Public Health Live! TRANSCRIPT
Person Centered Care in Planning and Practice
October 22, 2020

Moderator: Hello and welcome to Public Health Live. I'm Rachel Breidster and I'll be your moderator today. Before we get started, I would like to ask that you please fill out your online evaluation at the end of the webcast. Continuing education credits are available for a limited time after you take our short post test and your feedback is helpful in planning future programs. I also want to let you know that our planners and presenters of *Public Health Live!* do not have any financial arrangements or affiliations with any commercial entities whose products, research or services may be discussed in this activity, and no commercial funding has been accepted for this activity.

Today's program is entitled Person-Centered Healthcare in Planning and Practice, and our guests today are Tanya **Richmond**, a partner at Support Development Associates, and Kate **Barkley**, the Health Home Team Lead at Fort Hudson Care Management. In keeping with precautions being taken during COVID, Tanya is joining us via Zoom today. Also since today's program was recorded prior to airing because of these precautions, we gathered audience questions in advance. These will be addressed at the end of the program. Thank you for joining us.

So good morning and welcome to both of you. Thank you so much for joining us here today, even via Zoom and in person. We're so glad to have you.

Tanya Richmond: Thank you.

Moderator: So Tanya, to get us started today, would you please review the learning objectives that we have for today's program with our audience.

Richmond: Yeah, thank you. Today we're going to talk about a federal requirement, the Home And Community-Based Services or HCBS final rule. The requirement sets forth expectations for person-centered plans in the provision and delivery of homing community-based services. We'll also talk about how people are attaining better lives as a result of better and more person-centered planning and practices.

Moderator: So can you tell us more about that HCBS final rule that you mentioned?

Richmond: Yes, the HCBS final rule governs home and community-based services or HCBS services, which are types of person-center long-term care services and support that are delivered in the home and community, and a variety of health and human services can be provided. HCBS supports and services are often designed to enable people to stay in their homes rather than moving to a facility for care. The HCBS role, which was published in March of 2014, established new criteria with the goal of enabling Medicaid beneficiaries to receive services in settings that are integrated into the community rather than in facilities.

Moderator: So how has the HCBS final rule changed expectations for service provision?

Richmond: Well, the big change for us to talk about today is that providers are now required to include people in and keep them in the center of the planning process for services and supports. And they're also required to use a person-centered framework that is structured to allow the person to guide the process and to learn about the desires and preferences of the person in balance with their health and safety needs. Historically the system and those who provide services and support have been the deciders in people's lives. So plans have been more system-centric and they focused on the ease and convenience of service provision and have focused on what keeps people healthy and safe. But when we only focus on health and safety, we find people that are perfectly healthy, perfectly safe, and they still may lack a good quality of life from their perspective, but because of the expectations in the HCBS final rule, people, and those closest to them, are now making their own decisions about their lives.

Moderator: So how are person-centered practices and skills addressed by the HCBS final rule?

Richmond: The HCBS final rule specifically requires person-centered planning with people who receive HCBS services. So the skills and practices that we teach in person-centered thinking training then are the mechanism to be used when determining the desire for, the type of, the amount of services and who provides them. Because we want a system where people are supporting and having the lives that they want in their community, but we realize we're in an era where demand is increasing and public resources can't keep up with the demand. This means we have to change how we think, how we organize and how we deliver services, and the person should be the final decider whenever possible. We need real substantive change that meets federal and state expectations, but also improves the lives of those who use services and supports, and helps the people who are managing the organization, use their limited resources more effectively. And it also helps those who manage the system, learn how the changes they've made are working.

Moderator: So does this mean that people can choose whatever they want?

Richmond: No choice definitely has boundaries for all of us. And some examples of those boundaries are things like laws, laws that are imposed by society or expectations. It could be my values or the values of the people who are closest to me, and there are always trade-offs. So there are also boundaries around my resources. So resource driven boundaries, how much time I have, how much money I have and some boundaries exist when there's risk involved.

Moderator: So what more can you tell us about that concept of risk and how it applies here?

Richmond: Well, risk can be one of the boundaries of informed choice. And sometimes when we're in a support role, we find ourselves supporting someone who wants to do something that presents a risk. Some risks are just part of life. But there are risks that we create or contribute to by maybe not listening or not understanding or both. And some risks you just have to manage. So we can get really trapped into focusing on health and safety. When we don't take into account the things that matter most to the person. If we focus all of our energies on bubble wrapping people against all risks, we can keep them safe, but their lives are likely going to lack quality, purpose, and meaning. And on the other side of that, if people get everything they want without

understanding the consequences of choice without boundaries, they can be set up to be hurt. So people can be perfectly healthy and safe while being also quite miserable. And that's unacceptable. We all have the right to make choices, even bad ones. But on the other hand, we are really paid to look after safety, to look out for people. So where there's conflict, there's tension. And good service and support really lies in finding that balance. For people who present significant risk to others we also have to remember that we have obligations to the public, as well as the people that we serve. So for using person-centered skills that can really help us explore with the person and the people closest to them, the best approaches for mitigating and managing the risks in their lives.

