable partners for our vaccine confidence project and helping us get plain language and thinking about the things that you both just mentioned. We really appreciate the continued partnership.

Next we are going to slide over to Emily. Emily my first question for you is, what strategies have you been most effective in enhancing public health community education efforts especially and marginalize or multiply marginalized populations?

EMILY HOTEZ:

Great question. Now more than ever we have to be public messengers and communicators whether or

not we thought of that as part of our job before. I found that collaborating with diverse and interdisciplinary stakeholders who are involved with the communities I seek to serve, really inform my own efforts to engage in effective public health messaging.

Earlier in COVID, which now seems like forever ago, last summer, I led an AUCD CDC dissemination innovation many grant, and my team at UCLA, led by students, we conducted interviews with diverse stakeholders.

We spoke with individuals with disabilities themselves, family members, physicians, direct service providers, and researchers all with the goal of really understanding factors that predict vaccine competence, uptake, and access.

And it was really through these listening sessions that we were able to then subsequently deploy a social media strategy that was effectively able to communicate to these groups. Without really having those collaborations, and speaking to people within a diverse range of perspectives, I do not know that we would be able to implement an effective social media campaign.

This brings me to something else that I learned over the pandemic, which is really that, yes we should be communicating to neurodivergent people. People with disabilities, but we have to really recognize the heterogeneity of these populations. One of the reasons why public health messages just have not been so effective for reaching a marginalized populace in the past, is because they often treated marginalized populations as monolithic.

This is really something that I learned at communicating with a group who initially did not even seek to serve the disability community. They are a group called the hood medicine initiative, they emerged over the pandemic to reduce health disparities for BIPOC populations.

They recognize the critical importance of speaking to people who are multiply-marginalized, or have intersectional marginalized identities. Neurodivergent people, who are also part of the BIPOC community for example.

They really taught me and my students, who are working with me here at UCLA, to craft culturally tailored messages in order to reach her population.

And I am really energized that my group received a second round of funding from the AUCD, CDC joint partnership in order to actually create a four-part workshop series for all of AUCD's network focused on exactly this. Crafting public health messages that are really effective for reaching the diversity of neurodivergent people.

And we are going to be delivering this workshop series, monthly. Between April and July, is currently the plan. I am sure because you are all in AUCD's network, you will hear about this later. And I will send you some annoying messages, and bother you about these trainings. But I would love for as many people to participate as possible.

Because, this – our task of being public health messengers is really universal now. And I would like for us all to band together, and figure out the best way to craft these messages.

DANIELLE AUGUSTIN:

This is Daniel, thank you for sharing Emily, I think that builds so well on what Hasan was saying about the intersectionality of cultures. I know I myself am excited for those workshops, and I bet a lot of other people are as well.

My next question for you, knowing that none of this work happens in a vacuum, so what unique partnerships have help you to be successful?

EMILY HOTEZ:

As I mentioned before, working with these interdisciplinary teams is really critical for rupturing the silos that have historically existed between our fields.

Just because I work primarily in autism research, and with neurodivergent communities, that does not mean what Hood Medicine is doing is irrelevant for me. In fact, both groups we know, experience incredible amounts of stigma, which can contribute both directly and indirectly to health disparities. So being able to collaborate with this interdisciplinary lens has really been critical.

Also, empowering students who are the next generation of public health leaders. Both of my projects are student led, I really want my students to take a leadership role, in guiding these efforts. Because that is really a way to make sure our efforts are scalable, and continue beyond the pandemic.

DANIELLE AUGUSTIN:

This is Daniel, I really love that phrase, rupturing the silos. I appreciate you sharing that. Next we will go over to Mary, Mary, my first question for you is... There continues to be significant challenges in supporting rural communities during the pandemic. What unique considerations are important, and what strategies do you recommend for improving outreach to rural or otherwise underserved communities?

MARY WILLARD:

Grade. This is Mary. This is actually an area where there is a Silverlining. I would say that the pandemic has really leveled the playing field for rural versus urban.

Before, our rural consumers were really isolated, due to mounting barriers, because of community resource shortages like transportation. And I think that technology really helped to bridge that divide.

We learned a lot about supporting people in their own homes. What it is like to bring services to them via technology. Which brings its own issues, but sometimes the CILs had to supply the technology. Sometimes they had to supply the data to access the technology.

