ROUGHLY EDITED COPY

AUCD-UCEDD Directors Meeting-(Ai-Live to Zoom) Association of University Centers on Disabilities (AUCD)

JANUARY 27, 2021

CART CAPTIONING PROVIDED BY:

ALTERNATIVE COMMUNICATION SERVICES, LLC

www.CaptionFamily.com

* * * * *

This is being provided in a rough-draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings.

>> DAWN RUDOLPH: I do very much want to welcome everyone to the UCEDD director's meeting today. I'm thrilled to see your faces. Very happy. This is the meeting that we would typically be holding in person on the Sunday of our annual conference. And I'm glad that while we had the virtual conference this year, we had the opportunity to spread the meeting out a bit. And I am incredibly grateful for all of you being here and are hope this is a good time to share experiences and strategies. And commiserate with peers across the network. Can we go to the next slide?

Just couple of housekeeping items to touch base on. This event is being recorded. Except for the breakouts. So when we get to the Roundtable discussions, they will not be recorded. We do ask that you mute yourself when you're not speaking. And do share your video if possible just for help with engagement and seeing each other. And then there's also closed-captioning available. So at the bottom of your screen, you can click the closed-captioning button if you need that. And then can we go to the next slide? You got it? I do want to take some opening moments to acknowledge that some people joining this meeting may have some personal experiences with COVID. May have been on the frontlines providing care or support to people with COVID. Have witnessed some unparalleled suffering that we haven't seen in recent times through

service in our hospitals, or connections with the frontline worker. We know that our frontline worker are people at every socioeconomic level who are not always remembered or acknowledged.

We know that people in today's meeting may have experienced the loss of a loved one during this epidemic. We can and we should make time to take a moment to reflect on the fact that we are, ourselves, and each of the people in our work and in our community lives may be struggling with something related to the pandemic we as director and senior staff and other places may never know. There's an increase importance in necessity of self-care. Rituals long practiced or newly adopted. And there's similarly importance in talking about and practicing acknowledgement and kindness, and patience.

We are all called upon to better understand how to identify and disseminate or build wellness and resilience, supportive tools and resources into our work environment. So that the idea and practices of self-care are not only widely accepted but encouraged as a practice going forward. We can close this moment with being thankful with University leaders and committee partners that vaccines are becoming available. That good information is increasingly flowing. And that we have the capacity and desire to help in whatever ways we can to ensure that not one more person falls prey to COVID. If we in our various roles can help prevent it.

And now, if we could just for a moment take a maybe one or two breath together to transition from this moment to the rest of the meeting. Breathe in and out.

And in... and out. thank you.

And if we can go to the next slide. Our first few slides here are just updates on what we are doing at the UCEDD Resource Center. Your national technical assistance center for the UCEDD network. I'm happy to share these updates. I'll go over them briefly. But the PowerPoint will be available afterwards for you to share with your staff so everyone can click the link and see where they want to plug-in and what's going on. If we can go to the next slide, we've got our staff to highlight. And we always have new staff on the team. Laurie is still in her first year, so we get to count her as new. Maureen comes to us from the physician assistant education association where she was working in professional development and engagement.

Katie Johnson joined maybe 6 or 7 months ago. She was a trainee at the Delaware UCEDD. Thank you. Shout-out to the Delaware UCEDD. She's got specific interest in self-directed supports and intersectional social justice. And Jamie, Koenig and she comes from the Chicago community and has prior efforts in education access and workforce development. So you see their happy faces on the slides here with bullet

points about areas of our taking leadership in. So welcome to the new team. You've probably seen their names and emails.

And on the next slide, I do also want to offer some recognition for some directors who either have retired or are about to retire and incredible amount of work well done. Robin Hansen at the Mayan institute in California. Pat Morrissey in Hawaii. When I started here in AUCD in 2008, Matt Morrissey was just finishing her stint as Commissioner. Brent Askvig in North Dakota. And Wayne Stuberg in Nebraska. Stephen rock. Susan Hetherington and Donna Gilles in Virginia and we want to recognize. Who passed away in his sleep unexpectedly past year after Fred, giving many, many years of dedicated service to Alabama, to the sparks clinic in Birmingham and to all the network. Fred J. Biasini.

On the next slide, I want to welcome the new directors and our network. All of whom has a meeting buddy for this meeting if they had the opportunity to access a meeting buddy for this meeting since we're not in person. So please reach out and find them in the participants list in make them feel welcome. Sarah O'Kelley. Director of Alabama. Kiriko Takahashi who has been the Pacific basin and now interim director in Hawaii. Ran doll Owen, welcome. As the new director in Nevada after formally being the Associate Director in Illinois.

Erik Carter, co-director alongside Elise MacMilllan and Parthy Dinora is the interim director in Virginia. So welcome to everybody. I think this is not in person, but I hope that your meeting buddy helps and everybody on this call, everybody in our network wants you to succeed, and is willing to help you in any way possible. We have an incredibly strong peer support in this network. And you'll have fun tapping into it.

