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National Center on Advancing  
Person-Centered Practices and Systems

## **Transcript: “Person-Centered Planning and the Pandemic, Tools and Approaches for COVID-19 and Beyond”**

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>> Hi, everyone. Welcome to the July NCAPPS webinar, Tools and Approaches for COVID-19 and Beyond. Next slide please, Connor. So, my name is Bevin Croft. I co-direct the center with Alixe Bonardi. We're glad to have you join us for this free, open to the public NCAPPS webinar. So NCAPPS is an initiative that's funded by the Administration for Community Living and the Centers for Medicare and Medicaid Services. And our goal is to promote systems change, which makes person-centered principles not just an aspiration, but a reality in the lives of people who use long-term services and supports across the life span. These webinars are part of our center's activities, which also include technical assistance and learning collaboratives and a number of other things. On the next slide, I believe we have a few logistics for you. This webinar has a chat feature enabled and we welcome and encourage you to use chat to engage with the panelists and with each other. If you would like to engage with all attendees on the webinar or have all attendees see a question or comment, do be sure to select "all panelists and attendees" just above the chat message, so everyone can see it. This webinar is being live captioned in both English and Spanish. The English captioning is available to you within Zoom, if you click the CC button at the bottom of your screen. And the Spanish captions are available in a separate window using a link that you'll see on the screen and is also entered into chat. You can go ahead and click on that link.

We have built in just a handful of polls, which include evaluation questions at the end of the webinar. And actually, Connor, let's bring up the first poll now, and see who is here. So, you should have a poll question popped up. Please select whichever roles you self-identify as in the poll so that we can get a sense of who's on today. And the choices are person with a disability, family member, self-advocate, advocate, specialist, mentor, peer mentor, researcher, analyst, government employee, hospital employee, or HMO managed care employee. We'll give folks about five more seconds to finish up that poll. Connor, if you could display the results, please. Okay! We got a good number of folks on today, which is fantastic. And I see that the largest group that we have represented here are social workers, counselors, or care managers. Great! And a good number of family members, government employees, other provider employees, self-advocates, as well. So thank you for giving us all a better sense of who's part of this community. All right!

So, a few remarks before we begin. We want to just put on the table that since March of this year our worlds have all been turned upside down by the coronavirus from changes in routines and schedules because of social distancing to the loss of loved



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ones this spring and summer have been some of the most disruptive and unsettling months of our lives and there's no clear end in sight. At the same time, it's important that we acknowledge that health and wellness are socially determined and therefore social justice and wellbeing are inseparable. This spring we witnessed the murders of Black Americans, George Floyd, Ahmaud Arbery, and Breonna Taylor, and others. And we're now in the midst of a reckoning. Black people are almost three times as likely to be infected and to die of coronavirus than white people. This is a powerful reminder that the coronavirus and the move for social justice are all part of the same historical moment. At NCAPPS, we've been thinking about how we can promote wellbeing and social justice within long-term services and support systems. We are really hoping to work at the intersection of disability and race, and to better understand the roles that culture, trauma, and all of the isms play in person-centered thinking, planning, and practices. In the coming months, we are looking at rolling out events and resources to further these goals, and we are also continuing to listen and to learn from our community about how we can do more as NCAPPS to contribute to a more equitable and just society.

So, today we are carving out one piece of that conversation. And we're going to talk through how we can use person-centered planning tools and approaches to understand, cope with, muddle through this moment in history.

We've got a wonderful panel of experts.

And they'll be responding to a series of questions moderated by my colleague, Alixe. We hope you come away from this conversation with new resources, strategies to try out, and some insights about how we can emerge from all of this stronger and more connected than ever. Before I introduce the speakers, I want to share a couple of NCAPPS resources that might be useful to you after the webinar. And the links will appear in chat. But on our website, [NCAPPS.acl.com](https://ncapps.acl.com) there are two newish pages. The first is our COVID-19 resources page, where we really tried to curate tools and resources that are specific to COVID-19. On that page, you'll find a healthcare person-centered profile, which is a single front and back page form that you can fill out that will contain the most essential information that you would want a healthcare professional to know in the event that you're hospitalized for COVID for a hospital emergency. We have also worked with experts, including experts on the panel today to create a number of examples of filled-out healthcare profiles of people kind of with a range of backgrounds so you can get a sense of all the different ways that this tool might be useful. So definitely encourage you to take a look at that, consider incorporating it into your work or your life or your planning. And then also on that page we have a number of other videos, tools, resources for all different scenarios that people may find themselves in, whether that's social distancing or planning in the event of someone becoming ill. You know, adjusting to life as we know it. So, that's the NCAPPS COVID-19 resources page. The other set of resources I wanted to call your attention to is our NCAPPS shorts page, which is called wisdom during the pandemic. This is a series of videos. We're adding more every week or so, where we've engaged



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subject-matter experts throughout our network to reflect on how we can learn lessons from person-centered thinking, planning, and practice, to sort of cope with the pandemic, how we can ensure that we remain committed to person-centered principles at this time, and even how we can sort of use this time to strengthen those principles. So, those two resources are there and hopefully you will avail yourselves of them. So, let's get started. I will now introduce our presenters. So, the next slide please, great! So, we have today, let's see, Amye Trefethen. Amye lives with bipolar disorder, and has several family members who have disorders. Chacku Mathai works with the SAMHSA grant in New York and at Columbia University. Michael Smull is senior partner. He is a co-developer of essential lifestyle planning. Jenny Turner is member of the Life Course Nexus Team at the University of Missouri Kansas City institute for development. And Janis Tondora is associate professor at Yale and is an expert in person-centered recovery planning. So we are incredibly happy to have this panel of experts assembled for you, and I will turn things over to Alixe.

>> ALIXE BONARDI: Thank you, Bevin, and hi everyone. This is Alixe Bonardi. As we move into the next section of our webinar today, we are taking a moment to think about the frames that people bring. We will, I'm going to read this poem just to get started. And this is something we'll talk about for a few minutes with our panelists. So frames are both windows on the world and lenses that bring the world into focus. Frames filter out some things while allowing other things to pass through easily. Frames help us order, experience, and decide what action to take. Now, this is taken from Bolman and Deal's book, reframing organizations. And extending from this quote, and taking forward some of the ideas from Bolman and Deal a little further, we recognize that positive change happens through leadership, that considers and draws for multiple lenses or frames. And given that, we are asking all of our panelists today to recognize that each of us brings experience, expertise, and particular point of view or frame to this moment. And so we'll be asking our panelists to briefly introduce themselves and share how we frame, how you frame this moment in history.