And a lot of times they also had to support with some training on how to use it, breaking down some of that barrier. Once people got used to it, I would say that overall, Center for Independent Living axis for

consumers in rural areas is at its all-time high. CILs have more consumers than they have ever had before, and I think it is a lot to do with the fact that people are not having to... Wait an hour for paratransit to show up.

They are hopping in on a Zoom meeting. Centers are also offering a lot more virtual IL skills training, a lot more virtual peer support groups. Which makes it easier to accommodate people. So we are seeing an influx of more diverse consumers, it is easier to do ESL translation, have ESL captioning, when you are doing virtual.

So this actually was I think a really positive thing for us. But if I had to talk about any kind of differences between rural and urban, I think some of us in brain science, you know in rural areas, we just take a step back. And sometimes we have to remember the good old days.

A lot of folks still like phone calls. They still like mailing flyers. They still like doorstep drops. You know, just because they are old does not mean that they are worse methods. Some Center for Independent Living stuff, they would drive to somebody's house, and they would sit outside, and the consumer would come to the balcony and you know, they would drop some stuff to them, and just visit them from across the way.

I think, in rural areas, one of the most important pieces is to build that trust, in the relationship. So, I talked to people, you do not want to start right out with your data and facts, and what you want from them. Spent some time asking about what they like to cook, what you share in common, and you know, just building a relationship.

And know that you are not just there to take what you want, you are there to give them something as well, that is valuable to them. I think about, there is one example that I love, there was a CIL that was doing a COVID vaccine clinic in a rural area, and they really took the time to go out to the community.

They brought in embedded community members, which is so important, people that they already know and trust. Their peers, they had this big clinic and they gave away things that people needed. Gas cards, food cards, there was a food pantry there.

You could get those items without having to get the vaccine. So they were just trying to build trust, and get people to them. This was important because in this community there were a lot of folks, who some of them were undocumented. There were folks who rightfully had some distrust, of people coming into their community.

What they found was, they stayed for a few days, and they saw a lot of these people coming back and getting vaccines. And it was just the idea that, they were not just there to show up, they were there to bring something of value to the community.

And I think... The last thing is saying that making sure that you are just talking to people, and talking with them and not at them. I think... Especially in rural, this is so important.

You know, we love our neighbors, and we just want you to talk with us, and share with us, and we are willing to share anything you want, as long as we do not feel like you feel like you are better than us. And you are coming at us, and not alongside us.

That is all I have got on that. (Laughs)

DANIELLE AUGUSTIN:

This is Danielle, thank you Mary for sharing all of those wonderful success stories. And an excellent reminder I think we all need from time to time, to take off our expert hats, and just be a human and have a conversation. Thank you for that. My next question for you is, as we move forward in this work, what areas or issues do you believe CIL's need the most advocacy and focus in order to best support the disability community?

MARY WILLARD:

Thank you so much for this question. This is one that I really think is so important to talk about. Because, I am familiar with what a lot of you folks at AUCD do, and your work is so important to what folks are doing on the ground, we need you, and you need us, so I'm so glad we can work together. I would say, the number one thing we do right now to do effective advocacy is more consistent data.

Especially more consistent data on what is going on with our disabled siblings across the country, and congregant settings. This is an area that we have really needed to do a lot of advocacy on, and the data is disgusting.

And so, anything that you guys can do to help us with that, that is one of our number one priority areas. And that includes every congregant setting, nursing homes, psychiatric facilities, group homes, even people who are incarcerated. The data across all of these, we know there are people with disabilities in all of these places, but we do not know a lot about them.

And I think the other thing that I really think would be great to partner on, that could help with our communities, is to do a deep dive into what is already happening.

I would love field initiated projects that really truly came from the field. There is a lot going on right now, we were very fortunate that we have a lot of money, like CARES funding that came into centers for independent living, to do really great special projects.

What we do not know is, what are the impacts of those projects? We all know, that is what is most important. If you are going to go and get more sustainable long-term funding, we need to know if it is working. There were things like, you know, I would love to know, what are the (Indiscernible) of these programs? Centers are paying direct workers hazard pay, what does that do for somebody's personal care?

What happens to an individual's quality of life when you give them an iPad and data, and teach them how to use it?

Which was happening across the country. You know, I am interested in, there were these really great transportation programs that sprung up in COVID, with COVID funds, like people were putting together volunteer transportation programs where people were getting out and about, for nonmedical appointments. What does that do for somebody?

So I think there are a lot of things going on in the field, and we just need to make sure that we are finding them. And however you all can help support those initiatives, I will say one more thing on this, and it is that independent living is, we are facing the largest shortage of staffing that we have ever seen.