On the next slide, these 3 slides, I want to share an overview of the highlights of our TA activities we have underway. I'm not going to read everything on the slides. Again, you'll have this afterwards to click on things. Couple of things I do want to highlight on this slide, these fall into the category of Universal TA, these activities. So they're available for anyone in the network or out of the network at any time. What I do want to highlight, the little sub-bullet under the newsletter where it says public promotion request form to disseminate your updates. This is a shout-out to Anna Castilias on our form and response to all of you who had sent multiple emails at multiple times at request to share your awards and activities. And announcements.

And you can click on this button. It's on our website. You or your dissemination staff can click on there and submit your materials. It will go straight to our communications team. And we'll be able to include in these newsletters. I am keeping an eye on -- I'm trying to keep an eye on the chat. I can't keep talking, but I do realize I apologize, Lori, should have been included in the list of new directors in North Carolina.

Thank you, Lori. She's the Associate Director there for good number of years under Brent, and they have a beautiful succession. Other thing on this slide I did want to highlight also is under the bullet point for publications. The last piece there, the MOU library and analysis. This is related to the University UCEDD agreements, the memorandum of understanding or whatever type of agreement you might have with your University. The last time we did a full refresh of the library and the analysis of what is included in the MOU was 2008. So it's been a minute. And with the bulk of the large cohort of UCEDDs who will be writing their five-year application in the next couple of years, we wanted to make sure we get this updated for you. So you can keep an eye out when we send out requests for MOUs later this year. It's for that purpose.

On the next slide, listed are targeted TA activities. So these are targeted to certain sort of subpopulations within the audience of UCEDD's specific topic areas that are merging from the disability field within the UCEDD network or priorities of administration on intellectual developmental disabilities. On this slide, I do want to highlight our staff Natalie Martinez did a wonderful job of updating the data coordinator's orientation.

These are online learning modules that are in video format that are available at all times when you have a new data coordinator. Natalie can help them walk through these. But these are videos available so they can get detailed instruction on every single component of using NIR and able to track data coordinator when they work through each of the modules and when they work through all of them, we can send a certificate of completion and UCEDD swag and including the coveted newest hat. And when they are big, and they have faculty for data, that hat can come in handy at times.

And the other thing I want to point out on that page for a moment, sorry, is the equity diversity and inclusion action plan. This has been something that has sort of shown up in bullet points in these updates at these meetings for several years now. I do want to -- I recognize the authors of the equity, diversity, and inclusion action plan network. Dave, Barbara Wheeler, Torara Goode. And this work is years. This has been years of planning and implementation. And there was a significant delay in receiving approval for the final action plan to be disseminated to the network. But I really want to take a moment and thank the authors for making sure the plan was so closely aligned with our guiding legislation. With the DD Act. As we were doing our best to influence the prior administration to approve the plan and let us disseminate the plan and move forward on the plan, I truly believe that the reason that we got a yes from them is because it aligned so well with the legislation. There was no argument that it was relevant, valid, and needed. So I wanted to share that. Katie Johnson will be in touch and is leading efforts to implement the action plan right now with sort of building coalitions and interests, and in different groups across the network, leading up to implementation. So you'll see more about that coming in this year.

On the next slide, we've got our intensive TA. These are sort of where we dig in deep. Obviously, our COVID-19 response falls into this category. And also our individualized TA where we might work with you over a long-term to address, you know, where you might want to grow your UCEDD and grow and support the new director transition. We can work with you to really make some customized sort of long-term level term of TA you want. So I wanted to highlight that.

On the next slide, I'm going to hand it over to Natalie Martinez for a few minutes to touch on this topic of interest.

>> Yeah, thank you, Dawn. Can you all hear me? Good. So we are -- UCEDD is transitioning to a new 5-year guidance report. Final progress report guidance has been updated. Logic model has been updated to reflect the new intermediate outcome measures. This new logic model is now available on the URC website. There was a public call for comments, I believe, in spring of 2020. And, finally, I would like to thank the final report workgroup of MacMilllan and Dan Zine. Thank you for your hope. The important thing, annual, PPR template and five-year template have been combined into the same document. So you will want to double-check and make sure when you're going through that to make sure you're looking at the annual portion or the five-year reporting guidance.

And the good news is no changes in reporting for this fiscal year. Now, in NIRS, we have made couple of changes and like data entry. So we have added a new question to the training follow-up survey. And this question is from the five-year template that was, you know, recently released. So, the new question is, have you applied the knowledge and skills learned in the training program one or more times? So again, this has been added to all of the online survey for the former trainee and the paper form has been updated on the anywhere resource page. And, finally, we're working on the five-year progress report for UCEDD. This is in progress of being built. And will be in launch August with the new iteration of NIRS. And last but not least, due to being in COVID and how it has affected data and things that the network is doing, we are in the process of adding a COVID-19 check box for progress and activity and datasets. So if something is COVID-19 related, you can check on the check box that it is. And because of the new check box we're adding, we're also building a COVID-19 standard report that will be available for each center. Thank you.