Just a word about how we're going to be going through the next section in the panel discussion, I will be leading through and just calling on our panelists. We have five excellent panelists with us. And this will just help us go through. And given that we have lots to say and limited time, I'll probably just be moving things along. So with that, I will say one more thing for those of us who were joining us through this webinar, we will be bringing the slides down, taking the slides away for much of this part of the discussion so that you can see people a little bit more directly. If you're using the Zoom platform, you can toggle between speaker view and the gallery view by going to the top part of your screen and up towards the top right of your screen. There should be an opportunity to choose speaker view or gallery view. And with that, I will ask our first panelist to answer this question. Can you briefly introduce yourself and share how you frame this moment in history, and I'm going to start with Michael Smull.

>> MICHAEL SMULL: Thank you, Alixe. As you heard, I'm Michael Smull. And I've been working with People with a variety of disability labels for the past 48 years. And the frame that we're using got started well over 20 years ago as we were asked to help



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people leave institutions.

And we were asked to help people leave institutions in order to go to real lives in the community. And in order to do that, we had to understand how they wanted to live the day after they moved, actually the day they moved. Not try to discover how they might want to live six months later, but move into their view of a desired life. To do that, we had to learn what mattered to them in everyday life? What mattered to them in routines and rituals and relationships? And we also needed to figure out how to balance that because all of us make tradeoffs. And all of us are also seeking a balance between what matters to us and issues of health and safety. And the people we were helping move were people who had not had an opportunity to do that kind of reflection, to do that kind of thinking. And so guidance was provided. Learning occurred. And that learning was then recorded. We started thinking about that from the standpoint of looking at what's important to and what's important for. What's important to is what helps you be satisfied, content, comforted, happy, important for health and safety, and be able to describe that balance. But it's a focus on the immediate frame. How would you like to live tomorrow? How would you like to live the day after? And it informs a dream, but it doesn't describe the dream. It also gives you a way to reflect. Because what's happened with COVID is your choices, the boundary on your choices have suddenly changed. They've shrunk. And so what does the new balance look like? And when you think of all of the things that are stirring with the quest for social justice, it also gives you an opportunity to say what is really important to you. What matters to you and how is that going to change your behavior? So that's the frame that we use.

>> ALIXE BONARDI: Thank you, Michael. Next I'd like to ask Chacku to introduce yourself.

>> CHACKU MATHAI: Thank you, Alixe. While, in the introduction, I have a title, but I'm also an Indian, an immigrant. I came to the United States in '70s, and very quickly experienced xenophobia, people who did not want people of color in their neighbors, for taking their jobs, and being in their churches, and being on their sidewalk.

Experiencing a sidewalk that rejected me, I've been called ever since to transform that sidewalk. Not to change me, there was nothing wrong with me. The issues that I experienced, whether it was the bullying, the assaults, the hostilities towards my family and myself over the decades to that time. Even before I was 15 years old, I had attempted suicide, and dealing with voices and hallucinations, and overdoses. And the frame they wanted and the frame that my family wanted to experience from one person was one of personhood. That restored our sense of personhood, that every dehumanizing experience that we had experienced up to that point would somehow through the words and collection of experiences with a person and with a group of people, that they would actually work towards our liberation with us. Instead, we found at best neutrality. And a willingness to see change. Neglectful or in deniable or ignorant. And to need to assimilate. That was the wrong frame. So I come to you today with a frame that says we need at this time and we've also needed to be anti-racist. Not "not racist." It's not a duality of I'm racist or I'm not a racist. It's either I'm racist or I'm an anti-racist. And understanding racism as a collection of policies that are very powerful and justified by racist ideas. There are racist ideas that justify the



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tools that we choose. So, I'm really excited by even Bevin's introduction today that says we're going to be looking at every aspect of it. Means a lot to me and my family. Thank you.

>> ALIXE BONARDI: Thank you, Chacku. Next, I would like Janis to introduce yourself.

>> JANIS TONDORA: Hello, everyone. I'm joining you from a quiet corner of my house here in Connecticut.

And the frame that I bring to the webinar today really reflects a range of both professional and personal experiences. And as the quote that Alixe in the beginning reflected on, sometimes those frames can be limiting, and sometimes they can be enlightening. Professionally, I'm actually a clinical psychologist, and I've been at Yale for about 20 years, but I started off my career in a broader disability advocacy role after a family member sustained a head injury. I've become increasingly aware over time that aspects of that professional frame focuses too heavily on diagnosis and putting people into boxes without appreciating their own subjective understanding of their situation and how they want to handle it. And then another frame that I bring really comes from a more personal experience, where I developed a different and probably honestly a deeper type of expertise. When I was diagnosed about five years ago with a brain tumor. And that actually led to a pretty dizzying journey trying to navigate the healthcare system. It involved multiple specialists and surgeries to address the problems that I was having. But throughout that time, I had my voice and my choice really robbed from me more times than I would like to admit. So, as you might imagine, that personal experience has had a pretty profound impact on how I view what it means to be person or patient-centered, and how professionals really truly partner with people. So, the frame I bring today is one that really represents a collision of my professional and personal worlds, and the current point in time, with all that we're bearing witness to with the experience of the pandemic and the perpetuation of racial inequities, I'm really glad this conversation is happening and looking forward to being a part of it.

>> ALIXE BONARDI: Thank you, Janis. Amye, we'll love to hear from you.

>> AMYE TREFETHEN: hi, everyone. I have professional experience, but more in the peer universe. I think I'm bringing the frame of a person who lives with mental health challenges, and also parenting a child that has mental health challenges, and also autism spectrum disorder. And for me, the person-centered planning tools at this time have been a life preserver. I have experienced some trauma in my own personal life. And it's really easy for me to have suicidal thinking and thoughts. And I have those anyway. Even when things are going good. So when things are not going good and there's something terrifying, like COVID-19, and then just kind of more eye opening experiences, too. The things in our world that have always been there. And seeing how bad they are. It's really easy for me to feel completely hopeless. So, for me these tools are what takes this moment from crisis to what I like to call crisitunity, which I think I got that from The Simpsons. Even though we're seeing some awful things in our country, this is a chance to change. I am appalled that it took a crisis to get there, but I feel hopeful. And for me, the thing that switches my brain from hopelessness to hope is usually some kind of a tool. Because those tools bring me back to what I know



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when my brain tells me something else.