Moderator: So what would you say needs to happen first if we're focused on supporting choice?

Richmond: Our first task is to assume that the person knows best about their life, and that what we want for the person may not always be what they want for themselves. And then we need to partner. We partner with the person and with the people closest to them, and take a side by side approach when we help them get the information they need to make an informed choice rather than telling them what to do.

Moderator: So how do person-centered practices and skills help people make choices?

Richmond: Person-centered practices are a value-based set of skills, and they're designed to give those in service and support roles in someone's life, the skills they need to generate, to explore, to offer choices and those choices connect back to what's important to a person. So the skills help support us first, understand what is important to someone and then explore the choices that connect to those things that are important for them. While taking into account health and safety at the same time we're taking into account desires.

Moderator: So would you say that writing a person-centered plan is enough to help people achieve that balance as they describe it?

Richmond: No, not at all. Writing a good person-centered plan can produce compliant paperwork. However, better paper only makes a monitor happy. What we want is for all people to have better lives. So planning without real substantive change in a person's life is a hollow exercise. Using person-centered skills, whether it's for discovery and learning about people or learning from our everyday interactions as we serve and support people or in managing our staff and our roles in someone's life can all make for a better life.

Moderator: So can you tell me a bit more about the skills that are needed for person-centered planning?

Richmond: The skills we learn and we practice can be divided into three categories, and this is a basic toolkit for person-centered skills. There are many more than these. But all of the skills and all the categories support an intentional approach to developing positive relationships and keeping the person and those who care most for the person at the center of decision-making. So we have skills around discovery and listening, and they're about getting to know a person, understanding their preferences. We collect information that's important which leads to understanding the desired balance between what's important to you and what's important for a

person. There are everyday learning skills, which organize the evaluation of just everyday situations and help us learn what to do before we take next steps. And there are management skills that assist in the allocation of and support for staff. So managing our roles in people's lives.

Moderator: Now, you mentioned balance. Can you talk a bit more about that balance and how a person-centered approach really helps to facilitate that?

Richmond: Yeah, I'd like to emphasize that's a core concept on which all of our person-centered work is based. We're trying to maintain balance in our own lives. So it will be looking at how we can do that in the lives of the people that we serve and support.

Moderator: So how should people be thinking about the concept of important *to* a person?

Richmond: 'Important *to*,' I think of as the step that sort of sits at the core of the person in their heart, and it can be defined as those things that keep us happy, comforted, satisfied, fulfilled, uniquely who we are, pleased or at ease. So it's really the stuff that's right in the center of the person. And it could include the people in our lives, the relationships that matter to us, it could be how people perceive us or our status. And it's also the rituals and routines we practice. It doesn't just reflect what is present in our life right now, but it's also about what we wish we had. And it includes also what we wish was absent from our lives. So the things we want to not have present.

Moderator: So we really need to ask people what's important *to* them.

Richmond: Yes. And we pay attention to the things they do, their behavior, not just their words. When someone says something that is different from what they do, which do you listen to, words are deeds?

Moderator: I'm more inclined to pay attention to somebody's deeds rather than words.

Richmond: Yeah. So for people who use healthcare and disability services, we often need to look at the things they do or their behavior because the service and support system has done a really good job of training people to tell us what we want to hear or to not speak up. And when people don't use words to talk or they communicate in ways that are atypical, we have to listen to what they do, their behavior. Many people can only tell us through their actions.

Moderator: So it sounds like we do a pretty good job of paying attention to what is important *for* people. Would you say that that's correct? And if so, why do you think that is?

Richmond: That's right. We've always been monitored to keep people healthy and safe. And so we tend to be hyper-focused on health and safety. While 'important *for*' includes issues of health and safety, it also includes those things that we're paying attention to and helping the person be a valued member of their community.

Moderator: Help us understand a bit clearer what exactly you mean by a valued member of the community.

Richmond: If you have been around a teenager, you have likely heard someone ask them, "Where are you going dressed like that?" So the teenager is dressing to be a valued member of the teen community and the parent is asking them to dress to be a valued member of the larger community. And there can be a very big difference. If we want to help people be valued and seen in those places, in the community that matter to them, valued and seen by others, we need to pay attention to these things and we need to help the person pay attention to them.

Moderator: So how can we help people do more of what is 'important *for*' them while still honoring what's 'important *to*' them?

Richmond: No one is going to do anything that's 'important *for*' them, unless there is a piece of 'important *to*' connected to it. There has to be a hook between the two. And if we think about our own lives, things like healthy eating and regular exercises are good examples of when we do something that's important for us because it's connected to something that's important to us. So if I eat right and I exercise, my clothes fit better, or if I eat right and I exercise, I'm going to live long enough to see my kids graduate high school.

Moderator: So can you tell us more about this concept of sorting what's 'important *to*' versus what's 'important *for*.'

Richmond: Yes, this sort helps us organize information we collect to understand the balance as it currently exists in a person's life from their perspective. And it helps us learn with the person about their preferred balance, because this being able to see what's 'important *to*' a person and separating it from what's 'important *for*' them and then describing that balance from their perspective is a fundamental skill. We spend a lot of time in training helping people really grapple with this. We have to consider 'important *to,*' 'important *for*' first, before we consider anything or use any other scale.

