

Transcript: "Doing With Not Doing For: What it Takes to Facilitate Person Centered Planning"

This webinar was originally broadcast on January 6, 2021

>> Hello, everyone. Welcome to today's webinar: Doing with, not doing for: What it takes to facilitate person-centered planning

I'm Alixe. Welcome. We'll spend time today -- we are delighted to be with you today. People are starting to join this webinar. Thank you for joining us. Note -- this webinar is sponsored by NCAPPS. [Reading slide.] These webinars can be viewed after the fact on the NCAPPS website.

[Reading slide.]

This particular topic, focusing on facilitation of person-centered planning, especially staff competencies, is a key area we think is important to focus on. For the process to be truly person-centered, it's critical for staff to be able to facilitate the planning. Communication and implementation are very important. These competencies are part of NCAPPS's resource.

Next slide.

A few logistics about this webinar. [On screen.]

[Reading slide.]

Please be ready to respond to our poll questions so we can make this a little bit more engaging.

Next slide.

[Reading slide.]

We'll post the link in the chat.

[Reading 2nd bullet point.] [On screen.]

Next slide.

This brings us to our first polling question, which should have come up on the screen. We want to know who is here. In what roles do you self-identify. We have a large number of participants today. That is exciting for all of us. We are excited to have all of you with us. In a few seconds, our colleague, Connor, will close the poll. We'll give you a few more seconds to respond, and we'll get this going for you.



Thank you. We have a broad representation here. More than half are social workers, counselors, or care managers. We have people representing from service provider organizations, people with disabilities, self-advocates as well. Thank you all for joining us.

Next slide.

With that, I'll turn it over to Bevin Croft, my colleague.

>> Welcome. We have record number of participants here. That is an auspicious beginning to a new year. Please bear with us on the captioning and ASL interpretation. We are working on setting that up. Please know that we are on it. There will be Spanish captioning as well.

Dr. Tondora promotes full inclusion of people with disabilities. There is a document that accompanies this webinar, which she authored. We'll put the link in the chat. She'll tell us about the resource and how it was developed.

>> I'll do my best to share with you about this document in about 15 minutes, although it took us over a year to come up with it. I'll hit the high points I want to first acknowledge the history and context of the domain. Bevin were involved in a multi-stakeholder panel that worked together over 18 months to reach consensus of what quality looks like. It focuses on the systems needed. We needed a more concise user-friendly tool which would have a meaningful impact on the field. That gave rise to the development of this.

A note about the applicability of the domain. Working across systems, we are mindful of differences that can exist between systems. There are different preferences within those systems as well. That challenged us to focus on the "must dough's." What core competencies should all facilitators possess?

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I'll tell you about the Juniper-class. Our process was systematic, but not scientific. I collected 16 resources that spoke to competency and PCP facilitation. We looked at rules, guidelines, national objectives, foundational models, work in behavioral health, etc. We then extricated a master set of 400+ potential core competencies. That spreadsheet would not be a practical tool.

I made an effort to do a thematic analysis. I presented that to a team of people at NCAPPS. We then had a process where we went through and rated the 400 competencies in terms of the best domain fit. We had about 90% agreement on where and how they fit together.

The spreadsheet allowed us to identify the most frequently identified competencies, which could inform the must do's.

I'll tell you what that process resulted in. Next slide.



It leaded us to several core domains in person centered planning.

The next slide will give you a big picture of what the core competencies look like. I'll give you a quick description and representative competency in a minute. There is nothing magical about these five competencies. After looking at this as a team and vetting it, we feel like across the five domains, we've captured the most important knowledge, skills, and abilities the facilitator should possess.

I'll give you an example of each. This is Domain A. [On screen.] This is the essence of why we do PCP. This helps people live a good life in the community as defined by each individual on their unique preferences, including those informed by their cultural view and identity. You are looking to see if the facilitator can help with a strength-profile. They can demonstrate that competency in a variety of ways such as using worksheets, circle mapping to identify resources, etc. What goes along with that is having higher expectations that talk about real lives in the community having to do with hobbies, jobs, etc.

This is Domain B. [On screen.] This is about the facilitators' ability to connect people to paid and unpaid supports. Representative competencies are can the facilitator help navigate to resources that include recreation and leisure, housing, volunteer, financial entitlements, faithbased connections, etc.