>> Thank you, so much, Natalie. You can look forward to an excellent webinar from Natalie when that 5-year report is launched. We do recognize there will be five years of data collection that are required before the new format will be able to be submitted to OIDD and we'll be working closely with our project officer, Pamela O'Brien this year to plan that out. So there will be more information coming about that. And thank you, Natalie, for all your work in NIRS and data coordinators. Couple of save the

dates on the screen for you now. Our virtual TA institute is coming up early March and April. I believe there are save the dates in your calendars already. If not, here are the dates. And then I think the next slide is really just an update about what else we're going to be doing in this meeting in our time together today. When I finish talking, in less than a minute. There will be a panel on vaccine considerations through the IDD population and I want to thank Emily Graybill and Suzannah Iadarola and then we'll hear from John Tschida and details about the details and administration and what it means for the executive branch that we're working with and other considerations. And then finally, we'll have Roundtable discussions that will take the form of breakout groups.

So, with that, I'm done speaking. And I'm happy to turn over to Emily and Suzannah.

>> Thank you, Dawn. Hi, everybody. We're excited to offer some live and critical conversation today related to the topic of vaccine in the Disability Community. I'm Suzannah Iadarola. And I'm co-facilitating the discussion. And we have an excellent panel today that includes Kara Ayers from the University of Cincinnati. Max Barrows and Kathy Kinlaw from the Emily Center for Ethics. And we're going to do abbreviated introduction and dropping their full bio into the chat. Each panelist will have about 7 minutes to Apse questions. And then we'll have 9 minutes for open questions from the participants at the end. So feel free to use the chat function for that. And I'm going to turn it over to Emily who is going to introduce Kathy who will start our panel today.

>> KATHY KINLAW: Great. Thanks, Suzannah. And I am struggling with my copy and paste feature in the chat.

>> I'll work on it.

>> Thank you. So I'm really pleased to start off this panel with some questions and answers from Kathy Kinlaw and she's going to put the full bio. Kathy currently serves as member of the Advisory Committee on immunization practice or the ACIP COVID-19 vaccine workgroup. And previously, served as a member of the CDC ethics committee of the Advisory Committee to the CDC director. So I'll go ahead and get started with the questions for Kathy. So Kathy, welcome. And the first question that I have for you is going to be a combination of 3 or 4 questions. So that are all related and so I'll go ahead and read all of those to you now. So what is the role of the CDC Advisory Committee practices and the decision-making about vaccine prioritization and distribution? And what ethical principles guide this process? And just another question that I'll add to that, because it may be related to your answer is what is the targeted outcome of the vaccine distribution preventing death or preventing spread? And how has this targeted outcome influenced recommendations for vaccine prioritization and distribution?

>> KATHY KINLAW: Great. Lots of questions. Thank you for the invitation. I'll try to answer few of those. And I have couple of slides, but it might be easy for me to answer them out loud and show you something later if that comes up. So, yes, the advisory committee for immunization practice is a group that is charged with actually making recommendations for not only the tiering or the distribution or the phasing vaccines, but also actually recommending particular vaccine candidates for approval. And so, I'll make a dissipation between that group and the group that I've been on is actually been the COVID-19 vaccine workgroup. And our group, actually does a lot of the background work and sort of explores all the research. Actually meets with the vaccine manufacturers for information. And then we actually try to propose recommendations for the ACIP, the advisory committee for immunization practice. And we've been meeting at least once a week for since may. And so it's a very important ongoing process for the ACIP and it's a pleasure to be participating in that process.

So, one of the things that we did early on that I was very pleased about as an ethicist is began to look at whether there were ethical principles that might shape our thinking about how to consider prioritization and distribution. And so we came up with four ethics principles. And I can show you shows later if you wish, but let me just tell them to you now.

The first is on maximizing benefits and minimizing harms. And so, this is really related to how do we respect and care for the individuals that we are hoping to support in the vaccination process? How do we use best available evidence? And we're, of course, promoting public health, but we're also hoping to minimize severely illness and morbidity and mortality for patients. The second principal is mitigating health inequities. So all things being equal, we really wanted to try to look at existing health disparities that exist in many populations and communities. And if the burden of COVID-19 itself would be adding to those inequities, we wanted to try to mitigate against that happening. The third principal is promoting justice, which is very closely tied with health inequities. But we really wanted to avoid barriers to COVID-19 vaccination, for example. And then the last principal is promoting transparency. So to the degree we can, we want to make sure that all the ACIP is open. And there's an ACIP meeting going on as we speak and it's been going on for most of the day. It's open to the public and people can make comments. And as we talk about vaccine distribution just as you are today, we want to encourage people to ask questions if to understand as much as possible. I wish that we had even more opportunities for stakeholder engagement or Community Engagement. As we normally do in a lot of processes, but COVID-19 has been such a rapidly evolving process that we -- I have not as an ethicist seen much Community Engagement as we sometimes see in other arenas. And then I think this may be your last question in this bunch. But, as we're thinking about what are our outcomes? Where are we thinking is our goal in terms of coming up with phase and recommendations for who would receive

the vaccination early on? And there are actually several that came into our thinking. But we certainly started with the maximizing benefits, minimizing harm principal. And so, in essence, what we were trying to look at was how do we actually reduce COVID-19 infection? How do we really try to reduce severity of illness for individuals? Including hospitalization and death. So that's was very much in our thinking from the very beginning.