Moderator: So all of these sounds really interesting and I would love to see how this works in practice. How does the person in the professional role make sure they're giving people choice, giving people control and keeping what is 'important *to*' them in the center next to what is 'important *for*' them? It sounds as though it could be a difficult job. So let's hear from some professionals who work in care management roles.

> **Roll-in: Elizabeth Dobert**: As far back as I can remember, I've always had a strong desire to help other people. I can remember being a child, being in the school setting and a new student would come in, I would have this strong desire to go and help that person make them feel welcomed. And then when I graduated college, my flame was burning bright. I couldn't wait to get out and to help the world.
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> **Stephanie Romeo:** I've been doing this work for three years now. And I work primarily with individuals with mental health diagnosis, substance use, experiencing homelessness or some type of criminal justice involvement.
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> **Dobert**: This field, working with individuals, helping them where they're at, meeting their needs, going to their homes, really seeing the whole picture is something that I

enjoy doing. In my current position we are not only mandated, but also supported in being person-centered in all of our practices.

Romeo: I say person-centered just by exactly doing that. Like I genuinely care about the person I'm serving. My job is to ride alongside with that person and to assist them in reaching their goals, not tell them how they need to reach their goals.

Dobert: If the doctor is telling us that the patient needs to go to a medical appointment and that's their goal, we go to the client and their goal might be something totally different. By meeting that small need of the client that can be the bonus to getting the provider's goal met. And so you're meeting both goals, but the client's goal is the main goal.

Romeo: So I recently did an enrollment with an individual who has a long history of substance use, a long history of multiple relapses. I asked her, what does it look like for you if you're relapsing and how do I get you back if that happens? And she said, no one's ever asked me that before. Had someone asked her maybe a relapse could have been prevented, because if as providers we know how to approach someone and what's best for them, maybe would have had a better chance of reaching this individual.

Dobert: When I was in a previous job for many years where we weren't working necessarily person-centered, that wasn't the driving force. I noticed I can see that my flame was going out.

Romeo: In the past, I guess I have experienced some cultures of know where you have this like gut wrenching feeling like you're going to be in trouble for doing something that maybe isn't listed in your job duties as something you have to do, but it's also not something you shouldn't do to help a client.

Dobert: So I really enjoy coming to work every day. I've never been told, "Oh no, no, no, we don't do that, or we can't do that." Instead it's always been, well, if it's not us, then who is going to do it.

Romeo: As a team, we all get excited for our successes. I mean, we have our success wall and everything. That keeps my flame going too. Just knowing that everyone is equally excited about supporting our clients and seeing them doing well.

Dobert: I look forward to working with my clients and get excited about seeing the different changes that have taken place in their lives because of the opportunities I've been able to provide.

Romeo: I mean, we all have room to improve. So obviously like I'm mindful that, obviously there are days where I have thoughts in my head where, this is hard, this is frustrating, I don't want to do this, but I think about the clients and that like brings me back to reality of, okay, like how are we going to handle this? 'Cause obviously I care about the people that I'm serving, doesn't mean I don't get frustrated or like, recognize

that I'm not always perfect either. No one is. But ultimately it should be easy because we're in this field for a reason, because we care about people.

Dobert: Working with the client, supporting them, their goals, doing the person-centered philosophy and putting it to action. But then also having the support through the agency that we work for, being provided with the tools and the skills so that we could go into these homes and do the work. This is what keeps my flame lit.

Moderator: So it was really wonderful to hear those examples. And Kate, I'd love to pull you into the discussion now, can you tell us a bit more about those providers?

Kate Barkley: Thank you. I'm so happy to be here. The first speaker was Stephanie Romeo and she is just an absolute rock star who works with a particular demographic of people who might have serious and persistent mental illness, homeless, criminal justice involvement, substance use disorders. And those are the folks who the important to may not be perfectly clear or easy to swallow. Now Liz Dobert has been in the field for over 10 years and she can speak to the flame, the passion that leads many of us to this field. And she can also speak to the compassion fatigue that can occur over time. Liz enters her work with excitement and curiosity, which really allows her to keep her clients in the driver's seat.

Moderator: So I can tell that they're both very passionate about the work that they do, and they mentioned having a flame. Can you tell us a bit more about what it is that they call the flame?

Barkley: Absolutely. All of us who entered this field of human services, we do so because we're driven by a desire to help human beings. We all enter the work that we do with a person's best interest in mind. The flame inside of us is that intrinsic motivation to do this work. Of course our flame might start off bright. It might burn brightly at times, and then start to flicker out. It flickers over the years and it really does require fuel to keep it lit.

Moderator: Absolutely. So can you explain what the difference is or what you might refer to as the difference when we're talking about person-centered care versus a more traditional approach?