#2 talks about the types of resources we can connect people to and being mindful of natural community activities and relationships and being connected to the community and not just inside treatment or service systems. That may play out in a class and co-creating a person-centered plan that helps them get back to their natural community.

Let's look at Domain C. This is about rights, choice, and control. That involves basic, fundamental human rights -- the right to be safety and free of abuse and neglect. What are rights related to building a good life in the community. This is for inside and outside the community. The red shows representative competencies. When might they be experiencing discrimination and what resources are available. The bottom competency look at the facilitators' ability to teach a person to support themselves and advocate for them based on what is important to the individual.

Domain D. This is primarily about the planning process, meeting. Competencies include facilitators' ability to consistently start with preferences of the person served and talking about who they want involved, who shall lead the meeting, where the meeting shall take place, etc. The bottom competency goes to best practices in meeting facilitation. Are the meetings facilitated in a way that communicates respect and makes way for all voices in the room, especially the person receiving services and support.

One more competency. This is Domain E. Sometimes, the best laid plans don't work out as we had hoped. Getting that plan down allows it to become a tool of accountability and is a critical part of this process. That includes using the person's preferred name and identity



preferences; that identifying strengths are used and incorporated in the plan; and the facilitator regularly solicits feedback as to what is and is not working.

I want to talk about how these competencies can be used in practice.

I want to give a shoutout to the NCAPPS team in my home state of Connecticut. Connecticut was heavily involved in the development in these competencies. Are these consistent measures of quality? Is there a consistency in expectations for implantation in practice? Connecticut was very helpful for us in that.

Let's say you take a competency from Domain A. You want to focus on that. In column 2, think about if you are giving facilitators appropriate tools, resources, and training. Then, look across the training curricula and see where and how that might be being taught. It could be in tools, methodologies, mapping circles of supports, using a support star, etc.

Once you've confirmed that the competency is being taught to and there is preparation, check to see if it's happening. In the purple column, think about things like creating observational review sheets and audit tools. What indicators are you looking for in action? Similarly, look at the PCP that comes out of that conversation. Are there review tools that capitalize on the strength.

The most important source of information is going back to the person served and directly soliciting their input.

The last column thinks about practical expectations. We can think about places we need to beef up our training protocols, our prep training programs and what the undergrad curriculum teaches, HR decisions. Are we using these competencies to identify, not only areas of need, but where are the exemplary programs. Where are the superstars, and how can they help others come along?

There are some next steps here. A lot of these tools are out there now. Some states are taking these tools and making some modifications. There is a plain language version that is being released this week on the NCAPP website. We are hoping to take this to the next level and thinking about mapping quality measures onto the competencies. We are hoping a group can take on this project.

That's the high-level overview. I'll turn it over to Bevin.

>> It can be hard to keep up with chat. We'll post the link a few more times. Folks have asked about available of the slides and this recording. They will be available as soon as we can upload them to the website.

Now, we'd like to hear from all of you. Now that you've had a taste for the 5 domains, how might you use this resource in your life, work, and/or organization? Please select all that apply. If you have something else in mind, you can enter that into chat. While you are



looking through the options, I'll read them for you. [Reading options.] [On screen.] We are interested in what you are hearing. We'll give you 10-15 more seconds to respond to this.

It looks like folks have lots of ideas. The most common is training staff to learn these skills. Others are saying to help me speak up about what I expect. Folks may use this in a proposal process, use it in interventions, plan for the future, develop practical guides, employment, etc. [In chat.] This is awesome. This makes us feel really good. Thank you for sharing that.

Now, I'll turn to our illustrious panel. I'll give each speaker 10 min. to introduce themselves to you. Carol is the training director for the institute on disability in Georgia. She is a found director of Univ of Georgia's post-secondary education program. She is involved in lifestyle planning and is a fellow on the organization for intellectual disabilities. Please share your experience on PCP.

>> Thank you for having me. Thank you to NCAPP for your hard work in this area. In thinking about my experience with PCP, I thought it would interesting to look at the five domains and talk about the different roles I've had and to think about which competencies I felt I or we needed in the field and to highlight one of them as one that might be a domain that we can focus on collectively as we think about system change and focus on this work.