>> ALIXE BONARDI: Brilliant. Thank you, thank you, Amye. Jenny, we'd love to hear from you, too.

>> JENNY TURNER: Thanks, thanks Alixe. I have the incredible challenge of following such a powerful group of statements. I would echo what many of my friends and colleagues on this panel have shared that I think our frame starts with our own personal experience, and then it's built and shaped over time with the different experiences that we have that continue that initial trajectory. So as Bevin shared, I'm a big sister of a person with intellectual disabilities, and I didn't know that there was a word for something like "person centered" as I was growing up, because as families you are person-centered. You're automatically thinking about who your sister or brother or aunt or uncle or whoever that person is as a person. And you know them deeply.

I think because of that experience and because of really my parents and my mother specifically who was always looking forward, always trying to be positive. One of my favorite quotes is from Socrates. And he says the secret to change is to focus all of your energy not on fighting the old, but on building the new. And that was really the frame of my childhood, and it's the frame now of my professional career, I feel like. And I really, working for the Life Course Nexus and being to be a part of that community that is looking at how do we now provide some structure for exploring what that possibility and problem solving and decision making can look like so we recognize and acknowledge the experience of our past that have shaped our expectations, but also push and move towards change, like Amye said, especially in this time of crisis, looking for those opportunities, and really having a frame or a framework as it were to think about how do we move forward. How do we build what we envision as our best life, best system that really recognizes people as people.

>> ALIXE BONARDI: Thank you, Jenny. I'm so appreciate to all of you for what you're bringing to our experience together. Now, a couple of you have already kind of previewed the first question, which I would like to move into right away. And as you've been describing your frame, I've been hearing a little bit about how you define this time, as well. So, I'd like to ask why is person-centered planning important at this time? And to start off this section of the discussion I'm going to ask Amye to get started. We're asking for about no more than about two minutes per presenter just to make sure that people have a chance to chime in, but we will definitely, you know, make sure that we want to create space for people to say their piece. So Amye, I'd love to hear from you, sort of an extension of why you think person-centered planning is important?

>> AMYE TREFETHEN: For me, it's really a life preserver. It reminds me of what I know that I forget that I know when my brain tells me a different story. And the other thing is it allows me to model behavior that I'm trying to teach to my daughter. Because I want her to have skills for coping, so if I use a coping skill, she can use a coping skill. And then throughout my life, I believe doing these kinds of wellness tools, using these different frameworks, for me, they have rewired my brain. And I don't know that that's a scientific fact, but I have more pause. I used to just fill this ick. I can't even tell you



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what emotion I would feel. I would just feel this big ick that was like tar that I could not move past. These skills have helped me to learn how to navigate that. I can name my emotions. I can come up with an option of what I can do. And for me, it's been very empowering. I feel like I have what it takes and that I'm up to the task. So, that for me, so I guess life preserver, and then also modeling. Because as a parent, you know, you can tell your kids whatever, but modeling is so huge and that's a big thing for me because I'm a single parent and I really want to show my daughter that no matter what your disability, no matter what you have to live with, you have what it takes.

>> ALIXE BONARDI: Thank you very much. Jenny?

>> JENNY TURNER: I think I'll piggyback on what Amye shared. As we put it in a historical perspective about where person-centered thinking and planning came from, like Michael shared at the beginning of the call, it's about respecting the view and the perspective of the person, and not underestimating their ability to do anything really, but to especially think for themselves and make choices. Like you said Amye, it's learning how to articulate what you want and gaining some of those skills. Again, putting that in the context of history, we don't want to return to underestimating or undervaluing the individual and what they are capable of doing. And we don't want to build systems that respond to a perspective that underestimates the person. I think oftentimes in crisis, it's easy to kind of grab hold tightly and maybe unintentionally create power and control relationships and power and control structures. And I think in order to avoid that, we have to be very, very cognizant of respecting the viewpoint and the person and their loved ones.

>> ALIXE BONARDI: Bolstering the viewpoint of the person and their loved ones. Certainly. Thank you, Jenny. Janis, would you like to reflect on the importance of person-centered planning at this time?

>> JANIS TONDORA: Yeah, I'm going to do a double piggy back. The first is this idea of the life-preserver analogy, which I really like, because life preservers shouldn't be the only thing we get from professional services, it's about tapping our internal strength and resources. At least from my experience in behavioral health, we haven't always done a good job of that. And we've kind of surrounded people with this sea of professionals that they become dependent on. And what's happened during this time of COVID is when the bricks and mortar buildings are closed and we have less access to those professionals, we have to get creative. And we have to go back to what we know works. And we have to figure out what our own life preservers are. And we have to develop those internal tools and strategies.

And there's a wide range of person-centered tools that have historically at least in my experience been underutilized that have become absolutely critical during COVID. And they're also about what Jenny was talking about, which is not assuming that people have to be fully dependent on treatment systems. Right? Like our whole goal should be helping people draw on their own resources, their resources in their circle so they can live their life in the community.

So, at the next question, I'm going to preview a couple of those tools. But really just want to say the fact that they're being used more consistently now out of necessity I



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hope is really a preview of things to come, that they will be used well into the future. Well into the future. Michael, I think you want to reflect on the importance of person-centered planning in this time.

>> MICHAEL SMULL: It is a real pleasure to be presenting with people where it is a series of affirmations or way to build on what others have said, because this is an opportunity for learning. We are learning more about what works and doesn't work and how people want to be supported. We're also seeing that the default for a system is power over. And we are really seeking how do we have a system that doesn't default the power over and how do we make sure that we, when we're introducing people we're meeting the person. We teach people with you begin with what you admire about the person and you're not allowed to say anything about diagnosis in that process. And this becomes very important when people are experiencing COVID, wind up being hospitalized, and really reduced to a label. So people meet who that person is. We also want to recognize that as Janis was saying, there's significant amounts of creativity that are both required, but also happening in the world of intellectual and developmental disabilities. We've actually seen more individualized response to who people are, what matters to them, how to best support them. And we need to collect that information and use it to change the system as we get a new normal. I think finally in this, the issue that anybody with disability has experienced is trauma. I have a slide when I do formal presentations that says assumed trauma. Well, we're now in a state in this country where everyone has experienced trauma. There are very few, if any, who have not experienced. So, that should give us an appreciation. But it should also say as we engage in person-centered planning let's account for trauma. Let's respond to it and help people build resilience.