Barkley: Yes. So in this work, at what point does our flames start to pull us off of this person-centered path? And the answer is all the time. Maybe even every day. The solution is what I like to call the difference. So the difference is between being truly person-centered and keeping the person in the driver's seat versus acting upon what we believe is the best for that person, with all of our flawed, good intentions, judgments and barriers in our way. The difference really takes introspection and a pause button in our practice. It really begins with us as practitioners noticing that this difference even exists. The difference makes a difference for our participants and it really can be seen and observed and felt if we are honed enough in our self-actualization skills to take the time to see it. The difference is having the ability to ask what is 'important *to*' this person and not just focus on what is 'important *for*.'

Moderator: Sure. So person-centered care is not necessarily a new concept as Tanya pointed out. And we know that there are people who are working in these roles with clients, patients, participants, et cetera, who are well aware that person-centered practice exists. So what do you say to people who have been doing this and continuing to practice it all along?

Barkley: This is very true. A lot of us are doing it and we're doing it well. The truth is that this is not a new concept and some of us are doing it. We're doing some of it some of the time. That's why it's called a practice. We always need to continue. And we're never really finished. It's constant work to get to the place where we have person-centered in our thinking most of the time. We like to talk about Maslow's hierarchy of needs. So Maslow says that people must have their basic needs met before any other larger progress can be made. The same is true for us as practitioners. We need to know, is this my job description? What is my job description? Are our actions going to be part of the rules and regulations? Am I going to be supported in my actions? Only when we have our basic needs met, can we really go to that place of higher order thinking. And that difference can happen.

Moderator: So can you tell us more about the idea of the myth versus the reality?

Barkley: Absolutely. Acknowledging what is important to a person has not really been a major part of the paradigm before. It's always been what will make them safe? What does a good plan look like for that person? We may say that people have the right to risk or the right to fail, but we may not be able to stomach the idea of making a risk that we wouldn't take ourselves. There's fear there. And there's a sense of responsibility. There's that feeling of, can I go to sleep tonight knowing that that person made a choice that I wouldn't make myself. And the shift really starts to happen when we fully understand that it's not about us in the driver's seat, it's not about us. We have to acknowledge that.

Moderator: Absolutely. So what roadblocks have you seen from people when they start along this process towards person-centered thinking?

Barkley: This may resonate with people out there who feel as though they're working in a world full of constraints. You may be living in a culture of no if you are hearing or saying things like, well, we don't do that here, we have never done it that way before, that's not my role, the rights and regulations say, I can't do it that way. There's no resources for that. There's no time for that.

Moderator: So do you have any real life examples of times when being person-centered in your practice has allowed you to find a solution where otherwise the answer likely would've just been no.

Barkley: There are some pretty common ones. How many times have we heard of a client red flagged for being noncompliant, being a frequent flyer or a high utilizer of emergency services, maybe a chronic no-shower or called lazy or disengaged. For example, let's take a gentleman who goes to his primary care physician. The office says we need to discharge you. We can no longer serve you. You're a chronic no-shower, you don't show up to appointments. The common practice might be to take that no, for an answer, maybe find a new provider, but he'll only schedule no-show repeat until all bridges have been burned. The person-centered practice is to actually investigate, discover, get to know the person and find out why he's missing. In real life what we actually found out is this gentleman has a diagnosis of a traumatic brain injury and PTSD that he sustained in a really terrible car accident during a rainstorm. There is no way that there is any chance of inclement weather and him going to an appointment. So we have to be proactive. We have to be person-centered and understand that when we're scheduling these

appointments, we have to do it side by side with the forecast. We need to get the provider to know the person and understand that when he's canceling, it's the last thing he wants to do. Let's take another common one. A woman is told by her primary care physician, you're non-compliant with your diabetic regime, and you are not taking your insulin. A care manager can go into her home and discover there's an eviction notice. Your heat and electric has been turned off. You don't even own a refrigerator. When that woman's basic needs can first be met then she can start to think about meeting that higher order need and start to care for her physical health.

Moderator: That makes perfect sense. So what do you do in a world where there are so many barriers and so many 'nos', how do you move past all of that?

Barkley: We need to shift. We need to shift from that 'no' over to 'yes.' And somewhere in between, there can be a culture of maybe, or maybe it's worth a try, or maybe there's more information to be gained or things to find out that we just don't know about yet. We need to make the choice to walk alongside our clients and we need to go on a journey with them in discovery. We have to be able to say to ourselves and to them out loud, I don't know, I don't know the answer. And that's okay. It's not easy to say that. It's about ascending Maslow's hierarchy ourselves and getting to the place where we are making higher level choices.

Moderator: So it sounds like a lot of going above and beyond for clients. So I wonder, is this a sustainable approach to go above and beyond every time?

Barkley: It is. In order to notice the constraints and understand them, you first have to pause and you have to ask yourself, why am I being told no? You have to notice, is it inside of me? Is it in my environment? And you have to look at that no as an opportunity. The straightforward practice has been to get a no and stop. The person-centered practice is to take that barrier or that opportunity as a chance to be creative and explore possibilities. In a culture of yes or in a supportive culture of, well, maybe we can solve this, the options really could be limitless. You have to go back to the drawing board.