And a lot of that is because we cannot pay what people deserve to make. When we are seeing everybody else making more money, you know, you can go and work at McDonald's in some places for \$20, and we are not paying people that, we cannot afford to. So the more that folks like you can help us, show the importance of our work, so that we can pay people their worth. And keep doing the good work we are doing, I think we will just be able to make such a bigger impact.

DANIELLE AUGUSTIN:

This is Danielle, thank you for all of that Mary, I saw a lot of vigorous headshaking throughout the points that you made. I really appreciate the data piece as well. All right, the last question I will bring back to all four of you as a group. We will do the same thing, we will start with Max, Hasan, than Emily, and clothes with Mary. My question is forward thinking, this is something that Mary and I talked about prior.

You know, we are all kind of stuck in the now, and dealing with the issues at hand which is important, but you know, how do we start thinking forward?

What recommendations do you have for UCEDD leaders and members, on how to help the disability community move forward with resilience, to better plan for tomorrow?

MAX BARROWS:

I can start with that. There needs to be more focused on protecting people's rights during COVID-19. For example, a student told us last week that his father will kick him out of his house if he gets a vaccine. And we know of other people with guardians that are not allowing the person to get vaccinated.

Now, the PNA and protection and advocacy, they have offered to go to court to address this type of problem. But, the solution is often too drastic for most people. During the pandemic, most people with disabilities cannot afford to offend their families. We need to focus more on practical strategies for people with disabilities, teachers and providers need to get better at supporting someone facing the uneasy political climate in our country.

Finally, please focus on employment because many of us lost our job during the pandemic and maybe we can follow the current trend of getting jobs we really want to do, just like so many other people without disabilities are doing. I am wondering do you have anything you want to add? You can just talk

from the heart if you want?

HASAN KO:

For me, when it comes to the agency, we need to know more about what we need and what we want from them. Right now during the pandemic we some people have support for the people that need it. And for some people they do not have support for them anymore. Not when it comes to the pandemic and it is really hard to find for us for that. We need to tell them that we need somebody to support us, it doesn't matter what we are doing. That is all I want to say.

DANIELLE AUGUSTIN:

Thank you so much Max and Hasan, your experiences sharing with us it was so incredibly valuable. I will now go to Emily.

EMILY HOTEZ:

Thank you so much for sharing both of you. Something I think we can implement going forward and this is something that was always important but really came to light at least for my team and I at UCLA. No matter what sector you are in, how can you create a neuro- diversity orientation? In research how can you design a research that is no diversity oriented? That seeks to capture the diverse spectrum of differences that we have in outcomes but also in the methods that we use. How can we make sure that our methods are in alignment with the priorities and experiences of the population that we are studying in healthcare. How can we make sure the clinics are really created both culturally and environmentally for narrow divergent people.

How can we make sure that healthcare professionals are interacting in ways that are in accordance with best practices? In education, same thing. One way we can all accomplish that is through authentic and meaningful partnerships with narrow divergent people. So often, I come across the perception that it is more difficult, and so often I hear from researchers that they have to do something community-based participatory research study that is grounded in all of this theory and super complicated.

That is really not the case. I would encourage no matter what sector you are in, to do that reach out. Even if it's simple, just one person. Really try to integrate authentic meaningful collaboration at whatever level you are able to in the resource constrained environment that we are all in.

That would be the primary recommendation I have for all of us moving forward.

DANIELLE AUGUSTIN:

Thank you so much, Emily yes I do not think that we can say nothing without us enough! We will go to Mary to close this out.

MARY WILLARD:

Thank you Max for bringing up guardianship. I think this is an issue everywhere. This is something we are working on. I think this is an area where we could do some work.

I also just want to say... I know I am hammering this to the ground but we know that there are a lot of

congregate settings that are not ideal in the pandemic and it really highlighted it. Jude discussing points where, it's offensive. I understand if someone has to go there or wants to go there but the fact that they cannot get back out or get access to other people, to other supports...

That brings me to my third point and I think this happens because our community resources are depleted. I had a peer support pout yesterday with some Center for Independent Living and they were talking about how they develop more resources and their moral area. There are a few people offering services that they have waiting lists and waiting list. There is no housing available, there is no accessible housing, you know I think just resources in general have been spread really thin. This pandemic has highlighted that. I would love to see more creative projects around you know one of the UCEDD was doing community resourcing and they were trying to dive deep into the community and find out what really is there.