>> ALIXE BONARDI: Thank you. Thank you Michael. This brings up so many more things that we can get into in a little bit. Chacku, would you like to just reflect on the importance of person-centered planning at this time?

>> CHACKU MATHAI: Sure. First, I'd like to say I struggled with the language of person-centered planning, the development of it as a construct. As an Indian, a cultural community, there was ancestral knowledge and trauma. Spoke to a collective me that was much bigger than identifying just what I need. And it was tough to convey that, or to have that conveyed to me. The experience of person-centered planning did seem to move to a few different levels. So, for example, when I first saw people utilizing it and experienced it even, it was about being more loving and empathetic and hopeful and interested and curious and even imaginative about what I might want. The question Michael offered up what matters most was asked. What my strengths were was asked. The rest of the process, however, seemed to be swept away. The opportunity for the relationship was more about just getting me in the room or getting us into the room. It didn't matter whether we stayed and we didn't stay. And so the challenge I feel is about really when someone asks what matters most to you and the answer comes, I found myself realizing that that conversation about power, and my influence over what their ability was to get what mattered to them, do you know what I mean? In other words if someone said to me I want to live on my own in my own apartment, away from my family, or away from the providers who are all over me, my





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ability to actually help them make that happen influenced whether they answered the question in the first place. In fact, one time a man answered the question and said you're not going to be able to do that. They're never going to let you. You don't understand the questions you're asking. That made me want to influence the grouping of policies. That made me want to influence what are the inequities and how do I work back from there? Maybe if I work back from who is not getting person-centered planning and who is not experiencing the question of what matters most? Then we might be able to unravel some of the issues that we face. I think this is the time, this is the opportunity for us to be able to do that. I think there is more will and commitment to do that now than there ever was.

>> ALIXE BONARDI: Thank you, Chacku. I agree. This is the time. And is thinking about person-centered planning as a piece of a whole other set of structures and systems that are meaningful to people is important. I'm going to move us along to something that we hear a lot of talk about people wanting to get tangible, to make change, but with a tool. Can we come up with a tool? And there actually have been some brilliant tools and supports that people have developed, that people use. And we want to take some time to hear from all of our panelists about what tools they have found most useful. As Amye mentioned, tools can provide something to hang onto in a way. And so, for this part, we will be, a few of our panelists have shared a few examples. But I'm going to move us into the section and starting with Jenny, ask if you could share some of the tools that you find most useful and why those are.

>> JENNY TURNER: Sure. It's really exciting listening to the panelists, and my brain is going, going, going. And I would echo what has been shared. This is really an opportunity for us to seize the day, to think about how can we be innovative and individualized at the same time, and how can we sort of gather some of the collective experiences to move that system change forward? And so, I've got some quick examples of things that I think facilitate the person-centered planning decision-making, problem-solving process in a way that helps to explore and discover together. Many of you may be familiar with the Charting the Life Course trajectory. And that's a quick and easy way to understand what does someone want for their life. You can go big or small. This is a very specific example related to COVID. But you can also think about big picture, all of life. On the next slide, though, I think digging a little bit deeper and really thinking about all of the different quality of life domains is something I find incredibly helpful right now because we know that quality of life is more than just health and safety. Health and safety are critical, but we're seeing the impact of social and spiritual relationships that were the lack thereof during this time. Having a way to break that down and think through that is I think is critically important. I would also echo what Janis shared about the creativity that is happening right now. On the next slide there's a charting the life course ingrated support star. And using that as a tool to think through what are all the different resources and options.

Starting with what do I have? What are my personal strengths and assets? And really elevating begin the abilities and skills of the person, and building that into an integrated array of supports and services. I think it's a really creative way of doing problem



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solving, especially when maybe what we're used to isn't available. And actually, the last tool that I find, which is one of my favorites from the library, is mapping relationships and mapping roles. And I think it's important that we recognize that all people exist within the context of a family, whether that's a family that they born into, or a family that they've chosen. And especially during this time, as we're doing that creative problem solving, we have to understand the full dynamic of the family. And so exploring how that person is connected to those people in their life, or the resources, and how they provide different types of support, both caring about and caring for, is critically important.

>> ALIXE BONARDI: Thank you, Jenny, for sharing these.

And those who can just see a little bit, if you're using a phone or something, we will put the website where people can access these tools if interested for exploring a little bit more. Next, I would like Amye to pick up with the same question. And I think you have some other examples around tools that you found most useful.

>> AMYE TREFETHEN: Yes. I had training in wellness recovery action planning when I was a peer support specialist. I feel more comfortable with that. However, my daughter is more experienced in using a charting the life course, because that's one of the ways they would prep with her for IEPs. So, this is an example of her. We didn't have a very good printer. So, we ended up drawing on the page. And I wanted her to use this, looking at all those different life domains. Because I wanted her to think about what can I use in each of these to make me feel okay. And at this point in time, it was just the beginning of the COVID pandemic. We had just moved from the Kansas City area to Jefferson City for a job and then the lockdown happened and it was terrifying. She put a happy star in the middle because that is her happy.

And these are all of the things she can do out of these pie wedge domains to make herself feel good. You can go to the next slide. This I probably didn't use correctly. This is coming from my background in wrap. This is what I feel like when I'm doing well, and this is what I feel like when I'm not doing well. So normally, I would use this what's your feel good, happy life, you know, what is that? What don't you want? But I thought it was important for her and I to have a conversation about what are you like when you're well? What are you like when you're not well? And for us to have that conversation with each other so that I know this is what stressed out looks like for Olivia. This is what stressed out looks like for me. That's how we use this form. You know, you can see what she listed there. These are messy. I apologize. So, you can go to the next slide. This is actually from wrap. It's from a user, it's not an official sanctioned tool. I just happen to love it. This is called a feelings pyramid. I gave the link to the organizers. You can find it on the wellness recovery action plan. I love it because this connects me with what I'm feeling. The triangle, you center yourself, you do your emotions, and you write your coping skills all around the triangle. That's one of my go-toes. I like it because it makes me feel mindful. So the next two slides are just my version of the charting the life course tool. So I put in the middle my mood and anxiety and all the things that I could do to help myself. And things that I could avoid, too. Like not obsessively going down the rabbit hole with the news all the time with COVID. And then you can do the next slide. And it was just my version of what I'm



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like when I'm well, and what I'm like when I'm not well.