I happen to work for an agency where the director and the CEO have a general philosophy of support. Their motto, that becomes my internal voice, is if not us, then who? That allows us, it encourages us to think outside the box and really find solutions and move past the nos. We're reminded that the person is the expert in their life. So how do you remain providers that are person-centered? Keeping both important to, important for and hold a heavy caseload, remain fiscally responsible and not risk burnout. It's a lot. What you have to do is not make an insane list of to-dos for your clients that you're going to do yourself. You can't just make it about you. Instead, you have to empower and enable clients and enable their independence to make progress within their goals themselves, with us as their leaders, their life coach. When you keep the person at the center, you're really assisting in making positive change. And that is sustainable. We have to go back to that flame inside of ourselves. If we just throw more and more fuel and more and more tasks on our to-do lists, more and more problems, we're going to deprive that flame of oxygen and it will burn out. If you have the right amount of fuel and a culture of yes, fanning your flame, we're more likely to try and gain opportunities in our barriers, and we will have more inspiration in our work.

Moderator: So when you think of all of this that you're talking about, and you speak about it so passionately, what images come to your mind?

Barkley: I think of Mary Poppins. When I think of a bag of tricks that simply means having resources and tools at your disposal. But when you think about a Mary Poppins bag of tricks, she can pull a full length mirror out of her bag. She can take out of it whatever she needs in that moment. So in order to have a Mary Poppins bag of tricks, you need to have all of the things that have come up today. You really need that culture of yes that allows you to reach deep into that bag and deeper than the surface tricks that you're used to. You need a team of supporters who each have their own Mary Poppins bag that you can reach into and they can reach into yours. You need the persistence to reach deep enough into that bag, past all of those barriers. You need the ability to throw out the things that are in your way to get to the thing that you need. Those are the constraints that make answering your problem difficult. Sometimes you might actually need the ability to close that bag, throw it over your shoulder and walk with your clients, your person, your participant, and find the answer with them. And that's okay. You need to learn that you can share that process with someone else.

Moderator: So what does that look like in practice?

Barkley: My team brainstorms constantly. We are in a really fortunate position to have a lot of professionals with very different backgrounds. They have different expertise and different Mary Poppins bags. So we physically sit down in a room together. And when a barrier is presented, we combine our resources and we work it out as a team.

Moderator: Excellent. Thank you. Now, in this video clip of a brainstorming session, Kate's team is presenting barriers and constraints that their clients are currently facing.

> **Brainstorming Rollin: Barkley:** Okay, everybody so weekly meeting. Does anybody have anybody they're struggling with, having a hard time with, needs suggestions, needs help, needs tricks, resources, brainstorm.
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> **Lisa Mercantonio:** I'm working with this guy he's going to need to undergo dialysis. It's really not something that's important to him to have this procedure done. And I'm just struggling to figure out what the barriers are and how I can get his needs met while getting the medical need met as well.
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> **Barkley**: You're saying it's not important to him, what is important to him?
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> **Mercantonio:** Some things we do know about him is he really loves his music, he enjoys getting his cup of coffee every day. He looks forward to those kinds of things.
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> **Barkley:** Do you think he's uncomfortable with going to a new places, meeting new people? - Does he know, does he understand what dialysis is? Does he need the education piece? Because I keep thinking to myself, why isn't this important to him? 'Cause obviously as care managers, we're realizing this is important for him, for sure. Has he ever been? Has he ever seen the dialysis center? Does he know what to expect? Take the time to sit and meet him where he's at.

Mercantonio: Yeah.

Barkley: Okay, good. Okay, thank you. What else we got guys?

Stephanie Romeo: I have a client who is developmentally disabled and she would like to get her driver's license. But her mother feels that that is completely unrealistic and doesn't even want me to entertain it. And that just doesn't feel good to me because I work with the client, not necessarily the mom schools and it's important to her.

Barkley: I'm immediately going to what important to her? Why is it important to her to have this driver's license? Is it the actual driving, or is it something else?

Romeo: Like the sense of independence or freedom.

Mercantonio: I like what you said about what need is being met, and are there other ways we can get that same need met for her in a way that those are still fulfilled and still meeting a goal of hers.

Elizabeth Dobert: And maybe just starting with getting her, the book from DMV to read through and see what the rules are, kind of educate her.

Barkley: Yep. I have a hard time when I hear, nope, nope, unrealistic. That's a hard no. What else?

Dobert: So I have a client who was just recently diagnosed with a terminal illness. She's just got cancer. She's not looking good. But here's the thing. She lives in a van on a piece of property, she's by herself. I just feel that there's got to be something more for her. There's got to be a place that she can go.

Romeo: Does she want to move?

Dobert: You might be on to something. I don't know.

Barkley: Is this a YOU fear – for *her*, obviously, because we're worried about her? We have empathy for her. We care for her, but she actually, okay with this and this is perfectly acceptable for her? And it's just not a choice that we would make for ourselves.

Dobert: Yeah. I think you're right.

Barkley: Maybe she's okay.

Dobert: Yeah, I think I have to talk to her. I have to ask her how she feels about it. She is going to be alone, but that's the biggest thing. She's going to be alone going through treatment. When I dropped her off from the surgery the other day, that's what she cried to me about, was that she was going to be alone.