Is there a church that is helping or volunteers? Are there what is needed in the community? Do we need more, maybe we need to put together some sort of advocacy group in this community works led within, working towards better housing options. We keep talking about the lack of resources and the lack of resources and I would like to see us move forward and start addressing where do we go from here. And meet the resource need.

DANIELLE AUGUSTIN:

Thank you for that Mary, I think that is one of the disability strengths is we create that in a lot of situations I appreciate that sentiment. We have about seven minutes left and that's all of the scheduled questions that we had but we wanted to open it up to you all if you have any questions for the panelists. Please feel free to put those in the chat or if you want to unmute, use the raise hand feature and we can allow you that space as well.

We have a question for Mary, Karen asked you describe the data that you are looking for in the congregate settings-?

MARY WILLARD:

Thank you Karen yes. I will tell you right now that I can give you a couple of ideas but I would love to get your contact info and share more specifics. We actually have a group working on this, and institutional bias committee, all good people just interested in data about congregants settings.

Just off the top of my head, we do not know how many people with disabilities or how many people are in there, how many people are vaccinated, how many people want to get vaccinated but are not or cannot get vaccinated.

We do not know how many people that are in there that want to get out. And what are some of the reasons why they were put in in the 1st place was it health reasons, lack of resources, family? We honestly do not know anything. It's one of the least transparent areas in my opinion of where data goes.

DANIELLE AUGUSTIN:

Thanks for that Mary, that is something that the vaccine confidence committee is currently struggling with. We do not have baseline data of how many cases exhibits within the disability community so we have to go back to the basics I agree.

SPEAKER:

If I could offer, we used our vaccine funding to do a survey in the state of Texas to get that data that you were just talking about. We just presented it today, we had a vaccine summit with our DD partner throughout the state and human services partners and the other organizations that work with people with disabilities. We actually have some pretty good data, we had about 2000 people respond and it was not all DD, we had people with physical sites, hearing, other kinds of disabilities as well.

If anybody wants to borrow the survey, let me know we are happy to lend it to you. There are some questions about whether people are vaccinated and so we got that and then we have people who are not vaccinated, what were the barriers? The biggest barriers were, in terms of hesitation for vaccination of people with disability, a small majority were vaccinated but the ones who were not, people were result -- concerned about side effects for their disabilities. That was one of the biggest ones. The other one was not believing that they have been proven to be effective yet. There were a lot of accessibility you know, barriers as well even people who did get vaccinated. There were a lot of accessibility issues. I am happy to share that!

MARY WILLARD:

I would love to see that if you are willing to share it. I know some advocates, even just knowing that there is a place to start I think would be really exciting.

SPEAKER:

Yes, I guess I need to get your email I can put my email in the chat and anybody who wants a copy of the survey, it might be nice to compare states and stuff.

DANIELLE AUGUSTIN:

Thank you for offering that in our AUCD team can help coordinate contact information as well. We still have two minutes left so are there any other questions for the panelists or the panelists is something you want to say they do not have a chance to, feel free to do that as well.

Sandy just put her email in the chat for anyone who is interested. I imagine you will get a lot of emails (Laughs)!

MAX BARROWS:

I just want to say thanks having us on here to present. I just really hope you take this information and consideration that we shared as you move forward with your work. Even though I have no doubt that you all are doing your best, like all of us are.

DANIELLE AUGUSTIN:

Thanks Max, we echo the gratitude and we appreciate your input and support and it really does help our whole network and we are glad it can be a mutually beneficial relationship.

Thank you all so much, the four of you for agreeing to being on this panel today and engaging in this conversation. It was really informative and I will pass it back over to Dawn to move onto the next section. Thank you so much everyone.

DAWN RUDOLPH:

This is Don, thank you panelists, we appreciate your time, and we appreciate hearing it. I only have one last thing, which is really just a thank you.

Thank you all for joining, and thank you also for the planning committee who participated in setting the stage for this meeting, and picking the topics, and working so closely with Katie. Lesley Cottrell, Kelly Nye-Lengerman, Ilka Riddle, and Nina Zuna, thank you so much. And thank you to our federal partners, for your support and guidance, and for all of your beliefs that are collective effort makes a huge difference in the world.

I guess we will continue to imagine. Thanks so much, have yourself a wonderful rest of your day. And do not forget to click that evaluation link that Katie dropped in the chat box, let us know what you liked about this, and let us know what we can do better for you next time. Thanks so much.

Live Captioning by Ai-Media

SPEAKER:

Recording stopped.