>> ALIXE BONARDI: Thank you, Amye. I think we're just waiting for the next slide to come up. We may have had a little freeze there. And thank you so much. I think it's really fantastic to be able to see some of the concrete examples and how they're being put in use. Thank you for sharing all of these. With that, I think we will go to Michael, if you will share some of the tools that you think will be most useful at this time.

>> MICHAEL SMULL: Let me begin with a cautionary note, and it builds on what Chacku was saying earlier, and that is writing a brilliant plan that is not used is a disservice. I think it's actually a form of abuse. And one of the challenges is to begin with the why are you doing this and who's going to use it? Is it going to be used by the people who are developing it, in which case you're not too worried? Is it going to be used by this system, in which case you should have some concerns. But when you look at how the tools work together, we teach that you begin with discovery, you begin with how can you learn about the person, but there's some everyday-learning tools, which I think are intuitive, which can be very helpful in these circumstances where people's lives have undergone significant change. And one of them is called What's Working or Not Working, what makes sense and what doesn't make sense. The way to do it is to say right now at this minute, Amye could record and what's not working from her perspective. But then she could ask her daughter what's working and not working about mom from your perspective. And getting the various perspectives gives you a way to take a look at it and be able to say what's next or where there's disagreement, begin to have a process of negotiating. If you're looking at things over time, there's four questions that are really helpful to ask. Given the overarching question, such as since the pandemic started, what have we tried? What have we learned from what we tried? What are we pleased about? And what are we concerned about? And looking at those, and then saying based on the answers, what's next? And you can use this in conjunction with some of the charting the life course work. So if you defined a goal in your trajectory and you know what you don't want, and then you say here's what we're doing to try to get there, ask us those questions. Be able to see how you might make a mid course connection or continue on the course you're on. You also have, and Bevin referenced it initially, that one-page description that would help somebody if they had COVID and were going to the hospital and had it with the health passport so that you could look at who the person is, how to best support them, and how they're going to survive this depersonalized trip they're about to go on.

Finally, for anybody who is experiencing trauma, we should be asking three questions. We should be asking how they define safety, what makes them feel safe, and we should be asking them where do they need control, and what's that look like?

And then what relationships help you? What relationships will help you maintain that feeling of safety and the feeling of control and help you avoid those situations, those settings that create trauma. And those would be some of the tools I think would be immediately useful.

>> ALIXE BONARDI: Thank you, Michael. I know I've seen coming through in chat,



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some people have been asking for the four questions. And I'm wondering, well we'll make sure that we get to those or that we can maybe get them typed into chat.

>> MICHAEL SMULL: They can find them on the learning community website or the SDA website.

>> ALIXE BONARDI: Perfect. Thank you. Chacku, I'd like to turn it over to you.

>> CHACKU MATHAI: Great. Thank you. These have been wonderful resources. A psychiatric rehabilitation approach. A variety of what I've always called vehicles around the opportunity to be who I am and really be as Janis and Larry and others always talked about being in driver's seat.

I always appreciated that so much because there's just a shift in the construct that helped me see wherever it was, now is an opportunity for me to look at what works for me, and especially in a COVID environment, self-care is primary care. And that's the real way in which the decisions that I'm already making over and over and over again are now getting utilized and leveraged as strength. And ways in which I've been doing this and honored and recognized. So, that said, I think there are a few adaptations that we've had to make in a few different areas. Peer support is one of the biggest ones in terms of really making sure that we're not getting stuck on a tool and the mechanisms of a tool, and really honoring the experience of a person. I'll just tell you right away, one big example is we started a Healing for Hip Hop initiative, and that was done because we were trying to tell stories that didn't have words for it other than the words we created through verse. Through music, through fashion, you know, through tagging, through dance. These were cultural stories of emerging from trauma, as Michael said, that couldn't be captured in a workbook, but could be captured on a play list. It could be captured on a cassette drive. It could be captured on a Youtube video. So these are the experiences now that we've evolved to in terms of capturing what works for us and what matters to us. Because all I got to do to understand what matters to my 12-year-old daughter to take a look at her play list or a look at her library of who she's listening to on Youtube and really ask her about it and understand what matters. And that tool, from a cultural perspective, and from again, I'm going to bring back the anti-racism framework here. If I'm going to really understand that there have been disparities and inequities resulting from policies that create them, right? That make them happen, and belief systems that actually justify them, I want to recognize that well, you know what? Maybe the explanatory model that I've been somehow conveying, like a medical one, isn't where somebody is coming from. So the cultural formulation interview, for example, that was finally done, and offered a way in which to use the words of the person speaking to you, use the words of the family speaking to you to actually validate their experience. If I'm saying look, it's a conflict with my son. I don't know what you're talking about with all this other illness stuff. I'm talking about the conflict with my son right now. Or I'm saying I'm hearing voices. I'm not saying I'm paranoid. Really understanding where it's coming from. And then lastly, the model of a tool I think that has been very effective is really recognizing that communities have developed tools of their own. There's a desire to build, not be warmed by other people's fires all the time, and recognize the fire that I have built. And so there are racial equity tools. The website [racialequitytools](https://www.nacaps.org/racialequitytools) has a huge list of COVID-19



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resources people have used. They may not be directly applied to people with disabilities, but they are applicable. Don't forget that they belong in the mix of resources there. And lastly, I think the question that someone asked. I'm a facilitator of Hearing Voices Network. It's an international network of those of us who hear voices and other extreme tools. There's an approach that allows us to make room for the meaning that we're making out our experiences. And that is how I start to let go of the belief systems that have held me back in the first place. That's how I start to let go of the tools that never worked for me, that almost worked for me, but never really worked. And start to find ones that do. That's it for now.

>> ALIXE BONARDI: Thank you, Chacku. I've been seeing some messages coming through about whether tools are available or a list at least of the tools will be available just so people who are participating know yes we will be compiling what's been referenced and making that available, also, on the NCAPPS website in a couple weeks. I would also like to hear from Janis, if we could hear from you, your perspective on the tools that are working best.