Barkley: So when it comes to the fear of being alone, we've got some resources there. We've got, can we access an aid for her? Can we get some support care? If we end up getting there.

Dobert: I think the cancer center has a support group. I think I'II have to ask about that.

Moderator: So Kate, that was great to watch. What are some things that you'd like to point out and have our viewers really take away from the brainstorming session we just watched?

Barkley: There were a handful of things that I noticed. In Liz's scenario with the client who she was uncomfortable living in a van, I noticed her discomfort, but her ability to sit in that discomfort and realize that it was her fear, not her client's fear. She was able to be reflective and everybody contributed to looking for solutions that may not have been obvious to see it first. With the driver's license example, I saw the team grab wood to throw on her fire and not splash the water out and just kill the flame by saying, no, you cannot have that. I saw real attempts to put the client in the driver's seat.

Moderator: So talk to us about readiness for change and the scale of change and how people can prepare for it.

Barkley: Absolutely. So there is another scenario that comes to mind. I had a gentleman who really needed to go to dialysis, it was important *for* him to go to dialysis, but it wasn't so important *to* him. It's our job to meet him where he is on the readiness for change scale. That means that we're focused on getting our client to become ready to address their physical health issue. But if we have a face-off with that gentleman, it's not going to end in him going to dialysis and us being happy. It wouldn't get us where we needed to go. In this situation the next conversation would be joining him on his position, in his readiness to have a conversation about what it would look like to not go. Maybe we discuss palliative care. Maybe we talk about comfort measures or advanced directives. I had a real client in this situation. And after having that conversation about what the real life consequence would be, they ended up deciding not to get treatment. Other people might decide, oh, I should go. I should go right away. I don't want that. We also have to be prepared to walk alongside them if their answer is no, and we need to meet them in their position to walk with them for what comes next. When we have an open heart and an open mind to meet people and put them in the driver's seat in their own lives, we are more effective in our roles with them.

Moderator: So it certainly sounds like a shift that you're talking about, a shift in how things have traditionally been done. So can you talk about how you approach making that shift happen in your work?

Barkley: In order to make this shift really catch fire it needs to come from the top, it needs to come from the state, but it also has to be fueled by passionate people with boots on the ground at the bottom. We really need to get that positive message out. And I can tell you it is happening. I'm hearing from the top, ‘we give you permission to be curious, we give you permission to shift from that no to maybe, we give you permission to walk alongside your clients.’ Now, the expectation is that the person not the system or the provider is driving the plan. Their desires and

preferences, they're not only nice to know, they're how we structure our delivery of supports and services. It's not just the right thing to do. It's the required thing to do.

Moderator: Thank you. And Tanya, what is your perspective on the shift that's occurring?

Richmond: Well, the shift is happening at all levels and the federal government has not only cleared the way to give people more control over their lives, it has mandated that providers of home and community-based services do so through the person-centered planning provisions of the HCBS final rule. New York State has created supports for agencies and providers of HCBS consistent with federal person-centered planning expectations and has developed training and partnering opportunities to give providers the fuel that they need to progress towards person-centeredness. And many providers are making sure that they're spreading the word to family, getting their own staff train and making changes in the way they've always done business. But at a macro level, this is a civil rights issue. This idea is not new. All people have rights under our constitution and the presence of a disability or a vulnerability should not change that. And those rights are, they include rights to autonomy and dignity and family, justice, life, liberty, equality, self-determination, community participation, property, health wellbeing, access to voting and equality of opportunity and many other things. But historically people with many types of disabilities and vulnerabilities and chronic conditions have not been recognized for their contributions. And they've also been blocked from exercising and enjoying many of these rights.

Moderator: So Kate, how do we make the shift at a micro level? And do you think that person-centeredness can be taught?

Barkley: Hmm, can it be taught? It all really comes back to that flame, that passion inside of us, we have to have all of the ingredients. The flame has to be there, the desire to join the field in the first place. We also have to fuel that flame and we can light it and make sure that that fuel is accessible. Like our team, like our director, like our CEO, our philosophy. The environment, and the culture needs to fan that flame. We need to celebrate wins. We need to support one another. I think about the stages of the flame. And I think about Stephanie, who you saw, she really has a self-starting flame. She doesn't need a lot of external fueling. She can do it herself. She finds her own fuel. Now other practitioners, maybe the flame started out very bright. And for whatever reason, over the years, it started to die out. You can reignite that it may be harder and harder to reach, but again, you need those ingredients. Maybe it's coming from a supportive mentor, a teacher, a director, or a supervisor. Maybe it comes from having these conversations or practicing those skills that you can use at training.

Moderator: Thank you. Now, Tanya, what is your perspective on person-centered thinking, planning and practice at the individual and systems levels? And what words of encouragement would you give us?

Richmond: The individual and systems levels have to work in concert with one another. So never before in our history, have we aligned policy at the highest level with values-based practice on the direct one to one level, in such a way that people can have that balance in their life that they've described for themselves. So this is a watershed moment for people with disabilities and chronic conditions and for the people who care about them. At the highest level of our system, leaders have participated in person-centered thinking training and then use what

they learned to change the expectations about how services and supports are developed and delivered. And this became the HCBS final rule. So states have taken up the charge and they're clearing obstacles to service and support provision so that people who are doing the work can do it with confidence and they're in compliance at the same time that they're doing the right thing.