In doing so, if you will remember the first one A tiering involves healthcare personnel. And people living in long-term healthcare facilities, and we may want to talk more about that. But in those populations, we're actually looking at individuals who not only are at-risk of infection and morbidity and mortality, but also we're trying to help support individuals in terms of healthcare professionals can actually help preserve essential services that will allow us to care for patients. And be involved in the overall COVID-19 response.

And then other essential services that help society sort of at large continue to function. But we began with the intent to reduce infections occurring and reduce severity of illness and death. So, long answer, but I hope that helped.

>> Thank you, Kathy. I'll ask the next question now. How has the committee discussed vaccine prioritization for individuals with intellectual and developmental disabilities?

>> We had care in mind for particular population and particular communities where you know, there would be risk. Particular risks. There's vulnerability and there's risk. And so, even in the long-term care facilities, so the very first tier, 1a tier is what the CDC calls it. Long-term care facilities as defined by national healthcare safety network at the NHS, and is very much in inclusive of facilities and including intermediate and chronically disabled if ill individuals, that's been very powerful. And if you look at a lot of the CDC, webpages or other presentations related to tiering, you'll see very clearly identified that individuals with developmental disabilities are part of this understanding of long-term care facilities. Now, having said that, I'll say couple of things. One, not everyone with a developmental disability is in a long-term care facility or in a facility at all.

And so, again, one of the realities of coming up with the phases has been a recognition that we're in an interesting period where despite the fact that we actually have too little vaccine, right? We want more vaccine in the country at large. Right now, we are given the fact that we expected that demand would exceed supply at least initially, we had to come up with some ordering of what we thought was first. And then tier 1 being a tier 1c. So the intent is for everyone to get the vaccine was where we start was the question we were looking at there. And the other thing I want to say, we may want to talk more about this as well. There's been a lot of variation in the ways in which

states have actually responded to the recommended phases from CDC. There's a lot of variations in state interpretations. And so, I think we've seen some differing responses in terms of particular communities that we hope will be thought of very highly in the prioritization schemes and states. But states have responded quite differently. Where a.

>> So I think we've all seen very publically, there's been a lot of polls taken along the way, all through the last ten months or so about the readiness for people to take the vaccine. And so, there has been a lot of vaccine reluctance, or vaccine hesitancy. But it's been reported. And the population at large and in healthcare professionals as well. And much of the hesitancy has been at least reported as people feel like they may not have enough information about the vaccine, because the timeline for development and moving forward with emergency use authorization has been so much quicker than vaccines in the past and have gone for full licensing. So it is important to know that every phase of the vaccine approval process for emergency use though has been done, but that concerns people. People are concerned about this being kind of a novel instrument for vaccine delivery. It's not the usually viral delivery system. So that's raised questions for people. And a lot of people I think have said, you know, it's not that we're not interested, but we kind of want to wait. We want to see what the reaction is going to be. We're concerned about side-effects. And we want to learn from others. So there have been real reasons that people, I think, have been hesitant. And we may want to talk later. But I feel very strongly about acknowledging people's concerns. And how we might go about thinking and communicating vaccine hesitancy. Also, I will say there's been a good bit of usually the distinction is made between misinformation and disinformation. And so, misinformation would be where information is spread that is actually not correct. But the person spreading it actually beliefs it to be true. So they're just providing information, but it may or may not be accurate. Disinformation is where information is spread that is not true and the person who is spreading it knows it's not true. Right? So I think really thinking about where information is going out, what kind of information is it being thankful about that? And I also want to very much recognize, as an ethicist I feel strongly about this. I feel historically examples of people being mistreated and there were a lot of atrocities related to particular populations and communities that have led to distrust. And I think we need to really acknowledge that very seriously. And take that into account in terms of addressing and helping people think through vaccine hesitancy.

I think along with the actual phases or tiers, that there are really important aspects of how we actually distribute, and how woe make the vaccine accessible to individuals. So the process, the procedural ethics here is just as important as the information or the actual people in the tiers or the information about a particular vaccine. And I think we have a long way to go to make sure we have processes in place that allow for accessibility.

>> Great. Thank you very much. Important information, Kathy. Appreciate you responding and sharing. I'm going to turn it over to Suzannah now who will introduce or next two panelist.

>> Thank you, Emily. And thank you Kathy for your insights and particularly for your reflections on multiple facets of inequity which we know is so important to this group. We're going to transition and talk to Kara Ayers. She's the UCEDD director. University of Cincinnati and healthcare for people with disabilities. And her interest in disability identity, bioethics, community inclusion, and thank you so much for being here with us today.

>> KARA AYERS: Thank you for inviting me to be part of this.

>> SUZANNAH IADAROLA: So can you share about what UCEDD is doing, related to vaccine, related advocacy, and potentially thinking about what Kathy shared about inequity, whether there's specific points you like to make about that also.