I like visual tools and created a table. I'll walk through this. When I began my career in the 90s, I was a frontline worker, supporting people hands-on with activities of daily living and connecting people to services (paid and unpaid), reading the people's plans, and trying to make sure the person's goals were represented in the work I was doing. Those most relevant included what we were required to do such as documentation and implementing plans. This shows if we were in alignment. We were interested in helping people cultivate connections. The most important competency area for me, as a direct support worker, is that we recognized the rights, choice, and control of those with whom we were working. We also have the ability to become a barrier to that if we don't have those skills. I feel that is important when working with frontline workers.

Eventually, I was promoted to management and quality assurance. In this role, domains D and E were very important. I needed to communicate the attitudes and values of person centeredness to the people I was working with. As case workers, social workers, and managers, we need to understand and communicate what the essence of PCP is. It's strength-based and culturally informed and focused on the whole person, not just the billable services.

Finally, as Bevin mentioned, I moved into a role as a certified trainer in PCP. I did training in New Jersey on PCP and lifestyle planning. I work with providers and associations to help people learn and build skills they needed to be good PCP facilitators. In this role, I needed to have that whole person strength-based perspective. Focusing on the person's rights and self-determination, we communicated that it's about helping people make informed choices and understand their rights in the planning process and be documented in the work we are doing.



When working with trainers and communicating observable skills, having them understand their roles and communicating what they expect from direct frontline workers to help people meet their goals is really important.

I'm currently at University of Georgia and have founded the center that works with adults with intellectual disabilities. We use PCP to help them with their engagement and career goals. Documenting what a student wants in terms of academic and social engagement and their career goals and dreams is important. It's important to recognize rights, choice, and control of the students we work with. We work with peer mentors at UGA to help guide students. They need to understand that as part of this process, our students are making choices. They are being self-determined in thinking about how they want [Inaudible] on campus.

It's important that we cultivate connection within and outside of the UGA system. Having a good PC plan and approach is very important for the future success of the students as they become adults.

At Living Well Georgia, we look at some tools we put in place, including those that direct support workers use and thinking about how we use those tools in our documentation to improve our monitoring and build our capacity to have better monitoring systems in place. In this way, the domain E becomes really important for us, because we recognize that a lot of information is being collected in our system and should include what is important to and for a person.

In a nutshell, this is a higher level look at how I think we can use these competency domains. I think they are flexible and applicable across multiple levels in our system. In your work, you may find that some are more applicable than others. You can think about how you can start with one of them in one domain area.

>> Thank you. Next, we'll hear from Darien Todd from Georgia. He graduated from the academy for growth. He is a self-advocate intern and inclusive post-secondary education advocate. He's at Georgia State University. He has a disability called dyslexia. One of his strengths is in working with others. Please tell us about your experience in PCP.

>> Hello, everyone. I'll tell you about my experience with PCP. I did mine at Kennesaw State University. It was like a map. They'd map out the goals I'd put out for myself and help me get a grasp of what things could happen and the time period I wanted them to happen. One thing about PCP is helping that student gain that independence and employment or anything they want to do for jobs. For me, the best thing that a person could have going into PCP is being understanding, ensuring that the person you are working with is understanding. Not everyone works the same. Have an open mind when working with that student. Help them get an understanding of what goals and happen in the time that they want and what goals are logical and what you need to do to make sure the goal is doable in the near future.

PCP helps a lot of people with intellectual and developmental disabilities live their best lives and gain an understanding of who they are and where they can be in this world, give back to



their communities, and be their best selves. I hope that was enough.

>> Thank you, Darien. Finally, I'll introduce Amy, who has been working in the peer movement in Texas for over two decades. She supports organizations in development and implementation of peer programs. She's a certified peer and WHAM facilitator. Welcome. Please tell us about your personal and professional experience with PCP.

>> I always leave myself on mute! Thank you, Bevin. Thank you all for giving me this opportunity to be here today. I've been navigating COVID-19 for the past 3 weeks. My voice and energy are a little bit low. I may start coughing. A service provider supported me in living my best life. I have lived experience with emotional challenges. I worried about what people would think in team meetings. I was told to take it out of the space. That give me permission to be however I needed to be. For me, that's what PCP does for many individuals. Individuals advocate for what they need and find and use their voice.