Moderator: And can you speak to the relationship between this shift at the regulatory level and New York State's person-centered planning, training initiative? How are these values and skills being taught?

Richmond: Yes. Exciting things are happening in New York right now. In response to the HCBS final rule, the New York State Department of Health has rolled out a very large scale training initiative that gives people of all levels and in various roles in the system the information and support that they need to understand and then apply person-centered practices.

Moderator: And Tanya, can you tell us more about the statewide training initiative that's helping to open people's hearts and minds to a person-centeredness?

Richmond: Yes. That's a sign of the shift on the system level that's helping support the shift on the individual level. So go with your teams, we want you to go with your colleagues, reflect and use the skills. When people leave a person-centered thinking training or any of our person-center trainings, they have everything they need to begin to use the skills right away. Their charge is to go back into their agencies, go back into the communities and practice with the skill. So we ask that they use their learning right away so that they get comfortable and confident and that they help others use them as well. Because our days are busy we often revert to what we know in problem solving. So for people to take the skills that they learn in class, from practice to habit, they have to use them and they have to use them often. So we give lots of ideas about how to do that, and we give people resources for when they feel stuck.

Moderator: So what training has taken place so far through this initiative?

Richmond: In 2019, we did 95 training sessions, including full and a half day regional training on four topics that were highlighted here. And some multiple day learning opportunities called learning institutes. In all we trained 1,665 people in those learning opportunities. In April and May the training environment switched because it went to virtual because of COVID restrictions. And during that period, an additional 308 people participated in eight virtual sessions on two different topics. But coming up beginning this month, new virtual training modules are delivered on six related topics, including being person-centered in times of crisis or person-centered thinking and the HCBS final rule. We have one on person-centered plan development, one on person-centered skills, a person-centered practice for managers and a person-centered approach to cultural humility.

Moderator: And who has been attending the training so far?

Richmond: Training participants are people who are receiving, providing, and receiving services and supports in all parts of the service system where home and community-based services are delivered in New York. And on the slide, what you see as a snapshot of the diversity of sectors represented among the attendees at trainings in December of 2019.

Moderator: And what are training participants saying about the training opportunities they've received so far?

Richmond: Across the board for all the trainings, people are telling us that they're learning and they're using the skills. So we ask them to rate their knowledge coming into the training and what they gained from the presentation. And what people are telling us, and you can see this, all the trainings are helping participants increase their knowledge regarding person-centered practice, but the most exciting thing for me, however, has been the emails that I've received after trainings, where participants ask, "Hey, what do you think about this skill in this situation? Or will you take a look at my person-centered learning log and tell me where I can maybe focus my energy as I grow my skills." Those contexts are priceless to me because they demonstrate that we are building community and that people are reaching out to make sure they're actually doing it right.

Moderator: So would you say that the training is actually making a difference in how people do their work?

Richmond: Absolutely. Overall 88% of our training participants report that they're likely to make changes as a result of their participation in training. And in addition to that, 98% of participants say that the information and the tools that are presented in the training are really relevant to their work, or if they're an HCBS recipient to their lives, to their services and supports. And 94% of our participants said, as a result of this training, I feel more confident in my person-centered skills. And that's what you want. Confidence is going to lead to people feeling comfortable in practicing the skills and that practice is going to help them be more competent in their use. And so we're definitely seeing things trend in that direction.

Moderator: So, it certainly seems like a very powerful initiative. How do we know that this is working?

Richmond: Well, there are a couple of quotes from participants that I think are pretty powerful. And the first one really underscores that flame that Kate told us about. So someone said that she really believed that she could share her passion through the training. And another quote here, the second one was really about being more aware of what the person would like to work on. So not just what we think is best for them, but what they tell us that is important to them. So to me, that really is the crux of what we want people to take away. And their comments after training really are helping us understand that that is what they're taking away.

Moderator: Excellent. That's very inspirational, the quotes and the information that you shared. So thank you. We've covered a lot today. And as we prepare to answer the audience questions, I'll point out that viewers who want more information about the trainings can go to the state web page, which is ‘nydohpcptraining.com/events’ for more information.

So now let's take some questions that we have from our audience. All right, so the first question that we have, let's see, this is a question for Tanya. Tanya, what tools are available after we take the training for ongoing development of person-centered practice skills?

Richmond: There are many ways you can get your hands on additional tools. And I think the two probably best ways to continue to stay engaged are to go to the learning community for person-centered practices website, is at 'plcpcp.com,' where you can get not only the skills that we practice in class, but you can get examples and you can talk to people who are using the skills in all variety of situations. In addition to that, there is a Facebook page where we just sort of chat with one another about person-centered practices. People are doing this work all over the world and the learning community truly is that it's a community set up to teach one another, how the skills might be working in various situations and with different people.

Moderator: Thank you. The next question, does person-centered planning and practice work for everyone who tries it?