>> KARA AYERS: Definitely. I'm glad Kathy gave that perfect introduction, because it definitely relates. So our UCEDD is part of a collaborative effort. Center for dig fee and healthcare for people with disabilities. Along with four other UCEDDs, Marilyn, Vanderbilt University of Kentucky and human development institute and also the bog center. But in addition to our five, we collaborated with number of UCEDD across the network not only on the COVID work, but as I was looking back at what UCEDD contributed, I thought they fell into two buckets. One being the bucket for vaccine knowledge that we try to either create or connect to that's an accessible form. And we hope that vaccine knowledge will reduce some of that vaccine reluctance and increase acceptance and overall just understanding about what the vaccine does. And it's important to our community. So tools we've developed for that have included social story, but also some plain language materials that if we haven't developed, we disseminated incredible tools that other groups have. And in a second bucket is work around equitable vaccine allocation. So a number of us that are part of this center, we also have a workgroup that we've kind of gathered from all sorts of different groups, but several of us sit on other task forces that make or contribute to these allocation decisions. And we've definitely noticed a struggle to actually get towards equity instead of equality. So we notice a trend in decision-making is being made around one metric. So maybe around just age. Which all of which leaves out people in that age cut off who have developmental disabilities. Or it's being made around risk estimates to exposures. So some people who get their vaccines through an employer, one metric being considered is risk of exposure due to patient exposure. So that is, I think, being misunderstood as an equitable approach when that's more like equality. Many of us seen that visual of either the 3 kids standing next to the fence and they're each given the same box. If the kids vary in height, that box is great for one kid but not another.

There's a similar image from the Kaiser family foundation that was a bike. So everybody is given a bike. But if your leg is too short for the bike, it's not going to help you much. True equitable allocation would be considering different types of bike that would work for different needs. So we really need to do that in the vaccination process as well and consider multiple metrics as these prioritization kind of structures are made. And so, we've contributed that perspective on a number of workgroups. But also in trying to get this information out, which has really required all hands-on deck approach through social media and through different newsletters. We've worked closely with not only our DD network partners but also our wider ACL partners and that's been helpful to kind of leverage each other's strengths. But I'm also reminded that we need to remember the people not formally attached to any of these organizations, services or systems. Because that group, I think is potentially most at-risk to fall through the cracks. So I'm trying to echo that alarm as well to remember even if someone is not signed up with a county board of DD but they have a developmental disability, how do we include them in this planning process?

>> SUZANNAH IADAROLA: That's wonderful. Your team is so engaged in the efforts. So based on your own personal experiences and your group, what standout to you as primarily opportunities for related efforts?

>> KARA AYERS: Yeah, I think there's so many opportunities really across all. I thought across all four of the core functions. I think Continuing Ed training is important. Because we have so many people that are working closely with people with disabilities that have these high rates of vaccine hesitancy or reluctance and that in itself is a potential long-term danger to our communities. We still have a lot of unanswered questions about transmissibility after receiving the vaccine. So even if we have higher rates of vaccine acceptance among people with disabilities, if they're exposed to people who are not and working with them. So continue to go work around that issue. We also have to keep listening for these issues that six weeks ago, we wouldn't necessarily have predicted. One that popped up recently has been we're hearing that there's some increase use of restraints around administering the vaccine with people with intellectual and developmental disabilities. So we're trying to develop some guidance and listening to stakeholders and determine what tools can help people reduce or eliminate the use of restraint when administering these vaccinations. So I know we're short on time, but thinking across all four core function easier. There's policy analysis work that could be done. We have our disability data problem of states looking at us and saying, we want to prioritize you but show us the data. And we're penalized by the fact of being at a disproportionately lack of data because it's not collected on the health side of things. And I think I've mentioned some technical assistance that could be provided to make the distribution efforts accessible on a local and state level. And then finally, just ongoing

need for information dissemination, using multiple methods and really helping each other cross-pollinate, sharing what we're doing.

>> SUZANNAH IADAROLA: And I think those examples highlight how it seems like right now, our primary challenge is an ever-changing landscape. Thank you. So our last question is related to, I think many of us confronted the fact that state guidance for vaccine distribution might not align perfectly or might be contrary to CDC framework for equitable vaccine distribution. I think your points about conflating equality and inequity is an opportunity for advocacy at the state level. Thinks anything briefly you would add to that?

>> KARA AYERS: Just that I think your, I have more than just thinking, we are analyzing all 50 states to compare overall themes and approaches. And it would seem so far in our early analysis that most of them align with the CDC framework. So I think providing concrete advocacy training in your state-specific to your state guidelines would be extremely helpful, because advocates could pick that up and join you. And think, too, about the ripple effect if this was someone's introduction to advocacy, it would be just an excellent opportunity to make an impact and see how it works. So providing that concrete training that was specific to your state would be an excellent way to plug-in. Your that's wonderful. Thank you so much. I was taking notes as you were talking.

>> SUZANNAH IADAROLA: Thank you so much for joining us today and we'll look forward to your engagement on this topic in the future. Now I am delighted to syllabus Max Barrows who is the outreach director of Green Mountain south advocate where he works with truly people with inclusive and disabilities. And this work shares the message when you meet an individual with a disability, presume competence. It's very relevant to this conversation. Max is currently serving in the role of advocacy faculty for the Vermont LEND. And we're especially grateful he will share his advocacy and passion with us today. Welcome, max. So our first question for you, what are the primary concerns? And topics of confusion that you are hearing from self-advocates about the COVID-19 vaccine?