>> JANIS TONDORA: Sure. We have a couple of slides here. Amye and Chacku already referenced the current slide, which is a modified version of a tool. It's a tool that's been used for years developed by people with lived experience for people with lived experience and others by Mary Ellen Copeland and others. It's been modified in this particular application in the midst of COVID with an emphasis of how do we maintain the connection to other people who helped sustain our recovery in these challenging times. But before I go onto the next slide, I want to add a cautionary note, just like Michael did. When we start talking about tools, we really have to remember that the tools are only as effective, and they're only as good as the skill and the values of the people who are using them, right? So sometimes people use these person-centered tools all on their own, but oftentimes they may have a natural supporter or a professional helping them kind of apply these tools to their life and the life they want to live. It's really critical that we remember these are the kinds of tools we want to encourage people to use them and expose them to them, but we never want to mandate them or require people to then share them with a service system or a professional. Right? Because that goes against kind of the core values. So again, encourage them, but at the same time, we need to respect that there may be reasons why people may want to keep them to themselves. Wrap would be the first one. And the second is the sick-bed visioning tool. It's something, Chacku, I think you were touching on. It's an example of a community-based, grassroots, get-together, figure it out. It doesn't have to be a tool from a bunch of professionals. And specifically, I want to give a shout out to Famous and Veronica. It was developed in New York City and COVID was peaking in the city and people were dying all around them. And as you can see, it's got a whole bunch of different tools in there. Incredibly practical when you think ahead to the point if you actually get sick if you're hospitalized, who is going to take care of your pets, who is going to take care of your kids, who can do your laundry for you. And they're just things that we tend not to think about in advance, and these are great tools that kind of walk you through that. And there's an ongoing accessible Google doc that you can access and the tool can actually be adapted for use in any



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state.

The next one is the healthcare person-centered profile. Both Michael and Bevin have talked about this. I'm not going to go into detail other than to say when we developed these tools, we thought a lot from that frame of how they help people. You know, how do we help sort of honor people's preferences and choice at a time when they're in the midst of a COVID crisis and potentially unable to communicate their preferences. I think these tools really do that. But the other thing they do, sadly I think we've all seen the news reports of healthcare professionals who are desperate, who are sometimes the only person bedside, at a patient's side when they are at their most critical point, potentially on a ventilator. And those healthcare professionals sometimes have no information or very little about who the person is, how to connect with them, how to provide them comfort. So these tools actually give those healthcare professionals something practical to foster that connection and compassion. And finally, the last one I want to point out quickly at this sort of other end of the stage of moving through the COVID pandemic, one of our pioneers in the behavioral health recovery field, Pat Deegan, who has released a tool about coming out of quarantine. What have you been missing about activities and the people who are important to you? What does it look like to reengage with those activities? What are the costs and benefits of that? And based on your own personal cost-benefit analysis, what are you going to choose to engage in and how? Pat has put together a great one-pager or five-minute video. I used this when I thought about going away with my best friends from childhood on a girl's weekend. I decided to go, but I slept on the porch. It helped me think about how to engage in that activity, and do it safely, but not be confined in close quarters at night. Really encourage people to check them out.

>> ALIXE BONARDI: Thank you, Janis. This is a pretty terrific collection of tools. And for those of you who have been engaging in chat, if there are other tools that you're interested that you think are valuable, we can also collect those and make those available, as well, when we put them out. This is such a rich conversation and we have questions coming in and I want to make sure we have some time for Q&A. So to the panelists, there are a couple questions remaining. And you've got your questions. But what I'm going to actually ask is we combine our last two questions around your key considerations for person-centered planning as we navigate this pandemic, as we confront structural inequity and racism. So the final question I asked you, was planning to ask, was what's key message that you want the audience to take away. So, as we go through this next section, if you can sort of think about what you would like to present as both key considerations and a really key message that you want the audience to come away with, that would be great, and then I think we'll then have time to hear from some of the questions from people who have been participating in the audience. So, for this section, I'd like to start with Chacku. If you could start with your answer to some of these questions?

>> CHACKU MATHAI: No small task. For me, I need to start with the takeaway, or the takehome. There is a process that all of these different tools founded in this, and housed within this awesome framework of person-centered planning offer an



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opportunity for a co-construction, a mutual exchange, an ability to be transformed by each other's understanding and point of view. Those are the fundamentals in my mind that can be lifted to a place of social justice. It can be founded in the process of liberation. It's not going to be the liberation you are seeking. It's going to be different. There's going to be a different set of tasks that are required of you in order to be able to make room for their liberation of others. And it's the same. And I got to do the same thing. It's not a power this and power over scenario. Yeah, it may be limited power. No doubt about it. There's an oppressed group in any one of our communities that we're working with, and we need to be able to attend to and hear and center. And the ability to decenter ourselves in this conversation enough that we can actually be compelled to move towards them without necessarily losing your center about what's important to you, too, is the skill set. It's the art form that we're talking about. And that is a life-long practice.

And if I make that a life-long practice, I'm going to be seeing myself more like a river than a statue. And I'm not going to have any problem pulling those down. I'm not going to have any problem erecting and reerecting in your place. That's holding me back. That's not what I see. This is what I see. And so, I think the key considerations that I was thinking of and the original question, Alixe, there is always going to be a sphere of influence that I can take that is beyond what I might have thought in this process. And I'm always going to face a circumstance with every person and family I work with that calls upon that sphere of influence to go a little bit further. And if I can do that, I am probably going to be able to say in a better way that I am moving towards equity. I am moving towards and being an anti-racist, and not moving back to being a racist. Because I, too, will be in that place. I will, too, recreate the qualities that outraged me in the first place if I'm not reflective in that way. And the only way I can be reflective of that is if I'm with you in the room. That's the key to being with you. Thank you.

>> ALIXE BONARDI: Thank you. That's great framing and setup for us, as well, to think about how this is a journey that we're all on. A continuous journey for all of us.