Richmond: I think it takes a lot of practice and I do think it is something that you could immediately begin to practice after you've started training, or after you've been through training. But it's something that you grow in your knowledge of over time. So that practice into habit is really such an important concept. If people don't use it, they're going to revert to the way they've always solved problems. But the good news is person-centered skills work for human beings. So if you have a pulse, they work for you. It doesn't matter if you have a vulnerability or a disability, it really is about humans. So it works as easily with the people that we support as it does with our colleagues or our family or friends.

Moderator: Thank you. And Kate, is there anything you would add to that?

Barkley: I tend to agree. I think that it goes back to what Tanya had mentioned about noticing behaviors, noticing actions and words, and it takes a skill, it takes our skill and yes, anyone can do it if you have that flame.

Moderator: All right. Another question, if you are saying that what is right is what is required, what does that mean for our work? Anyone. There's not a particular person that's addressed to, so either one of you can speak to that if you'd like.

Barkley: Tanya mentioned that writing care plans is often a hollow exercise, if it's purely to make a monitor happy. Simply writing a care plan, simply doing it is not enough. Repeat the question for me.

Moderator: You know what, the question… I apologize.

Barkley: That's okay. We've spoken about this, Tanya can you add.

Richmond: I can. I think for all of us, we come to this work very much what Kate was saying, we come to this work because we have a value around human relationships, around really supporting people to be able to be engaged in their community. And the work really lights us up. So we come with a little flame built in and we know that being person-centered because it feels good when we're doing it, it tells us, this is the right thing to do. This is the way I would like to be treated if I were receiving services and support. But at the same time, the federal government has said those values that you carry as a person in the human services role, and supporting people that is the required thing to do. Your organization really needs to be asking people what does

balance look like for you. Are you having things that are important to you in your life? In some kind of balance with what is important for you. So as we support you to be healthy and safe, we also want to make sure that we're honoring your preferences. And it's very easy to get into a situation where we might dictate to someone what life should look like. And this allows us to take a step back, it actually requires us to take a step back and say, what should it look like from your perspective? How should this work?

Moderator: Thank you. The next question we have is for you, Kate. If we're having trouble getting buy-in to using a person-centered approach, how can we work on that?

Barkley: I doubt that you would get trouble finding a participant or a client who doesn't want to buy-in. Nobody is going to say, please run my life for me, make decisions for me. Everybody has input on their own life. When it comes to staff who, oh, well, I've never done that before, or, oh, I'm not used to that, again it's what we've talked about today. It's engaging in your team. It's fanning the fire to your flame. Why are you in this job to begin with? It's to help people. We're all on the same page. Our goal is to meet the person's goal, it is reminders and it is constant talk and pause and introspection.

Moderator: All right, thank you. The next question is for Tanya. Are there requirements to document that the balance between important to and important for are met? In other words, what are the documentation requirements for person-centered plans in the HCBS rule?

Richmond: So a person-centered plan can look like any plan an organization is already doing. The documentation really comes in the form of showing that you've asked the person about their preferences, that you've not only asked for their words about their preferences, but you've looked for actions that confirm that you're aware of how the person sees themselves living. And that you've done something to address those desires that they have about how their services and supports are provided. In addition to that, we'd be asking people about who they want to provide those services? Who do they want in their life in terms of supporters? Who do they want in their life for social situations? And we'd ask a lot of other questions, a lot of this happens through discovery. So all of that should show up in the plan. But people will say, is there one uber plan? And there's not, there's not a plan from on high, but what there is are varieties of plans that providers use, where person-centered information can be documented to show that we are asking about preferences and desires in balance with those things that a person needs for their health and safety.

Moderator: Thank you. And I think we have time for just one more question. If I want to learn more about using person-centered planning and practice skills, where do I go?

Barkley: I highly recommend the trainings I've been to three, I've been to three. One, I went a second time. So I could go with staff and practice those skills. I highly recommend the websites in the world of COVID. I recommend attending them virtually. And I might even consider attending them a third time.

Moderator: Terrific. Thank you so much. I want to thank both of you for joining us today. This has been a terrific discussion and you both bring so much passion and expertise to the table that I think this has been a terrific conversation to have with our viewers this morning.

Richmond: Thank you so much.

Barkley: Thank you.

Moderator: And I'd like to thank you very much for joining us today and for making us your ongoing resource for public health continuing education. Please remember to fill out your evaluations online. Your feedback is always helpful to the development of our programs, and continuing education credits are available for today's program for a limited time. To obtain CNE, CME, CEUs, or social work continuing education hours, learners must visit 'www.phlive.org' and complete an evaluation and post test for today's offering. This webcast will be available on demand on our website within two weeks of today's show. Please join us for our next program on November 5th, focused on *What's New With The Flu* at 'phlive.org.' Information on *Public Health Live!* and relevant public health topics can also be found on our CPHCE Facebook page and Twitter feed. Don't forget to like us on Facebook to stay up to date. You can also let us know how you use *Public Health Live!* by taking a brief survey at 'phlive.org.' I'm Rachel Breidster. Thanks for joining us on *Public Health Live!*