My lived experience comes from mental health. I've been hospitalized between 40 and 50 times and was told all of the things I couldn't do. I didn't feel like I had a voice and couldn't trust myself. My last hospitalization lasted almost a year. That helped me find the life I have today. There, someone said I could get better. At the first team meeting, they sat down and asked what I wanted to see and do. At that time, I couldn't answer. I had been told that I'd live in and out of institutions for the rest of my life. The idea that I'd have something different was so out of my purview. They said I could, and that was the hardest thing. This was the first me I felt that I was in partnership with my team. They helped me find my voice. They supported me in writing things down so I'd have a list to show with what I needed. When my needs hadn't been met, I got frustrated and gave up because there wasn't a lot of hope. I see this in my work today.

The other thing about PCP was that they didn't look at medication management or looking at spaces that had been harmful to me. They asked what I wanted to do, who I wanted to be, and what I wanted my life to look that. That was in April 1996. I started to cry. I hadn't seen myself living in a world with possibilities.

My psychologist worked with me on making a "dreams list." I wanted to live on my own, get off of disability, and have a convertible. Most of the things that were way out there was things that everyone wants. I wanted to go back to college. I didn't want to live in a board and care home or places I had lived at. From April 1997 to August 1998, we created a plan. That included getting enrolled in college, making a plan to find an apartment. People on that team pushed against me, but I had the support of people around me who helped me get there. That's what I see as PCP. They didn't see what I wanted to accomplish as things I couldn't. I left that hospital and haven't been hospitalized since. One thing that was very different was that I could take psychology classes. They supported me in getting a therapist outside of that community. I met that therapist and a case worker before I left. I had strongholds to hold onto when I left there. That made a big difference. I got to say what it was that I wanted to do.



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Some things worked, and some things didn't, and that was fine. It's OK to fail. "Fail" is not a bad word. We are learning each and every step along the way. When we support PCP, sometimes, goals aren't met, and that's OK. Then, it's important to find out what else they want to do. When I was on the ACT team, I had a case manager who stood for me. There were other team members who wanted to keep me safe. I then got a job that led me to working at a state hospital. I've been off of disability for many years.

I needed them to hear what I was saying. The transition from ACT to going on my own would have been a lot easier than it actually was.

Being in peer support has led me to where I am today. That peer support piece is so important. It's individuals with their own lived experience supporting others with their own lived experience. It's walking along someone else and supporting them to get the life of their dreams. I've had the honor of being a PCP supporter of other individuals. Being able to use my lived experience and share stories of what did and did not work and supporting people's dreams is what I do. The heart of PCP is about individuals using their strengths and having others support them so they can live the lives they choose and want. I did get that convertible!

>> There are a lot of chats coming in for you. There is big appreciation for Amy for your candor and resilience and amazing story. Darien and Carol -- you are getting shoutouts too.

Now, I'll do another polling question. Next, we'd like to talk about the who. Who needs to be involved to make the process to smoothly? Amy gives a strong endorsement for the power of peer support. We know that PCP is a collaborative process and involves the community.

We'd like to hear from you. Who else needs to be involved to make the PCP go smoothly? Where are the touch points? [Reading options.] [On screen.]

If you have other ideas, put them into chat. Check all that apply.

All right. Almost all endorsed family members and service providers.

There was more than 50% for every category. Thank you, Connor. You can take the poll down.

Now, I'd like to hear from the panelists about who has been most influential for you. Specifically, what were their skills. This webinar is about competencies.

>> For me, and obviously, I have a bias towards peer support. In the pre-planning process, peer supporters are really able to support individuals. We used something called "In the Driver's Seat." We identified areas of people's lives that were and were not working. Then, they had a better idea of who they were and what they wanted to get out of their time at the organization. For peer specialists, I think about people who listen. That goes across all domains. I like to talk about respectful curiosity. A person may say one thing, but they may be looking to do something else. It takes a proficient facilitator to get there. For me, the case



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managers are important. They work typically alongside an individual the most and help support them to get those needs met and find some of the resources. Someone who can connect people to places and be a good bridge in the broader team is important. Sometimes, there may be differences of opinion. In PCP, having all of those voices heard is really important. I'll stop there. I know others have more to say.

>> I got that down. Resource breaker. Excellent context. Let's hear from Darien next. Who is most influential for you, and what skills did the person have?