>> MAX BARROWS: Well, I have 9 issues to describe on this session. Just like most Americans, self-advocates are trying to understand when they will be eligible to get a vaccine. Number 2, one barrier we have been facing all along is having accessible information about COVID-19. Most people with intellectual and developmental disabilities struggle to understand medical information in general. And another challenge is keeping up with all of the changes. So once it is our turn, to get vaccine, we need clear information about how to sign up.

Please remember that many people with intellectual and developmental disabilities do not get home and community-based services. We as disability advocates need to

make sure the process for getting a vaccine is easy for people who have difficulty reading, have no access to the Internet and rely on public transportation. Number 3, self-advocates recognize that if they have a guardian, they will need their permission to get a vaccine. We wonder how that will be handled when registering for the vaccine.

Number 4, we have been having vaccine conversations weekly since December. Some people with intellectual and developmental disabilities are still confused between getting tested and getting the vaccine. Also several people are confused about test results. Some people continue to think that a positive test result means you're okay and you are good. They're mixing up what it means to get a positive or a negative test result. Number 5, self-advocates are having a hard time understanding why their staff are getting the vaccine before people with disabilities are getting it. Number 6, people are intellectual and developmental disabilities are being bombarded with so much nonscientific information about the vaccine.

We need clear information based on science. It is hard to differentiate between opinions and facts about the vaccines. And we are constantly hearing opinions on social media from family, support staff, and friends.

Number 7, we need to keep reminding people that wearing a mask is more about protecting others. there are other things we must do to reduce exposure to the virus. Keep reminding people all of the many steps they must, you know, they must take to be safe. Number 8, it has been scary people knowing in congregate setting that have died from COVID-19. Make sure that people are getting the emotional support they need to deal with friends who are dying.

And number 9, finally, I'll say the medical system has many strategies for supporting people who are afraid of shots. And these strategies must be used for COVID-19 vaccination.

>> SUZANNAH IADAROLA: Thank you so much, max, for those important extension of the raised by the panelist if bringing us back to the emotional care that was made at the very beginning of the meeting. So the next question for you. What has the self-advocate community done to help address these concerns? And what still needs to be done in this area?

>> MAX BARROWS: So, star tech, and that is the national self-advocacy center. And starting in March, self-advocates have been facilitating two meetings using Zoom a week. Peer leaders from up to 40 states are participating. We have had several sessions about the vaccine. Other things we have, we have produced a plain language booklet, a plain language booklet about COVID-19 vaccine that is available at this website. Self-advocacy info.org. That's actually our star tack website. And please be aware that this booklet is part of a series of plain language guides we have produced.

And please check out our resource called a guide to COVID-19 for self-advocates. That's what it's called.

We recommend that advocates in each state make sure public health information is in plain language. Offer opportunities for people with intellectual and developmental disabilities to have informal sessions with ample opportunities to ask questions. And these sessions need to be run by self-advocates. We appreciate the guidance from professionals, but having a peer in charge makes it easier for us to voice our concerns.

And this is great opportunity for UCEDDs to work as equal partners with the self-advocacy organization in your state. And, finally, I want to thank each and every one of you for taking the time to share plain language information about COVID-19 created by star tack and Green Mountain self-advocates and many other self-advocacy organizations.

>> SUZANNAH IADAROLA: Thank you so much for all the work that you've done developing those resources. And many of you might have seen that links to the resources are dropped in the chat as well. So we have one final question for Max. What could our University and medical communities could do to better support the vaccine efforts and help decision-making for people with disabilities?

>> MAX BARROWS: University and medical communities need to make sure state health departments are listing, listening to people with intellectual and developmental disabilities. That's the first thing. Second thing is as medical entities, you can make sure that strategies to help people who are afraid of shots get put in place for COVID vaccinations. And, number 3, self-advocacy organizations have limited budgets. And you can help us out pie supporting us to get our information translated into languages other than establish.

>> SUZANNAH IADAROLA: This is terrific information. And I'm not sure if you can see the chat. But there are many thank yous. And complements going into the chat for you as well. Thank you so much for being with us today and offering your insight into our responsibilities and potential roles we can play in our communities.

>> MAX BARROWS: You're welcome.

>> Thank you to all our panelists. This was, I promise something that was lively and engaging. And I think you definitely over delivered on that. I think because of the time, we might skip the verbal Q&A. Is that right, Dawn? Would that be most helpful? Okay. If you have additional questions for our panelist, if our panelist can stay on the meeting, I'm happy to gather them from the chat box and consolidate them and send them out later so your questions can be answered at some point. And I think with that, I will thank Emily for co-facilitating and turn it back over to Dawn.

>> DAWN RUDOLPH: Thank you so much Emily and Suzannah. And panelists, that was a really wonderful discussion. I am very happy to introduce John Tschida. Most of you know John. He's our Executive Director at AUCD. And I must say it's been an absolute pleasure to work with John this past year in the role of Executive Director. It has been a hard year for everyone, as we know. John, our team, our staff is so grateful for your very thoughtful, I don't know what the word is I'm looking for. Measured, thoughtful, careful, supportive efforts for all of our staff this year. Thank you.