>> JENNY TURNER: I would like to build on what Chacku said. It's well said that it's co-creation. Janis and Michael shared cautionary tales that are resonating with me. I think it's important that we recognize who person-centered planning is for. It's become a function of our various systems, right? It's something that we do. Unfortunately, oftentimes, to people, instead of with people or for people. So, as we think about that, we have to recognize that person-centered planning is about meeting human needs. It's not about meeting system needs. And if we're really going to do that, then person-centered planning has to be holistic. We have to think about all of the different quality-of-life do mains. It has to consider the experiences and the preferences and the realities of the person that is living that life currently. It has to recognize and build on the skill sets. We've talked a lot about the person who is kind of the focus of the planning, and what skill sets they have, and how are we facilitating the person-centered planning process that builds their own capacity for planning and decision making. I think if I had to pick one key takeaway from such a robust conversation, I think it would be that. That person-centered planning is for the person. And if we can center



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ourselves in that mindset, then I think it changes the way that we approach the conversations. It changes the way that will we use the tools. It changes the way that we then use the information that we gather. And that's my vision of really true successful person-centered planning.

>> ALIXE BONARDI: Thanks, Jenny, and such an important reminder for all of us who are working with large and complex systems, too. Janis, I'd love for you to reflect on this, too.

>> JANIS TONDORA: So, our group, collectively, we had a really lively conversation and thought provoking. And it prompted me to think a lot more about the interface of person-centeredness and the pandemic, and racial inequities. And at its core, I think person-centered care is about freedom. It's about freedom to build a good life in the community of your choice, freedom to be free of discrimination, freedom to control choices that impact your life. And both the pandemic, and recent violence against people of color have made clear that not all people are equally free. And honestly, even in treatments we continue to have disparities. Disparities in access to care, health, community, and recovery outcomes. The use of involuntary and restrictive interventions. And in this sense, people of color, and other individuals with marginalized identities, they often experience an additional layer of trauma. But that trauma happens both inside and outside our systems. So, I really believe that truly committing to person-centered care and planning means acknowledging that we are not immune to the types of discrimination and oppression that plague our broader communities. I think it's critical to remember that the full impact of this kind of work can't ever be realized unless we're explicitly talking and actually doing something about racial injustice and trauma. Because if our goal is really in person-centered care to help all people live a good life in their chosen community, we can't stay violent in the sense of these injustices, and we can't perpetuate injustices inside of our own systems of care. They can't be implied. They have to be explicit. We have to actively work on it. I'm glad these conversations are coming together.

>> ALIXE BONARDI: Thank you, Janis. Those are such important and wise words that have come from all of you. And I'm so excited, too, that these conversations are coming together. I feel like there is an important connection. Amye, you're up next on my list. Amye?

>> AMYE TREFETHEN: The main thing I can say, I've had good experiences, and I've had negative experiences. As a person receiving treatment. I did not learn to be the captain of my own ship of wellness, so to speak, until I did this on my own.

And I made mistakes. And I might have fallen down 11 times, but I got up 12. That's what matters. It is my life. Those are my decisions. A lot of that power was taken away from me. Maybe the decisions I wanted to make weren't healthy decisions, but they were the best I could do at that time. And for me, it's been a process, a life-long process of being able to do what I could do for myself when I was ready to be there.

So, I think it's important if you're with an agency and you're using any of these tools that it really needs to be that person doing this for themselves. And if I use any of these





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tools with my daughter, I don't tell her this is what your life needs to look like, and this is what your healthy needs to look like. I'm just showing her the tool. The other thing I liked, and I can't remember who said it. I think it was you Jenny, that these are personal tools that I shouldn't have to share with you unless I choose to share them with you. This is my personal wellness. And it's little decisions every day that add up to something. And what I want to do maybe isn't what you think I should be doing, and what my wellness maybe isn't wellness to you. But from where I'm coming from, I got up, brushed my teeth, put one foot in front of the other, best day ever.

>> ALIXE BONARDI: Well said, Amye. Thank you. We're getting a lot of requests about whether this will be recorded. The answer is yes. That will be available. Michael, you are the last to be able to sum up. And I leave it to you for your comments on key considerations and a takeaway you'd like this audience to have.

>> MICHAEL SMULL: Well, if you think about what we've all said, and if you think about what many of the people on chat have said, we're all advocates. We all seek to be change agents. And the downside of being a change agent is you can forget that you also need to be a change target. That you need to be somebody who is reflecting on your own inherent biases. You need to be somebody who is are the outcomes that you're achieving the outcomes you desire. Janis was talking about we need to reflect on our own systems. Well, we can get sucked into having people tell us what awesome change agents we are and forget that we're flawed humans. Who need to reflect are the actions that I'm taking getting the desired outcomes that I'm looking for? Am I actually thinking about the fact that benign paternalism is often another word for oppression? And am I reflecting on the ways in which I need to change my own behavior and my own actions in order to really achieve the goals that I state that I'm looking for.

>> ALIXE BONARDI: Thank you. Thank you, Michael. That's such a great sum for all of this. I said this earlier and I'll say it again. I have such great appreciation for all of you, coming together in this conversation, and what you shared particularly with your individual and wise personal perspectives. We've had some questions come in and Bevin has been tracking that. At this time we're opening it up a bit so some of the questions that have come in can be posed to our panelists. I'm going to turn it back over to you Bevin.

>> BEVIN CROFT: Okay, awesome. And wow, I have been really enjoying this conversation with our panelists who are just speaking their truth so beautifully, and also the amazing stuff that is happening in chat. Wow, what a community we have. If you have other questions, type them into the chat and we'll see if we can get to them. We have 15 more minutes.

So, we have a question about time and timing.

And I think we have a lot of providers a lot of direct support people, a lot of planners, I think on the call. On the webinar. So, this questioner is wondering, it says that it's difficult to put a lot of these theories and tools into practice during planning meetings when everyone is rushing out the doors. Do the folks on the panel have any tips about how we can really elevate these theories in the realities of what many of the planning



processes are?

>> CHACKU MATHAI: First of all, these are principles, if it's not working, something must change. And that is at the end of the day the obligation that I have. And I think that's been the rub, right? Being afraid of maybe losing my job being perceived as problematic or disruptive. But the reality is if the housing, I mean just to use Bevin and Alixe, that requires a different process than a hierarchical organization may allow. What are we actually doing different in order to make that happen? So managing up. And to be honest, it's time to exceed your authority. Start challenging the questions that have not been answered. Or asked.

>> MICHAEL SMULL: Teaching people how to write their own plan. I remember always a couple of the examples where a mom wrote a plan with her son who is in special education, walked into the planning meeting and said here is his IEP. It's up to you to translate it. Because it was written in everyday English and not professional English. A friend of mine who has bipolar disorder would take her plan every time the professional staff changed, would come in and say here's my plan, read it, and then we'll talk. But we're not going to talk until you've read it. It's very powerful if people can learn to write their own description, their own version of a plan and then use it. And part of what you have to look at is the planning meeting actually structured to result in a plan. Or was it structured to result in compliance? And if it's structured to result in compliance, then the planning actually has to occur somewhere else.