>> When I was doing PCP, I had my family and friends and my academic advisors. Anyone that wanted to see me succeed in life. Someone that wants to celebrate your accomplishments. I believe that if you go into PCP, you go into these things where people want to see you succeed and thrive in your life. These are bound to work. You also want to go in knowing who you are and where you belong. It's OK if you go in and don't know that right away. Maybe when you get out there and find where you belong, you'll come into your yourself. I believe that everyone that I just said needs to be in your PCP as well as your classmates, who can probably help you get in contact with people who want to work in the same field you want to work in. Your PCP isn't just helping you seek out opportunity. It's also a great opportunity for you to advocate for yourself. It's a great networking skill for people with disabilities to go out there and live their best life. I also believe that the people you have in there should always have in the back of their head that everyone with a disability isn't the same. I'm not the same as someone else with a disability. We all learned differently and talk to different people. We are not the same. Have an understanding of knowing how to work with people with disabilities and making sure that person isn't saying that something isn't possible. It's possible if you have faith in that student. I have a disability, and the best way for me is embracing your disability is something you can seriously work towards doing. It doesn't happen overnight. Some people have a disability and have trouble with contact. That's OK. We are people. Some people like to talk about their disability, and some don't. Everyone is different. It's a good idea to go in there saying, "I love my disability. I applaud my disability. I share my disability. I appreciate the hard work I do. I'm enough. I'm important." You are powerful in what you say and do. Keep your head up. Nine times out of ten, anything you think you can do will come true.

>> I love the idea of surrounding yourself with people who want to see you succeed. How do we hire and train people who have that desire? Let's all figure out how to do that. Janice -- I want to hear from you next.

>> You are all tough act to follow as are the folks in the chat box. I think about how you define "influence." Some people like influence to power. Who in the room has the most power or decision-making power? That's an element of it. I want to talk about "impact." Sometimes, the person with the least amount of power has the most influence and biggest impact. In the chat someone said that really good peer supports do all of this. We have a lot to learn from peer supporters. Based on shared lived experience, they are oftentimes in the best position to make connections with people. That makes them uniquely qualified, especially with visioning, goal setting, teaching, supporting self-advocacy, and connecting



individuals with persons, places, and things in the community. It's important to use supporters in planning to get the most traction. Often, they are underutilized.

>> Thank you. I'll put in a plug for Martha Barbone. She's on our advisory group. She developed a resource for us for one of our webinars that builds off of some of Janice's work. She lists 10 ways that peer supporters can assist with PCP.

Carol -- please share your views with us. Who is most influential and what skills does the person need to have?

>> I echo Janice. It's hard to come behind Amy and Darien and their shared experience. In the chat, many expressed that it should be who the person wants to be part of their planning process and who will be champions for them. In my experience, in systems with power differentials, self-determination may not come as easily because of structures in place or issues the guardianship. I think those people need to be present to hear the person's goals, desires, and dreams in an authentic environment.

It's okay if you fail. Not everything goes perfectly. Our systems are designed to protect people from failure or getting hurt. Have people in the room who can recognize that there are risks with some of the choices and putting forward that the person has clausal agency in their own life. It's important for them to realize that they have power over their decisions. The more we can have people listen to what they want and commit to being champions for them -- those are the people that need to be in that meeting space.

>> Thank you, carol. These are all good points. I feel like we could do a separate webinar on each of these questions. I'd like to move to another topic, which is on self-advocacy. We know that PCP isn't something you do to or for a person. It's done with a person that is driven by the person -- at least that is how it's supposed to go. At NCAPP, a key ingredient in that shared power dynamic is the person having the skills and being empowered to advocate for themselves and speak out when things aren't right and they need more control. That is the topic we'll turn to next.

We have a polling question for you. [Reading question.] How do we create demand for the skills we've been talking about. Again, if the idea isn't here, please enter it into chat. [Reading choices.] [On screen.] The plain language version of this document will be coming out soon.

Pick any of these that you think sound good from your experience. Feel free to add to chat. Take 10-15 more seconds to look over it and weigh in. I'll start reading what I see in chat. [Reading chat.]

Thank you. Keep those coming in. The most endorsed resource is self-advocacy skills training. Thank you for that.

Carol -- what is the best way to make sure people accept and demand these skills?