>> JOHN: Thanks, Dawn. Greatly appreciate it. I'm going to spend just couple of minutes talking about the transition to the new administration. I know number of you have been through this process before. But many of you haven't. I can run through a few slides and allow time for questions. And I know Rylin is also here to answer questions as well. next slide, please.

So we're exactly one week in to the Biden Administration. I'm thankful the day of the inauguration was itself a peaceful transition of power. With this comes a significant and fundamental shift in governance philosophy. A very different view on the role of the Federal Government. And that is already been very pronounced in the appointment process and there are many powers that come with being in charge of an administration, control over the executive branch is certainly one of those primary powers and one of the key levers. You have the power to appoint leaders and the philosophy of the President. The Trump Administration with a different philosophy of government left many, many slots unfilled. The current administration really has referred to this as a rebuilding of many federal agencies from a capacity standpoint. And when we talk about political appointees, what are we talking about in terms of volume? As you can see here, there are more than 2,000 political appointments. Little more than, or little less than third of them need Senate confirmation or permanent status. You can appoint someone in an acting role and they can serve for six months or 210 days, whichever is longer. The previous administration used acting, often a series of acting, individuals rather than have to go through the process of Senate confirmation that is not the approach that we are seeing with the Biden Administration. They have been aggressive in their appointees to date. And virtually every cabinet and assistant secretary level appointment has been made. So it is their intention to fill many of these slots and to try to fill them quickly. Next slide, please.

So, if we look at other levers of power or control and influence that administration has. Judicial appointments is certainly one of them. Yes, they need to be confirmed by the U.S. Senate. The President still has the authority to nominate those positions regardless of who's in control of Congress. We know as a result of the Georgia elections, we now have a tied Senate that's 50/50 with the Vice President able to cast the deciding vote so that that become necessary. And of course, not just nominees to the federal bench, but to the Supreme Court as well.

Executive orders and I'll dive into this a bit. But these are directives from the President that carry the full force infect of law. They do not require the consideration or approval of Congress. And President Biden has already issued a few dozen of these. Similarly, if we look at regulatory authority, that goes with control over the executive branch rule-making, which is one of the dullest most drawn out bureaucratic processes known to man. There's a reason the word red tape exists. But it is a significant power. And gives by virtual of his appointees, gives the President the ability to put people in positions who share his philosophy of governance in the key roles in order to determine how federal programs and services are administered. And you can see couple of issues here. I'm not making judgment or these or partisan, but Medicaid for work requirements was a hot issue that was done through the rule-making process. As was some of the immigration policies and significantly controversial immigration policies. There's localities of other appointment power the President has. Commission, panels, U.S. attorneys in every state. Many others. But these are the highlights here.

Next slide.

So, executive orders. What are they and why do Presidents lean on them? As I mentioned, they do not require any Congressional action. They are often a trigger for future Congressional action if Congress doesn't like what it is the President has done or has tried to do through an Executive Order. We often see them challenged in the courts by stakeholder groups and stitch see that do not agree with the executive orders. But, really, they are designed to reverse previous policies and we've seen that in a number of Executive Orders coming from this administration. Where are they signaling priorities or key areas of focus, where the President in the administration wants to take action immediately. I've listed some examples here. I will not read through them. Something I should have had first on this list because it directly affects our lend program and the curriculum that they railroad responsible for enacting as well as many of our UCEDD from our training capacity. And that was an Executive Order from Biden. The first day of his presidency, it had a rather vague title advancing racial equity and support for underserved communities through the Federal Government. But there were many, many elements of this Executive Order that were rolling things back things done by the previous administration as part of that Biden revoked the Executive Order that talked about combating race and sex stereotyping. That was the Executive Order that printed contracts and subcontractors providing thorough workplace diversity training and programs.

So, the prohibition on things like bias training. Diversity training. Diversity equity and inclusion, many of the prongs of the plan that was developed by UCEDDs and that has been approved by the department, and that we have been promoting many of the elements in there. That has since been rolled back.

Next slide. As I've mentioned, if we look at key appointments that effect the network in particular, what has been done to date. I mentioned all cabinet secretaries have been nominated. Most assistant secretaries. Couple of key roles with the Administration for Community Living. Alison Barkoff, a known entity to many of you. Certainly known to us at the aqua staff. Worked very closely with her and her role for the center for public representation. She's an attorney. She was an attorney in the Obama Administration. In the Justice Department, a great advocate for individuals with disabilities. Broadly, but certainly for the IDD community given the personal situation she has herself with her brother. She is the acting secretary for aging and administrator. Yes, there will be another name forwarded hopefully in the near future. The former are true to the New York who will serve in this role, Alison will become the principal deputy which is the number 2 within the Administration for Community Living. This was the position previously occupied by Mary Lesair for those who know and worked with Mary. And Lance Robertson, the previous assistant secretary now has moved back to Oklahoma. Alison is serving in both roles for now.