>> JANIS TONDORA: Bevin, can I jump in and give a quick shout out to peer specialists and the role of peer specialists in the use of some of these tools. Because we do understand sort of the raiser thin margins around productivity and time management. At least within my experience, and my work, you know, anyone can get alongside someone and help them use these tools and help them think through what's their vision for a good life? But doing that does take time. And sometimes we don't capitalize on the talents of other people on our teams, and I would argue that peer specialists, people with lived recovery of the disability experience are often in the best position to get beside a person and to help them use these tools to chart the pathway forward. So, it's just something to keep in mind, because it's not only an effective engagement strategy, but it's also efficient. You're spreading the word around.

>> BEVIN CROFT: Thanks. And I'll put a plug in for our August NCAPPS webinar, which is on peer specialists across disabilities. We have peer specialists with experience working in a number of different sort of arenas and fields to talk through the different ways that peer specialists and peer values can be supportive, and also kind of the current challenges. So, I'm really excited to share that with you. Great!

All right, so anything else to say around this question around sort of managing time and these tools, which as all of our panelists have rightly pointed out is connected to a host of structural issues that we really need to reckon with?

>> JENNY TURNER: Yeah, one thing I might just add is something I've personally found helpful with my own family and with friends that I've maybe supported through this is to recognize that planning isn't a meeting. I think our system has sort of made that flow, and it's kind of gotten us into this habit of thinking planning happens in a meeting,



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but planning happens over, it's always happening. So, I think one of the things I found helpful with these tools is it's a way to capture and gather information. It's just a note-taking device for some people. With my sister, for example, we're constantly jotting things down on her trajectory or on her star. Even just a piece of paper. It doesn't have to be anything fancy. But it helps us to capture the conversations we have, when she may not even be intentionally telling us what's important for her vision for a good life later, but we were at the lake and she said this. And oh, we needed to capture that information, because as we move into deciding how are we going to structure her supports, we need to keep that in mind that she made an offhand statement. So I think for me recognizing the tools not as something to be filled out in a meeting, but something to capture information over time has been helpful on an ongoing basis.

>> BEVIN CROFT: Awesome. Okay! Any others before I move onto the next question? I think we have time for a couple more. Okay. Here's a question from Tobias. As an advocate involved in community housing that supports people with disabilities, we're incredibly challenged by the logistical barriers during the pandemic. Our community's rituals and routines around being involved with each other in a physical space, and folks are struggling with the trauma of losing these everyday routines of seeing people in person. Are you all aware of any innovative strategies for connecting people with their advocates who are not family members? Other than Zoom? We all know about Zoom at this point, right?

>> CHACKU MATHAI: I'll just say that some of the strategies that I've seen is first of all not settling for who is showing up on Zoom, and really taking a look who is not showing up on Zoom. And figuring out the organizational strategy for going out to get them. So teachers have been doing this. There's a lot of examples out there of you need to take some measured risks, of course, around that. But figuring that out, as a team, as a community, as an organization, and really evaluating what are we going to do. Are we really going to wait to find out that somebody died? What is the moral responsibility on us at this time? Just like people decided whether or not they were going to protest and organize. Just like we had to decide. It's the same question. He, she, they didn't show up.

>> BEVIN CROFT: Other strategies for connections? Fostering connections?

>> MICHAEL SMULL: You know, all of this also points out the technology have and have not divide. Because the way that people are connecting, if it's not Zoom, Houseparty, which a lot of people have been giving good reviews. But it all comes down to do you have the hardware, do you have the connection? And one of the issues that we need to confront is having that tablet, that basic computer, or that smartphone is going to have to be seen as fundamental as any piece of support that we give to people.

>> BEVIN CROFT: I just want to acknowledge that our community has put in all kinds of amazing ideas in chat. And now is probably a good time for me to tell you that we will work to compile and pull through all the insights in chat as best we can and compile this into a document that will be posted on our website. And we'll be sure the links and everything are out to you, as well. Worry not. We will retain all of this awesomeness.



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This question, we only have a little time left and I'm hesitant to ask it, but I want to. Chacku, I think you'll have an answer, and others may reflect, as well. It's an important question and doesn't have an easy answer. If I wanted to rephrase anti-racist as a to-do statement, is embrace diversity a workable option? And I'm going to quickly say, I'm not panelist, but Ibram Kendi's book I want to highly recommend to people, because it takes up this exact question of why we use the word "anti-racist."

>> CHACKU MATHAI: I'll just say it's time to end the euphemisms. I've been asked to soften the words. I've been asked to reframe it to make it gentler. I don't even use structural racism and constructural racism. Ibram Kendi says that, too. It's not about you're a bad person. We're talking about supporting or not supporting policies. Or coming up with new policies. You're either moving towards equity or away from them. So removing the pejorative experience of the word "racism" allows me to say yeah, I've been a racist and I will do that again tomorrow if I'm not reflective enough about what I'm doing if I want to. I need to experience that. That's just my short version of it. And I think talking to each other about that is very important.

>> BEVIN CROFT: Thank you, Chacku. We're going to do more with this, too. I raise it as a teaser. But stay tuned. I think we're ready to go there together and I'm really excited to do that. All right! You know, I think we're going to quit while we're ahead because this discussion has been fabulous. I'm just so grateful for this community. So, thank you everybody for tuning in. All of this is retained. Our job, Alixe and I, have to facilitate resources and connection. And so we'll do everything in our power to do that. So, this webinar will be available to all of you to share and we're going to keep going with these conversations. So thank you. Connor, if you could put up the evaluation questions. And just, before you leave, if you could take a moment to respond to these seven questions. We are always here and we're always listening. Please reach out to us. If you would like to subscribe to our mailing list, you can also send a message with subscribe. Also like and follow on Facebook. We are on Facebook now. And we'll keep the resources with you and discussion going. We'll leave these evaluation questions up as long as people need. Thank you. And I hope everyone has a good afternoon.

>> Bye, everybody!

>> Bye!

>> We will leave and there's another link for you in your calendar invite.

>> Bye, everyone!

>> Nice job! That was great.