>> One thing we can do, especially with these competency domains, is enhance training. I think that we can view this in a number of ways, including making sure these are represented in training curricula for people involved in PCP across sectors. It seems that we have a lot to learn from peer specialists and have room to grow there. We can work it into job descriptions. We can work in a job performance evaluation so that we can identify points where someone might need additional professional development and do targeted training. We need to make sure to capture the voice on the people on the receiving end of the process and make sure that they are providing voice to us around what we need to have reflected from their perspective around the process.

>> Thank you, Carol. Amy -- what do you think about building demand for these skills.

>> There are a lot of things we can and need to do. I think providers are still afraid of people finding their voice. There is a fear. There is a belief that it causes more work. In reality, when people find and use their voice, that is what you want to have happen. I think all people should understand that self-advocacy is important. I think there are fears there. We've looked at what those fears are, and they are real. It's not always pretty when people start finding their voice. That can look beautiful. There are trainings for individuals about find and using their voice in a way that can be heard. That's where peers come into play. We talk about what it looks like. Looking at all angles is important. I love that you are coming out with a plain language version of this document. This could be incredible. Often, people just don't know what they can expect from services and don't know that things are available unless people tell them and that is one place where peer support is so great. Coming from the place of having been there and done that --

We need to do it a lot and often. Often, people are given information when they first come for services, and that can be overwhelming. There is a lot of paperwork and talking. You never know when someone will hear something for them that makes them find their own voice.

>> Thank you, Amy. Darien -- what do you think? How do we build up those self-advocacy skills?

>> Teach young people how to find their voices. Inspire people. From an early age, we need to bring it into our schools and make sure that the teachers and principals and anyone in the school system can teach students to speak up for themselves and teach them, "Your voice matters. If you don't like or agree with something, speak up about it." Teach them that what they are saying is relevant. In everyday life, we speak up for what we want. It's like someone asking me what I want for dinner and I tell them that I want pizza. That's advocating.

What do you want to do? What gets you out of bed?

Teach them that they can do whatever they want to do if they put their mind to it.

We need to start in the school system and teach them, "Using your voice matters."



Teach them to vote. That is one thing that can teach a teenager/child to use their voice. You are touching a screen to tell them what you want in America. "Changing the world with one speech at a time," is something I say. Teach them how to go about asking for accommodations if they need them. Teach them how to advocate and speak up for themselves.

>> Thank you, Darien. These are true words of wisdom. Janis -- what is your take on building demands for self-advocacy?

>> I have a different angle. I don't think you can create demand until people have a vision of what they can and should expect. Whether you are talking about a webinar, infographic, etc., anything out there has to be concrete to raise expectations. People have to understand that you can expect different kinds of outcomes. I don't think people always see it as being different. Years again, we tried talking to people with lived experience and asked them if they were actively involved and satisfied. The majority said they were activity involved and it's all good. I knew that what we were doing was not PCP. We were surprised that people said that. We went back and asked them what being actively involved meant to them. They said that it's a piece of paper they sign and send somewhere to get paid. That is a tragic reflection of how low people's expectations are. To think that's OK is just unacceptable. In what ways does the plain language document look different. The competency domains get us a little farther, but we have a ways to go.

>> Thank you, Janice, Darien, Amy, and Carol. I've learn so much as have the 1+ people on this webinar. We are running out of time. There are many questions in chat. In addition to posting the webinar, slides, and resources, in a few weeks, we'll grab the questions in chat and work with the panelists to prepare a resource document with responses to these questions so we can give the questions the time and attention they deserve.

>> There are a bajillion plus one questions. I've been documenting them. There is one question I can put to you, Janice. When you talked about making sure the plan was implemented according to the person's wishes, does this include throughout the journey?

>> I'd say yes. Sometimes, there is an expectation about facilitating a PCP. For us to achieve the power of PCP, facilitators should have more power and authority over monitoring the implementation and making sure that the person's goals and what's important to them doesn't change regardless of who is in the meetings.

>> Apologies for not being able to answer all questions. Now, we'll move to real-time evaluation questions. We'll leave this up as we say our thank yous and good-byes. There are a total of six (6) questions that we are asking you to respond to. Thank you to our panelists and for this reach conversation. We think we had a record number of attendees. We'll share the resources in the resource document. The notion that it's important to focus on this earlier kept coming up. We'll have a webinar on PC IEPS.



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Best wishes for the rest of this day, months, and 2021.

[End of webinar.]