The new Julie Hocker, if we want to look at it that way. Reyma McCoy McDeed will serve in that role. She comes from the State of Iowa where she ran a Center for Independent Living. She will serve as the boss to Jennifer Johnson for those of you who know Jennifer who is the Deputy Director of the administration on disabilities. This is the hybrid role that was created with the reorganization of the department at that time, the Commissioner, the DD Commissioner role who has been historically present and also wrapped together with independent living role and the position no longer requires -- well, it does still require Senate confirmation. But IDD Commissioner combined with others. I won't run through these other names. I think these two names are the most important names for us to know. A will be meeting Friday with Alison and with Reyma with heads of the other two DD Act agencies, the DD counsels and the protection and advocacy group. They have reached out and want a meet-and-greet meeting immediately. Know that many of us are interacting with different parts of the transition. Rylin and Liz have sat in on constituent meetings with the disability meeting involving the newly nominated secretary of education as well as the newly nominated Secretary of Health and Human Services.

So what happens next? Quickly. They will begin subsequent cascading appointments going further down into agency depth. Key roles that are vacant at the Department of Labor. Office of Disability Employment Policy. NIDILRR within ACL. We're hearing names, we know people have been interviewed. Hopefully an appointment will occur there in the future. All of the major appointments within the Department of Education, within the Office of Special Education and rehab services. The assistant Commissioner level as well as overseeing the VR program and employment program with the rehab services administration. And the Office of Special Education

policy as well. We know the administration is moving aggressively and quickly. And the Obama Administration, it took many months for the sublevel appointees to be named. But I don't think we'll see that this time around. Next slide.

Top administration priorities. And these have been repeated. These are the talking points of all of the nominees that we have been hearing from. More nationalized approach to the COVID crisis, both the management and overall policy, but certainly looking to accelerate vaccine distribution and we've seen additional purchasing of doses in the last few days. Economic stimulus and recovery. Looking to quickly pass another initiative to get more dollars into the hands of those suffering the effects of the economic turn down as well as businesses and employers, and just a crisis management mentality to this entire situation. They are really bringing the sense of urgency and action and looking to everything they can as quickly as they can to make things happen. Next slide.

I mentioned Congress is divided 50/50. This gives President more flexibility, although with a whiskers breath of majority. There will be need significant compromises made. A lot of new relationships that need to be developed. If this is really where you come in as well. Next slide. We've got 9 new Senators. We've got 60 different representatives. We really need new folks to be developing relationships with those new members. Reaching out and talking about the values of the centers, especially with COVID context and all the great work you've done over the past year. They are looking for organizations to help them, especially, when their constituents need assistance. So we want our network to be that first call for help. We operate as pragmatist with Congress working on both sides of the aisle of disability. Disability is not a partisan issue and we talk about that consistently. Looking at these not as transitional relationships but long-term relationship. And if you have an existing relationship with these members, it would be great for us to know that, similarly with the new appointees as well. And I will stop, Dawn, and look to you for guidance as to whether we have time for questions or not.

>> DAWN RUDOLPH: Gosh, I'll put that question to Katie. I don't know, Katie, do we have time for questions?

>> We want to make sure to save much time in the breakout room. If you can direct the question to AUCD staff, we can connect offline. That would be great.

>> DAWN RUDOLPH: In that case, I think we're turning it over to Maureen to give us instructions for how to get to our breakouts.

>> MAUREEN JOHNSON: Yes, thank you, Dawn and John. Hello, everyone. My name is Maureen Johnson program specialist on UCEDD and NCH team and I'm going to cover some instructions before we move out to our discussions. So next activity, you will need to change your Zoom name to indicate your breakout room preference to

change your name, you would click the participants button at the bottom of your screen. Hover over your name and click the blue more button and select rename. And enter your name, comma, breakout room. Next slide, please. For breakout room discussions, we have number 1, taking a disability lens to racial justice. Number 2, engaging diverse communities in research activities. Number 3, emerging issues around telehealth. Number 4, supporting the social and emotional well-being of staff. Number 5, opportunities for HCBS transformation post-COVID. Number 6, State and Federal budgetary challenges. 7, navigating policy environments post election. 8, navigating changing dynamics. And finally number 9, sustain, the course. So please take a few minutes to review the choices and change your name. I know I ran through that quite quickly. But we do have the link to the PowerPoint that has the visual representation as well.

>> Welcome back to the plenary room. How are we doing on people coming back.

>> Everyone is back.

>> DAWN RUDOLPH: Welcome back, everybody. My apologies that the breakouts were slightly shortened. But I hope the opportunity to converse with your colleagues was helpful. I know I took some great notes and I learned a lot myself too. So I hope you did as well. Thank you for spending your time with us today. We are down at the bottom of the next 2 hours. We've been together for two hours. I definitely want to thank our Planning Committee, Emily Graybill. And Valerie Williams for helping us a craft and meaningful meeting. Did not mean to be all M's but there you go.

Also I definitely want to thank our federal partners, our project officers, and our team at the Office of Intellectual and Developmental Disabilities has been a tremendous champion through this past year and doing a great job with flowing information up and down from the community, through you, through us, to them and in the reverse. So Shawn Callaway, Allison Cruz, Jennifer Johnson, David Jones, and Pam O'Brien have been great champions. And I, not on the slide, but I definitely want to thank Katie Johnson for her efforts to pull together the planning committee, pull together the meeting, incredible attention to detail. Way to go Katie! Thank you everyone. We will have meeting materials and notes shared with you in the next week or so. Take good care. Take care, give care. Be well.